


## Life with Sickle Cell Disease and Kidney Failure Minimizing Fear with Knowledge

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I grew up watching family members plagued with various comorbidities (usually some combination of diabetes, high BP, and heart disease) navigate the world. Some had kidney disease due to one of the aforementioned maladies, including my father. Some had sickle cell disease accompanying their other ailments—so, acquiring one or both was always a fear. Because my father was a minority health expert focused on sickle cell anemia for much of his career, I have always been acutely aware that health disparities across racial and socioeconomic lines are a critical problem in the United States. Such disparities come in the form of fewer resources for treatment and research, including access to transplantation. In this issue of *CJASN*, Bae *et al.* (1) look at issues of mortality and access to kidney transplantation in patients with sickle cell disease–associated kidney failure.

Extensive sickle cell disease research only started in the 1970s and remains relatively slow; thus, we are at a disadvantage in the understanding necessary to have proper resources or innovative treatment. After the inevitable happened and I got my CKD diagnosis—and even now post-transplant—the fear of missing signs of serious complications remains. When you live with a disease that can cause other issues, you live in perpetual fear. Sickle cell disease is unique in that it almost exclusively affects Black Americans and, more recently, smaller numbers of Hispanic Americans and others. Since acquiring diabetes at the age of 12, I have always gone to the doctor regularly—although distrust in the medical complex permeates the Black community. As an adult, I understand why. From the Tuskegee experiment to Black maternal mortality rates today, such distrust is warranted.

So, in addition to the perpetual fear of developing a disease, there was always the fear that if I did, I may not get the treatment I deserved due to a lag reinforced by decades-old biases in health care. Although I have been fortunate to be in a socioeconomic position that allows me access to exceptional medical care, I understand that biases exist everywhere, and I have always tried to educate myself on my conditions as best as possible to prepare for every scenario. There are arsenals of resources available for cancer and heart disease, as they affect a large multiethnic swath of the United States, but searching for information on sickle cell disease or even kidney disease is harder. Given all of the

trouble I had finding information, I could not imagine not having access to the internet, having to rely on limited resources at my health care facility, or not knowing exactly what to look for.

Most people living with sickle cell disease know that one of the many complications is organ failure. Using kidney failure as an example, part of the problem is that manifestations of sickle cell disease outcomes can vary, and if you are not well versed in kidney disease, it can be hard to tell the difference. As a patient with kidney disease, I have experienced symptoms that I attributed to medication/kidney disease side effects when they sometimes are simply due to, for example, aging or a significant change in habits. It takes understanding your body well to be able to make informed judgments about what is an indication of something more serious that requires attention.

Anemia, neuropathy, and dehydration are common in sickle cell disease, kidney disease, and diabetes. Now with coronavirus disease 2019, a patient with sickle cell disease may misinterpret symptoms of a common sickle cell disease problem, like acute chest syndrome, for coronavirus disease 2019, or vice versa. Ultimately, as patients, we need to be responsible for our own health, but if we do not have proper measures or information, how do we recognize the signs of something serious? Additionally, the scope of complications for sickle cell disease is so wide and unpredictable, there are many things to watch for. Also, if you have sickle cell disease and get diagnosed with any stage of kidney disease, you have to re-evaluate and re-educate yourself to traverse the “sea of comorbidity” daily.

Early detection of kidney disease benefits patients, doctors, and insurance companies. A good place to start would be to implement preventative kidney disease measures in the sickle cell disease community and incentivize insurance to allow such measures, including monitoring protein in the urine, carrying out regular checks for worsening anemia, and performing regular GFR (or eGFR) tests. Because people with sickle cell disease are already familiar with disease maintenance, it stands to reason that incorporating an eGFR would not be too difficult. However, I know patients who would not think to ask for these tests, or they have asked and been told the tests are unnecessary. Transplantation is a complicated issue as well. As Bae *et al.* (1) find, the “sickle cell population was less likely to receive

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transplantation, even after waitlist registration." Access issues are further compounded by attitudes regarding donating and receiving organs, which are affected by personal experience with health care providers, shared stories/history, and, sometimes, religious beliefs. Poor provider attitude and knowledge, which I have experienced myself, do not help either. I knew that a transplant would make my life easier and was fortunate to have had an easier time than some individuals in minority communities in getting listed and finding a match.

Ultimately, fear is dispelled by knowledge and proven results. For me, access to information and proper care from health care providers makes me feel "seen" and better prepared for the challenges of life with a disease. I want that same feeling for everyone with sickle cell disease and kidney disease.

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1. Bae S, Johnson M, Massie AB, Luo X, Haywood C, Lanzkron SM, Grams ME, Segev DL, Purnell TS: Mortality and access to kidney transplantation in patients with sickle cell disease-associated kidney failure. *Clin J Am Soc Nephrol* 16: 407–414, 2021

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See related article, "Mortality and Access to Kidney Transplantation in Patients with Sickle Cell Disease–Associated Kidney Failure," on pages 407–414.