

Kidney disease patients' experience of care and illness can take a large emotional toll

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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 and 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, Ph.D. 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."

More information: Ann M. O'Hare et al, Emotional Impact of Illness

and Care on Patients with Advanced Kidney Disease, *Clinical Journal of the American Society of Nephrology* (2018). DOI: [10.2215/CJN.14261217](https://doi.org/10.2215/CJN.14261217)

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