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ReachMD
www.reachmd.com
info@reachmd.com
(866) 423-7849

Integrating the Patient Voice in FSGS Management

Announcer:
Welcome to CE on ReachMD. This activity is provided by Medtelligence and is part of our MinuteCE curriculum.

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Dr. Sise:
This is CE on ReachMD, and I'm Dr. Meghan Sise. Today, we're going to cover patient-reported outcomes and health assessments in FSGS.

Patient-reported outcomes, or PROs, are health outcome measures that are reported directly by the patient without interpretation by the clinician. PROs are valuable tools in understanding the impact that a disease like FSGS can have on patients’ lives. They can help doctors understand patient factors which may not be fully reflected in their lab values, such as the disease burden and the impact on their social and emotional wellness and quality of life. PROs provide insight beyond traditional markers, like proteinuria and serum creatinine, and they can reveal the burden of symptoms, like fatigue, pain, and edema. They can capture how patients are feeling and functioning and how they're experiencing their health and physical, mental, and social well-being. They can reveal the impact on a patient's daily activities, work, and school.

We know that labs, like proteinuria and creatinine, provide quantitative metrics but these are metrics that can really only be elicited in open conversation with our patient. So when we ask open-ended questions like, “What is the hardest part of having FSGS right now for you? What's changed in your quality of life since the last time I've seen you? What types of things are you cutting back on in your physical activity and in your work life?” are really important to allow patients to have that space to tell you what's going on beyond just their labs.

There's also existing PRO tools that can elicit patients’ perspectives, and PROs can and should be factored into treatment decisions. Currently, there’s no validated FSGS-specific PRO tool, and most work borrows from CKD PROs, such as the KDQOL-36 or PROMIS measures, focusing on things like fatigue, pain, and physical function.

So next, let's hear from a patient with FSGS. They can tell us a little bit about their experience, working with their healthcare team, and using PROs to help create their care plan.

Matt:
So when I was initially diagnosed with FSGS, I didn't ask a lot of questions. I really just wanted to know, what are we going to do about it?

And I was described what the standard course of treatment was and sort of followed that and didn't really ask a lot of questions.

But the more I came back in for treatments and the more lab work I had, I began to pay more attention to the labs and, I think, become more informed of what the labs were telling me about my symptoms and what I was feeling. And that led to kind of more discussions and really talking about the specific labs, like why is this number changing? Do other patients go through this?

So the more I got into it, this is really over the course of 4 or 5 years, I became much more comfortable talking about the labs, what they mean, what can we do to change things. Is this expected? Is this unexpected? You know, I wish I'd paid more attention earlier on to those things, but earlier on, you just want to know what you have and what the plan is to fix it. That was my experience.

And at the same time, I definitely had symptoms. And I was uncomfortable with the swelling, I was kind of tired, lethargic, and I was wondering, should I be taking time off of work?

As I mentioned, I had just started a new job that required travel, and there was a lot of anxiety around that, in that I didn't want to let it interfere with my work, but I didn't want to continue to work if it was going to slow down my recovery or add to my symptoms. So that was kind of a stressful period.

The benefit of going through this process is I think I've had much more informed discussions with the nephrologist at the clinic where I go, understanding what medicines impact what symptoms, and asking about alternative treatments that are coming online.

And then the nonmedical aspect of our conversations, which is around what do I want to get back to doing that I wasn't doing before? In my case, it was running. I had run marathons in 2018, 2019, wanted to do ‘20, but these symptoms arose and prevented me from doing so. But I started to run, and that was really my key metric, that we would talk every 6 months. And my appointments were how's the running going? How are you feeling? Are your legs swelling?

So I’d have discussions with my nephrologist, and she was very encouraging to do as much as I felt comfortable doing, which kind of led to me running my third marathon this year, so 5 years after my diagnosis.

Dr. Sise:
Our key takeaways here are that PROs capture a patient's own assessment of their disease, their symptoms, function, and quality of life without clinician interpretation. Patients with FSGS face more than proteinuria. They face fatigue, edema burden, medication side effects, and psychosocial impacts that are substantial in their quality of life.

Trials and treatment plans that ignore PROs risk missing what matters most to patients.

So our time is up, but I hope you found this information helpful and our patient’s perspective enlightening. Thank you for joining me today.

Announcer:
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