Trust Patient Insights at Both the Individual and National Level

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As a newly appointed Patient Voice Editor for the Clinical Journal of the American Society of Nephrology (CJASN), I appreciate the unique decision of the CJASN leadership to elevate patients as contributors on their team. The strategy provides patients the opportunity to share practical health consumer perspectives along with experiential context to select journal articles. Also, for tens of thousands of patients with kidney disease, caregivers, and policy advocates who are not current readers of CJASN, they will now be able to read articles that accompany Patient Voice editorials, thus ensuring the growth of CJASN as a source of valued and shareable information across the patient community.

Two articles in this issue, “A discrete choice study of patient preferences for dialysis modalities” (1) and “Re-establishing brain networks in patients with ESRD after successful kidney transplantation” (2), are thought provoking and relevant in light of the renewed call for patients to become more engaged in their care and the changing national terrain in kidney disease innovation (1,2). Both articles focus on patient comprehension of how treatments align with their individual interests on the basis of their comparative outcomes. Taken together, they reinforce the principle that patients deserve objective counseling on all treatment options before kidney failure and should be trusted to make their own decisions. This means that medical professionals and providers have an obligation to fully discuss with their patient’s preemptive transplantation, home hemodialysis, home peritoneal dialysis, transplantation, and in-center hemodialysis.

In the first article, New Zealand subjects identify their clear preference for home dialysis on the basis of their understanding of flexibility, comparative independence, and better survival rates (1). I doubt that the Kiwi researchers have arrived at a conclusion that would differ greatly from that of their American counterparts—if American patients were better informed about the benefits of home dialysis. Recent breakthroughs related to home treatment, including new remote monitoring technologies and home dialysis devices as well as Congressional authorization for comparable reimbursement for remote home visits, are keys to spurring an upswing in home dialysis. Time will tell if doctors and providers, presently the most influential forces shaping patient treatment choices, work more closely with their patients to align treatment choices to patient aspirations, including the pursuit of meaningful work and careers.

The second article, involving subjects in China, highlights the negative effect that ESRD has on brain function, even when treated with dialysis, and how transplantation reverses some of these effects (2). This is not news to patients who have lived through the rolling mental fog that accompanies dialysis. For transplant-eligible patients currently on dialysis or contemplating dialysis, this is precisely the type of practical information that they should be told. If patients eligible for transplantation knew the potential effect of transplantation on mental function compared with dialysis, including the capacity to more fully assume family obligations and career pursuits once forfeited to disability, I believe that the number of patients electing transplantation, including preemptive transplants, would markedly increase.

At the national level, within the most influential levels of policy and innovation, patient judgement is fully trusted, and their involvement has accelerated across nearly every substantive effort aimed at disrupting the status quo in kidney disease treatment. Patient demand for greater flexibility and longer life expectancy has intersected and fueled positive trends in innovation and investment as well as federal efforts to proactively streamline clinical trial, regulatory, and reimbursement pathways in anticipation of new therapies. The shared philosophy among key national decision makers regarding patient inclusion is simple: respect patients as intelligent consumers of health care, capture and apply their valuable insights and experiences, and include them and affiliated patient advocacy organizations at the decision table at every point on the continuum that affects development and approval of devices, diagnostics, and biologics.

Top examples of engagement philosophy in action and where patients are driving both research and action alongside medical professionals include the Food and Drug Administration collaboratives with the American Society of Nephrology (ASN), the Kidney Health Initiative (KHI), and the Clinical Trial Transformation Initiative at Duke University as well as the KHI-led RRT regulatory roadmap project. Other examples include...
the Center for Dialysis Innovation at the University of Washington, the Kidney Precision Medicine Project at the National Institutes of Health/National Institute of Diabetes and Digestive and Kidney Diseases, and the Kidney Innovation Accelerator recently unveiled by the Department of Health and Human Services at the ASN Kidney Week in New Orleans.

I believe that, despite our frustrations as a disease community, especially as they pertain to comparatively rapid breakthroughs in diabetes, hepatitis, and HIV/AIDS, kidney professionals and patients together are at the cusp of a revolution in disease management and treatment. My belief is on the basis of my own experiences as both a patient who has managed kidney disease for over 36 years and a policy practitioner who managed policy implementation in senior roles under four United States presidents. The elements for great change are in place, and momentum is on our side. The time for self-flagellation as a disease community is over.

If you are a young and ambitious medical professional or researcher starting out in the kidney field or have served admirably and yet feel distant from the idealism that first brought you into this disease, you owe it to yourself and your patients to lend your ambition and energy to one of the aforementioned national innovation efforts. If you cannot join, then trust and recommend a patient you know to become involved. By doing so, you will be closer to future breakthroughs and have another opportunity to honor the lives of patients whose examples of courage have been a source of inspiration to your career.

The more knowledgeable that patients and medical professionals are of how we each view the quantitative and qualitative aspects of research and treatment, the more successful we will be in the battle to meet our mutual responsibilities to extend the lives of every American diagnosed with kidney disease so that they, in turn, can pursue a life of meaning and purpose.

Disclosures

P.T.C. serves as the President of the American Association of Kidney Patients and is a 2017 recipient of the American Society of Nephrology President’s Medal. He continues his public service career as the Chair of the newly launched Food and Drug Administration Patient Engagement Advisory Committee. He is a member of the following: Board of Directors, Kidney Health Initiative; Clinical Trial Transformation Initiative, Regulatory Review Project Team; and the Patient Advisory Board, Center for Dialysis Innovation.

References


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