



PRESS RELEASE

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SHOULD PHYSICIANS RETHINK TERMS USED TO DESCRIBE KIDNEY HEALTH?

Study finds that some wording is distressing and confusing to patients

Highlight

- A new study has found that common terms used by physicians to describe kidney health may be distressing or too difficult to understand for patients with kidney disease.

Washington, DC (June 25, 2020) — Results from a new study indicate a need to reconsider certain medical terms and phrases that clinicians use when communicating with patients who have kidney disease. More patient-focused terminology may improve patient autonomy, satisfaction, and health, according to the authors of the *CJASN* study.

Communication between physicians and patients is critical to ensure that individuals can understand physicians' advice and can make informed decisions about their care. When considering chronic kidney disease (CKD), some of the language commonly used to describe kidney health may be imprecise, misleading, and hold different meanings for patients and clinicians. To look into this, Allison Tong, PhD (The University of Sydney, in Australia) and her colleagues designed a study to gain the perspectives of patients and caregivers on terms commonly related to kidney health. "We wanted to understand the impacts that the terms for kidney health have on patients and their families, and to find ways to improve the terms being used," said Dr. Tong.

The study included 54 patients with CKD and 13 caregivers from the United States, United Kingdom, and Australia who participated in 10 focus groups to discuss terms for kidney health (including kidney, renal, CKD, end-stage kidney disease, kidney failure, and descriptors for kidney function).

The researchers identified 4 themes:

- *provoking and exacerbating undue trauma* (fear of the unknown, denoting impending death, despair in having incurable or untreatable disease, premature labeling and assumptions, judgment, stigma and failure of self);
- *frustrated by ambiguity* (confused by medicalized language, lacking personal relevance, baffled by imprecision in meaning, opposed to obsolete terms);

- *making sense of the prognostic enigma* (conceptualizing level of kidney function, correlating with symptoms and life impact, predicting progression and need for intervention); and
- *mobilizing self-management* (confronting reality, enabling planning and preparation, taking ownership for change, learning medical terms for self-advocacy, educating others).

The authors noted that some patients despised the term “pre-dialysis” because it was unnecessarily precipitating the need for dialysis—“it assumes you know what the future holds.” Others interpreted kidney “failure” to mean that their “physical existence is failing,” or they had “done something wrong.” Some also perceived the term “end-stage” to mean the “end of a healthy life, the end of a positive mindset,” and initially thought there was “nothing you can do about it.”

“We found that terms such as ‘end-stage kidney disease’ can cause undue distress in patients. Terms may also inadvertently imply impending death and be stigmatizing,” said Dr. Tong. “There was also frustration, uncertainty, and fear because some terms were confusing and ambiguous.”

Using consistent and meaningful language that patients can understand may help to improve patients’ health and satisfaction.

An accompanying editorial by Paul T. Conway (American Association of Kidney Patients) addresses kidney specialists, stating, “If our shared agenda is to have more patients to participate in clinical trials and research, take better care of themselves, and become more involved in advancing policies that support innovation and research—ask yourself a simple question: did the last conversation I have with a patient inspire confidence that their kidney disease is manageable and that their unique patient insights are valuable and needed in the fight to help save other patients?”

Study co-authors include Andrew S. Levey, MD, Kai-Uwe Eckardt, PhD, Samaya Anumudu, MD, Cristina M. Arce, MD, Amanda Baumgart, BPsych, Louese Dunn, Talia Gutman, MPH, Tess Harris, Liz Lightstone, PhD, Nicole Scholes-Robertson, BAppSc, Jenny I. Shen, MD, David C. Wheeler, MD, Dave White, BS, Martin Wilkie, PhD, Jonathan C. Craig, PhD, Michel Jadoul, PhD, and Wolfgang C. Winkelmayr, MD, ScD.

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The article, titled “Patient and Caregiver Perspectives on Terms Used to Describe Kidney Health,” will appear online at <http://cjasn.asnjournals.org/> on June 25, 2020, doi: 10.2215/CJN.00900120.

The editorial, titled “Nephrology Nomenclature: How to Accelerate Patient Anxiety, Suppress Engagement and Mire the Advance of Medical Innovation,” will appear online at <http://cjasn.asnjournals.org/> on June 25, 2020, doi: 10.2215/CJN.08730620.

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