

# Personal Experiences of Patients in the Interaction of Culture and Kidney Disease

Daniel Cukor,<sup>1</sup> and Dawn P. Edwards,<sup>2</sup>

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Patient perspectives can be a valuable component in understanding some of the factors contributing to health inequities. The inclusion of first-person accounts and the patient perspective is in line with recent academic trends (1) and movements within nephrology (2). The following accounts highlight the ways that culture and social determinants of health can combine in complex ways. Social risk can inhibit health-promoting behavior; increase risk of detrimental environmental and lifestyle exposures; reduce access to, and quality of, health care; and increase stress demand; all of which can lead to negative kidney outcomes, directly and indirectly, through increased prevalence of comorbidities (3). We have chosen to highlight some personal vignettes and stories by placing them along a timeline from diagnosis through treatment.

## CKD Diagnosis

“Kidney disease is not as ‘popular’ as heart disease, therefore, so many of us—especially people of color—are unfamiliar with how at-risk we are. In my community, the thought is that it happens to someone else, but not to me because my doctor hasn’t told me anything as a diabetic or hypertension patient. These individuals believe their doctor has everything under control along with all the answers they need, and that they themselves don’t necessarily have a responsibility of learning more on their own or asking the simple question of ‘What does this mean for me?’”

“When I was diagnosed with kidney disease, I was 23 years old. I had no idea what kidney disease was all about. I was told I had to change my diet and wasn’t appropriately educated on my treatment options. The symptoms weren’t blaring out at me, so I didn’t really pay attention to how bad I was feeling. As a matter of fact, I was hoping that I was pregnant. I was having headaches daily and instead of going to the doctor to get checked out, I took an old family remedy of headache powder and cola. I found out later that this headache powder only exacerbated my condition and hastened my kidney failure.”

## Early Intervention

“Of course, I crashed onto dialysis; we didn’t have the luxury of dealing with too many problems upstream. We were constantly overwhelmed and putting out fires.”

“Originally, I’d considered [that] my kidney journey began with my initial visit to the peritoneal dialysis consultation as a patient in kidney failure, when in actuality, it started with my CKD diagnosis 5 years prior. I believe I didn’t count this initial span of time simply because I was in a haze; I wasn’t thinking clearly or fully understanding what CKD meant for me or what lay ahead. I don’t recall a time when the nephrologists I met with early on gave me a clear picture of what was going on with me, nor was I introduced to a nurse or staff member who could help me navigate this new chapter of my life. To be blunt, I feel these doctors failed me.”

“As I think back over the past 27 years with kidney disease, I often wonder why the physician that diagnosed me didn’t encourage me, a young capable woman, to do home dialysis. Did he think that I wasn’t smart enough to do it myself? He said, ‘You don’t want to do peritoneal dialysis because you’ll get an infection and die.’ Three years later, another doctor encouraged me to try home dialysis and it changed my life around for the better.”

“I believe modern medicine has made outstanding progress ... but the truth is, disparities hinder medical progress by limiting access to adequate resources needed to address the health problems among people of color.”

## Kidney Failure

“Being told that I had to change my diet was like telling me that my life was over. Food was a huge part of my family dynamic. To us, food meant love; everything that we did revolved around good old soul food.”

<sup>1</sup>Behavioral Health, The Rogosin Institute, New York, New York  
<sup>2</sup>The Rogosin Institute, New York, New York

**Correspondence:**  
Dr. Daniel Cukor, Behavioral Health, The Rogosin Institute, 505 East 70th Street, New York, NY 10021.  
Email: [dac9227@nyp.org](mailto:dac9227@nyp.org)

“When diagnosed, beer and pizza were a main part of my daily diet. Managing kidney disease at that point was unbelievably challenging; the foods that I was told that I should eat were not readily available in my neighborhood. Finding good, healthy produce was a challenge and food that wasn’t processed was almost impossible. So, I ate the best that I could and continued my dialysis treatments, and naturally I felt worse and worse as time progressed.”

“I knew I was going to be one of those people that would ‘make it’ in life, and the only way I knew how to do that was by being singularly focused on my career. I wanted a better life for myself and refused any distractions. When I was first diagnosed, I treated this like any other problem: I saw my health as a threat to my success, and I ignored it. I could not imagine myself on disability, collecting a check; I wanted to achieve on my own. No wonder I was such a ‘bad’ patient in the beginning.”

## Transplant Listing

“When I learned that getting a kidney transplant would keep me from having to go to dialysis three times a week, I was so excited, but much to my dismay, I discovered that there was no one in my immediate family or friends that was able to donate to me because everyone either had high blood pressure or diabetes already.”

“My family thought I was out of my mind to ask them to give up one of their organs. They believed that they were born with two for a reason, and no matter what any doctors told them, they needed to hold on to both.”

“In my community, many people won’t even get listed as deceased donors because they are worried that doctors will suddenly become more interested in harvesting their organs than providing health care.”

Health disparities exist across the CKD continuum, and understanding the patient perspective can be a powerful step in addressing them (4). Certain themes arose out of the comments of the panelists. There was a general sense of medical mistrust, including preference for home remedies, a value on underreporting, and a general suspicion of doctors and researchers. Another theme that emerged was that the patients and their families often did not have the emotional or financial resources to prioritize the distal consequences of chronic health conditions because they were most often addressing other pressing problems. Finally, a third commonality was that the patients suggested they went on a “journey” toward acceptance of their diagnosis and its treatment. They emphasized the dynamic nature of their adherence behaviors over time and the need for continued education. They highlighted that, without full understanding and acceptance, self-management and adherence to the complex medical regimen (5) are further complicated.

With the goals of precision medicine permeating health care, the lens with which medicine views the patient runs the risk of becoming increasingly narrow, focusing on

only individual-level factors. Beyond the inclusion of the Engel biopsychosocial model (6) in understanding patients with kidney disease (7), expand even further outward and consider the Bronfenbrenner social-ecological model (8), which argues that we should consider people as members of communities and society in general. We need to include an appreciation of the complexity of the threads running through people’s lives—their wide range of influences, experiences, and beliefs. Understanding people with kidney disease in the context of their value systems and communities is essential to understanding them at all.

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\*The New York Academy of Medicine’s 2020 Alison Norris Symposium included a panel discussion of patients and frontline mental health professionals, with David White, Cecilia Santana, Dawn Edwards, and Mozelle Lafleur presenting and Daniel Cukor moderating.

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See related Perspectives, “Social Determinants of Health in People with Kidney Disease: An Introduction,” “The Pathogenesis of Race

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“Social Determinants of Kidney Health: Focus on Poverty,” “The  
Seen and the Unseen: Race and Social Inequities Affecting Kidney

Care,” and “Reducing the Burden of CKD among Latinx: A  
Community-Based Approach,” on pages xxx-xxx, xxx-xxx,  
xxx-xxx, xxx-xxx and xxx-xxx, respectively.