Reframing Disability: Shifting Perspective to Better Care for Patients with Disabilities

By Bridget M. Kuehn

Ken Sutha, MD, PhD, a pediatric nephrologist at Stanford University School of Medicine in Palo Alto, CA, was diagnosed with focal segmental glomerulosclerosis at aged 10 years. In his second year of medical school, he received a kidney allograft from his father. The treatment came with its ups and downs, Sutha said. Ten years later, he experienced loss of function of the kidney allograft and underwent 2 years of peritoneal dialysis as he started his fellowship, before receiving a second kidney allograft. “Through all of that, I never thought about myself as being someone with a disability, and that hindered me from reaching out for help and asking for accommodations I would have benefited from,” he said. “I was fortunate that I worked with people who were very understanding and able to work with me through my difficulties.”

Sutha now identifies as a member of the community of people with disabilities, and he shared his experience, the legal frameworks that protect individuals with disabilities, and the diverse perspectives of members of his community during the “When the Patient Becomes the Teacher: Exploring the Intersections of Disability and Kidney Diseases” session at Kidney Week 2023 in Philadelphia, PA. He challenged attendees to rethink how they view disability in patients and in their practices.

“Although my journey with kidney disease has been difficult, there are many wonderful and beautiful things that have come to me because of [it],” Sutha said, “Experiences that I’m able to bring to bear in the care of my patients by sharing my lived experience and how that impacts the way that I view their care.”

Disability 101

One in four adults, or 61 million people in the United States, live with a disability (1). Sutha explained that the Americans with Disabilities Act (ADA) (2) defines disability as a physical or mental impairment substantially limiting one or more major life activities. However, he noted that people under this legal umbrella may have diverse views of their condition, identity, and experiences.

Some disabilities are apparent, such as with those who use a wheelchair, whereas other disabilities may be invisible, such as living with a chronic disease or mental illness, Sutha said. Some are temporary, whereas others may be long-term. People with apparent disabilities may not have a choice whether or when to disclose their condition; however, those with less-visible disabilities can decide with whom to share the information. Both have their challenges, he said. People with apparent disabilities may face preconceived notions about them, whereas those with invisible disabilities may face stigma or disbelief, he noted. Some people with disabilities prefer person-first language describing their condition (i.e., “a person with a disability”). In contrast, others identify as a “disabled person” because they feel it is central to their identity and experience, Sutha explained.

The ADA requires accommodations for people with disabilities at work, school, and in other areas of public life. However, not everyone with a disability may choose to request accommodations. Sutha said he was lucky to have support from his fellowship program despite not requesting formal accommodations and could work full-time while undergoing peritoneal dialysis. However, he has spoken to many trainees and fellows who experienced challenges because they did not seek formal accommodations under the ADA.

Intersectional identities, such as being a member of racial or ethnic minority groups or identifying with a sexual or gender minority, may also affect an individual’s experience with disability, Sutha said. Some groups have higher rates of disability, whereas others may be less likely to identify as having a disability, he added. For example, 3 in 10 American Indian or Alaska Native individuals have a disability, compared with 1 in 4 who are Black, 1 in 5 who are White, 1 in 6 who are Hispanic or Native Hawaiian or Pacific Islander, and 1 in 10 who are Asian American (3). These individuals may also experience discrimination, or “ableism,” based on their disability, as well as racism, sexism, or discrimination based on their sexual orientation or their gender identity.

People’s experience with disability may also vary based on their circumstances or resources, such as social support, socioeconomic status, employment, or access to assistive technology or accommodations, Sutha said. For example, he noted that some individuals may have the same need for dialysis that he did during his fellowship but not have the resources or space for supplies required for home dialysis. As a result, they may require in-center dialysis multiple times each week, which could impact their ability to work or care for their family.

Physicians tend to view disability through a medical model as an impairment to be fixed, Sutha said. “This takes away decision-making capacity from them, making them an
object of charity, someone to pity,” he explained. “It’s only the ones who rise above whose stories get lifted up.”

However, an alternate perspective considers disability as a part of human diversity and people with disabilities as deserving of equal rights. “This focuses on autonomy, choice and freedom, and consent for disabled individuals,” he said. “It says society should be doing the work to support disabled people, and the community should be adjusting to make things accessible.”

Patient priorities

More than one-half of physicians say they welcome patients with disabilities in their practices. Still, fewer than one-half feel confident caring for them, and only 20% strongly agree that people with disabilities treat their quality of life as much higher than physicians do. For example, a study of emergency care professionals also found that only 18% imagined they would be glad to survive a spinal cord injury, and 41% felt resuscitation efforts for people with spinal cord injuries were too aggressive, whereas 92% of people with spinal cord injuries were glad to be alive (5).

“This is one of the big reasons many patients with disabilities face health inequities,” Surha said. He noted that one in three patients with disabilities does not have a usual care physician. The same proportion has unmet health care needs because of cost, often linked to low incomes or challenges with employment. Patients with kidney diseases often face low employment rates. For example, although 84% of the general population are employed, 38% of patients with kidney diseases are employed 6 months before initiating dialysis, and after starting dialysis, that number drops to 24% (6). Black and Hispanic patients with kidney diseases are disproportionately affected by unemployment, Surha noted, adding to these burdens. “This is a population of people that have missed opportunities. If properly accommodated, they could be employed, be contributing, and that could be beneficial to their health and well-being,” he said.

Unemployment can contribute to food insecurity and housing instability, which both may drive the development of disability, said Cynthia Delgado, MD, FASN, a professor of medicine at the University of California, San Francisco, and associate chief of nephrology for clinical operations and the director of the dialysis program at the San Francisco Veterans Affairs Health Care System. These factors contribute to higher rates of obesity, smoking, heart disease, and diabetes for people with disabilities, Surha noted.

Dialysis may contribute to frailty, particularly in older patients, and many patients with chronic kidney disease (CKD) also report difficulties with activities of daily living, Delgado said. She added that many patients lose mobility and the ability to do things independently.

“If you asked on your rounds what patients did on their non-dialysis day, they will tell you they didn’t do anything,” she said.

Delgado noted growing awareness among nephrologists about the importance of patient experience and that the Standardised Outcomes in Nephrology (SONG) initiative developed core outcomes for nephrology research, many of which include focusing on patient quality of life (7). For example, SONG issues include fatigue, the ability to travel or work, dialysis-free time, pain, stress, anxiety, sexual function, financial impacts, and the effects of their conditions on their family and friends. “How are we going to help our patients re-engage with life?” she asked. “One way of doing it is having the awareness to ask the right questions.”

She noted that the Centers for Medicare & Medicaid Services has also recently created the End-Stage Renal Disease Quality Incentive Program (8), which includes quality of life as a metric in the dialysis unit. She said the goal is to remove burdens from patients so “they’re just individuals thriving, living with CKD.”

Delgado added that this may take new and creative approaches. For example, she cited a pilot study by Diedra C. Crews, MD, MS, FASN, Johns Hopkins University School of Medicine, Baltimore, MD, which identified patients’ challenges at home and deployed a team—including a maintenance person, an occupational therapist, and a nurse—to their homes to complete up to $1300 in repair, modifications, or device installations to help patients overcome physical barriers (9).

Delgado also highlighted the interactions between exercise and physical functioning. She cited evidence that interventions to gradually increase patients’ physical activity, such as wearable physical activity monitors (10), can help patients with CKD improve their physical function. “If we address it early, we may be able to reverse it,” Delgado said. “(Physical)

limitations lead to loss of independence, financial stress, and social isolation, stressors that we don’t want our patients to also experience with the burden of CKD.”

Healthcare humility

Despite the high rates of disability in the US population, people with disabilities are under-represented in health care, accounting for 5% or less of the workforce (11). Surha noted, which may also contribute to poor care. A survey at Stanford University found that 5% of medical students and just 3% of practicing physicians identify as disabled, Surha said. He noted that fear of repercussions from disclosure may cause some not to disclose. “We need to be superhuman to work in medicine,” Surha said. “We celebrate doing 24-hour calls and the amount work we do while we are sick and never having to ask for help. That is a detriment to us as health care [professional] and ultimately to our patients.”

He noted that health care practitioners with disabilities bring valuable, lived experience with the challenges of living with disabilities and managing appointments and medications that may benefit patients. Colleagues working with clinicians with disabilities may also help by getting to know them and their capabilities. “Disability doesn’t mean inability; when we are properly accommodated, we can accomplish as much if not more,” he said.

Surha emphasized the importance of physicians exercising humility when caring for patients with disabilities, listening to them, and believing them. He also said health care must embrace universal design to make spaces accessible to everyone and be mindful of language. He noted that often universal accommodations may benefit everyone. For example, curb cuts created to accommodate people using wheelchairs help many people, such as those with rolling bags or strollers. “We need to recognize the authority of people with disabilities as experts on their own lives and elevate their voices,” he said at Kidney Week 2023. “ASN has been doing a great job elevating patient voices, and I’m glad to see that at this conference.”

References


Are you a fellow and have a tip or idea you’d like to share with your fellow peers and the broader kidney community?

Send your idea to the ASN Kidney News Fellows First column at kidneynews@asn-online.org