

Considering Our Patients and Tempering Terminology

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A word is dead
When it is said,
Some say.
I say it just
Begins to live
That day. —Emily Dickinson

Among major concerns for all involved in health care—on the supply side (doctors, nurses, technicians, and suppliers) and on the receiving side (patients, families, and friends)—are communication, understanding, and action that influences outcome. As nephrologists, the words we choose to inform our patients truly matter, particularly in this rapidly changing present era. CKD confers many burdens on those affected, and how we as clinicians explain issues related to altered kidney health in CKD may influence prognosis and outcome. Given the increased risk of life-altering and life-threatening adverse events and mortality and the possibility of requiring KRT, each and every patient faced with CKD will need support and education to navigate the choices that may arise. We all know that clear, nuanced, and positive communication between patient and health care professionals is crucial, but too often, such communication has been suboptimal. To understand patient needs and to effect better care, seating them at the communication table is key and, fortunately, finally gaining credence.

For example, in this issue of *CJASN*, Tong *et al.* (1) present the results of a study in which they used a thematic analysis technique to analyze qualitative data from focus groups consisting of patients with CKD, along with some caregivers, who considered terms presently used to describe various facets of kidney health. The terms discussed included kidney, renal, CKD, ESKD, kidney failure, and various terms for kidney function. The findings corroborate the sense many of us have—words matter deeply, not just for patient understanding but for actual prognosis, for choices patients make, and for cost and many other facets of health care.

Why only now are we at this point in our communication with our patients? First, our field, nephrology, has changed greatly since the mid-20th century, the birth of nephrology as we know it. Our field has matured; presently, complete loss of kidney function can be treated effectively, and active CKD can be managed, optimally, without progressing. Thus, the

finding that compromised kidney function has a different meaning for a patient now compared with prior eras before treatments were available for both acute and chronic kidney failure is not surprising. Remember that it was only toward the end of World War II that Kolff developed the first hemodialysis machine (1943) and that the approaches to hemodialysis and other forms of KRT have evolved greatly in the 77 years since that first machine (2). Furthermore, kidney replacement through transplantation has also evolved—the first successful transplant (between identical twins) took place in 1954 (3); 23,401 kidney transplants were performed in the United States in 2019 (4). Until these developments first occurred, patients with advanced kidney disease would inevitably succumb, and it took decades until therapy for those with CKD became commonplace and standard of care.

Much else has changed—in the 1940s and 1950s, the relationship between clinicians and patients (and their caregivers) was paternalistic; patients largely accepted what they were told, or at least they did not ask their doctors many questions. Indeed, “the truth” was often held back from patients. In the ensuing decades, the approach to informing patients and their families and, indeed, collaborating with them in their care has undergone major changes—full disclosure is the currency of the day. However, aiming for “everything in sunshine” is not without many interfering clouds—aspects of the economy, political exigencies, the widespread availability of information on the internet, and unexpected events, such as severe acute respiratory syndrome coronavirus 2 and the coronavirus disease 2019 pandemic that it has caused. Such things notwithstanding, communication is more open, and clarity is more important than ever before.

Since the millennium, both clinical practice and clinical research in nephrology has paid more attention to patient perception and needs. Emblematic of that shift was definition in an Institute of Medicine (now the National Academy of Medicine) publication, *Crossing the Quality Chasm: A New Health System for the 21st Century*, in which six major categories to anchor health care were defined and discussed (5). Not surprisingly, one of those categories was patient-centered care: “Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (5). A number of studies have since explored these issues (6–10).

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I, like many practicing nephrologists, was attracted to our discipline by the complexity of the kidney, an organ with many functions beyond filtration, resorption, and excretion. Given that complexity, the terms used to describe, explicate, and teach about kidney disease take some time to grasp. Beyond that, the concomitant evolution of overlapping terms for those of us using the English language can be confusing. We do not always remember that, as trainees, it took us each some time to understand both the concepts and the terminology. With the exigencies imposed by case load and visit length, how can we explain newly diagnosed kidney disease to our patients? Is there a way to facilitate optimal communication, knowledge growth, and better outcome through words (9)?

Tong *et al.* (1), commissioned by Kidney Disease Improving Global Outcomes (KDIGO) for presentation at a future KDIGO conference *Nomenclature for Kidney Function and Disease* (which this editorialist attended), explore the importance of words in our communication with patients. The authors note that the terms used to describe kidney health are not easy to parse, much less fully grasp. The authors note that patients and families may hear these terms differently from how we health care professionals intend. Some of our terms are unfamiliar. Kidney and renal mean essentially the same thing to us, but many patients, irrespective of their educational background, may not know what “renal” means. The study reported by Tong *et al.* (1) is, in effect, quite straightforward in that the investigators held a number of small, facilitated focus groups—ten in all, with a total of 54 adults with CKD and 13 caregivers from the United States, the United Kingdom, and Australia—to consider terms in use for considering kidney health. Among these terms were kidney, renal, ESKD, and kidney failure, as well as various terms for kidney function. The investigators then performed thematic analysis (11).

Given the qualitative data that focus groups produce, the investigators chose thematic analysis (11) to study the transcriptions of these focus group meetings. It is worth noting that thematic analysis was developed to detect patterns or themes within data by identifying concepts and describing them and is used in social research, psychological research, and health care research. Furthermore, depending on the anticipated prevalence of a “least prevalent theme,” the number of instances of the theme sought, and the study power chosen, a power calculation can be performed (11)—and was in the Tong *et al.* (1) study. Here, four main themes that carry major implications emerged about kidney health-related words and phrases: first, a theme of provoking and exacerbating undue trauma; second, a theme of frustration due to ambiguity; third, a theme of terms that allowed patients to make sense of the prognostic enigma; and fourth, a team of terms that enhanced self-management. The first two are generally negative, whereas the latter two are helpful. Examples of each are explored within the article.

The study participants were diverse—aged 18 to a few over 70 years, with a variety of kidney diseases, education, and socioeconomic statuses. Sixty-three percent were white, 22% were black American or black British, only 6% were Asian, and 9% were other race-ethnicity. Thirty percent had received kidney transplants. Of importance, the identified themes were not related to differences among participants,

and they included concerns about stigmatization, fear of the unknown and of death, despair about the implications, and sense of failure. The negatives, coupled with confusing terms, according to participants, rendered understanding of the prognosis and empowering coping mechanisms more difficult. The patients and caregivers who participated in this qualitative study had clear suggestions worth considering, particularly that how clinicians communicate information about health issues affects patient mood and, ultimately, adherence and outcome, not only the level of understanding. The participants suggested that we need to avoid using terms such as ESKD because such terms can cause distress and confusion and to use “kidney” instead of “renal” because it is clearer and to avoid ambiguity. Furthermore, they emphasized the importance of educating patients using personal approaches in sharing or developing tools to explain terms that connote stages of CKD, measurement of kidney function, and the implications. Additionally, the participants felt that the very term “disease” needed clarification, as did “kidney failure.” Understandably, participants asked for information delivery in a compassionate, individualized manner.

This study had evident strengths, including its analytic qualitative analysis method and the conduct of focus groups that were held in an open-ended manner and that independently identified similar issues (provided in supplemental material). Limitations the investigators noted were that this was a study in only English-speaking nations, that participants included few truly older patients, and that most had a high level of education. Another limitation, of course, is that patients and caregivers who agree to participate in focus groups may differ from those who do not. Also, naysayers might note that compassionate and individualized care is central to what we should be doing as nephrologists and clinicians, terminology notwithstanding.

Despite limitations, this work has much relevance to us as nephrologists. Clarity in description and terminology helps understanding, whether it be ours as professionals or that of our patients. The message from Tong *et al.* (1) is that we can do better, and how we frame our message has an important effect on outcomes.

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See related article, "Patient and Caregiver Perspectives on Terms Used to Describe Kidney Health," on pages 937–948.