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What You Don’t See: A Patient’s View of Living with CKD-aP

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Dr. Fishbane
This is CE with GLC, and I'm Dr. Steven Fishbane. Here with me today is Dr. Nancy Helou.

Nancy, let's review how CKD-associated pruritus symptom clusters manifest for patients, and what does it mean for a patient's quality of life?

Dr. Helou:
CKD-aP frequently shows up indirectly. A patient may not say, “I have pruritus,” or “I am itching.” They may say, “I'm not sleeping. I'm exhausted,” “I feel on edge,” or “My skin is driving me crazy.” Sometimes distress is visible only as rubbing or scratching, poor concentration, or being withdrawn during dialysis.

One of the biggest barriers is normalization. Many patients have lived with itching for months or years, so they stop reporting it. They may have accepted it as part of their disease. Others feel embarrassed, especially if there are scratch marks. Some believe nothing will help or that clinicians will dismiss it as minor. But communication is part of treatment. So I would use a nonjudgmental normalizing approach, saying a lot of people with kidney disease experience itching, and it can affect sleep and mood. I ask everyone about it because we can help.

Then I would ask 3 focused questions: How bad was your itch in the last 24 hours, 0 to 10? Does it keep you from falling asleep or wakes you up at night? And are you scratching enough to cause marks or bleeding? Those questions uncover symptom clusters. If they say the itch is an 8 and then they say they slept only 3 hours, we are no longer dealing with a small complaint. We are dealing with fatigue, emotional strain, reduced ability to function the next day.

And if they say they avoid social events because they scratch in public, then CKD- aP is affecting dignity and relationships. If they describe anxiety and low mood, we need to respond to that too.

In fact, structured prompts can be integrated into dialysis rounds. Nurses can ask and document the severity, skin findings, sleep disturbance triggers, and treatment adherence. Physicians can review differential diagnosis, adjust the treatment. We can also teach patients to keep a simple symptom log and report early flares rather than waiting until it becomes severe.

The key is to make patients feel believed. We should say clearly this is a real CKD-related condition, and it is worth treating. That statement alone can reduce shame and open the door to better care.

Dr. Fishbane:
Nephrologists, other related clinicians, nurses, dietitians, and others that work with dialysis patients on a daily basis have come to understand that we have effective therapy for people who have CKD-associated pruritus. However, for some there may be a lack of awareness of some of the literature as it has evolved in recent years.

So I'd like to remind people about the KALM studies, the first one published in the *New England Journal of Medicine*, which was a placebo-controlled study. This demonstrated the effectiveness of difelikefalin compared to placebo, and I think was a real revelation in that we came to understand that there was effective therapy and that, compared to placebo, we could achieve real benefit in terms of patients not just itching, but yes, itching improved very significantly. But both in the initial studies that were published and in subsequent studies, the effectiveness in terms of patients' quality of life, and that involves the spectrum of sleep quality and other aspects of how patients experience day-to-day life.

We have evidence from the DISCOVER CKD study and others. And truly, on a day-to-day basis, as we take care of people on hemodialysis, we understand how their lives are affected by this disease. Every additional problem on top of that, and CKD-associated pruritus is an important example, further complicates and degrades patients' quality of life and experience.

So I think that we have seen important efficacy demonstrated and have had the pleasure being able to establish that and work with it in actual clinical practice.

Thank you. This has been a great discussion. Our time is up. Thank you for listening.

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