What It Means to Live with Focal Segmental Glomerulosclerosis

Kent Bressler

On reading a recent CJASN article entitled “Identifying outcomes important to patients with glomerular disease and their caregivers” (1), I had a flashback to when I was diagnosed with FSGS by biopsy in 1984. As a person with kidney disease, I know that patients care about being listened to, that patients want to tell their story, and that patients want to be reassured. Reassurance helps provide hope.

Living with glomerular disease, as reflected in the study (1), is scary, difficult, and filled with disbelief, fear, and in some cases, depression. In my experience, early on in the journey, there is an absolute fear of “what is going to happen,” “how long do I have,” and “am I going to die?” No one wants to be sick; everyone seeks normalcy and a good life. The problem with glomerular disease is that it is progressive and marked by a continuous adjustment by the body to survive. Through all of these major adjustments, life goes on. As a person living with glomerular disease, you still have to be productive and support your family. To support your family, you must survive, and that is always on your mind. Hope is essential. Hopes comes from a positive attitude and in my case, a profound faith in God.

Many people with glomerular disease do not report their feelings because they do not feel that they have anyone to talk to who can relate. In many cases, you do not look like you are sick, but inside, you are wasting away little by little. My saving grace was a caring and intelligent nephrologist who carefully took the time to explain the gravity and severity of the disease and the options open to my family and me. My wife of 50 years has been my rock of love and compassion and has given me hope through this journey. My reflections here are my own. No two people with glomerular disease are the same, and the disease progresses differently in everyone.

Everyone benefits from a mentor (advocate), someone that they can rely on and trust. Mentors who have been living and fighting through kidney disease or are actually on the same journey as you are the saviors of sanity. Valuable life survival techniques can be learned from those who are on dialysis and/or who have had a transplant. The key gatekeeper in my mind is the nephrologist as reflected in the study (1); all of the participants were “nominated by their nephrologist.”

My early course of treatment was laced with high-dose steroids and antihypertensive medications mixed in with diuretics. There were times in which I was so sick that I did not think that I was going to survive. I was physically and mentally sick, and, if not for Dr. Paraic J. Mulgrew, my nephrologist, I would not have survived. At that time, my only mentor other than my wife, Catherine, was Dr. Mulgrew and some key fellow employees who understood what is was like to have kidney disease. I would have loved to embrace the counsel of someone who had gone through what I was about to experience. Looking back, along with a mentor, a solid support group would have been beneficial. A group gives added support when you really need it and provides for periods to laugh and be at ease. Every nephrology practice and hospital would benefit from a kidney/transplant/dialysis support group.

As my clinical numbers worsened and I became sicker and more debilitated from fatigue and anxiety, I became more fearful and angrier until, thankfully, my brother Kip stepped up and gave me one if his kidneys on April 30, 1987. Throughout the years, post-transplant visits have always been difficult because I have to face the numbers. If you have FSGS, the fear of it returning never leaves you. Every blood draw and clinic visit give rise to anxiety. Is it back? Am I going to lose my kidney? What should I focus on?

I am 70 years old now. The kidney that I borrowed from my brother is 68 years old. What is it that I care about as an aging patient with glomerular disease? Living and helping others with this disease is what I care about. I have been a patient mentor and advocate for 30 years. In direct partnership with the nephrologist and kidney community, we need to use every tool available to us to promote early detection and preemptive transplant. Social media, support groups, professionally trained personal mentors, and more can be used to inform and educate people living with glomerular disease.

To my nephrologist friends, the “patient voice” is one of healing and experience. Your large group practices are conducive to developing “mentoring positions.” Consider developing a mentorship program to help your patients overcome their fears and anxiety and connect them with people who can relate to...
their experience. It is then less about numbers and more about people. If we listen, we can serve.

Disclosures
Mr. Bressler has nothing to disclose.

Funding
None.

References

Published online ahead of print. Publication date available at www.cjasn.org.

See related editorial, “Ask and It Shall Be Given: Patient-Centered Outcomes in Glomerular Diseases,” and article “Identifying Outcomes Important to Patients with Glomerular Disease and Their Caregivers,” on pages 594–596 and 673–684, respectively.