

Transcript Details

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Beyond the Cure: Addressing Psychosocial Needs in Gene Therapy for SCD

Announcer:

You're listening to *Project Oncology* on ReachMD. On this episode, we'll hear from Dr. Victoria Coleman-Cowger, a licensed clinical psychologist and Associate Vice President of Neurology and Cell and Gene Therapy at Emmes, a full-service clinical research foundation. She'll be discussing her research on psychosocial support during and after gene therapy for sickle cell disease, which was presented at the American Society of Hematology 2025 Annual Meeting. Here's Dr. Coleman-Cowger now.

Dr. Coleman-Cowger:

It's important to understand that the decision to undergo gene therapy for someone living with sickle cell disease is a complex one that requires an individual to weigh the risks and the benefits both to themselves and their families. So just getting to the point of undergoing gene therapy can involve quite a few psychosocial stressors. And some of the challenges that could be experienced during the process of undergoing gene therapy involve emotional health challenges, like depression or anxiety, and concerns around prolonged hospitalization and inability to work or go to school.

And then after gene therapy, there may be concerns about where to seek care. If they received curative treatment, would they still be considered a sickle cell warrior? There may be some identity issues or concerns about reintegrating into the sickle cell community and whether or not they would be accepted in the same way. And gene therapy also requires a lengthy follow-up period, and that can sometimes feel burdensome when someone's feeling better and not experiencing the same pain symptoms.

Our research was conducted as part of the Cure Sickle Cell initiative, which is an NHLBI-funded initiative that's aimed at accelerating genetic-based cures for sickle cell disease. So back in 2020, a patient readiness and resilience work group that consisted of behavioral health clinicians and scientists with expertise in sickle cell disease as well as adults with lived experience with sickle cell and a caregiver was established to provide guidance on how best to support psychosocial health for people living with sickle cell and undergoing gene therapy.

So the recommendations for pre gene therapy assessment were presented at ASH two years ago and were published in *JAMA Network Open* in August of 2024. This year, recommendations have been drafted for during and post gene therapy. Just as a summary of the key strategies, we essentially are recommending to start with a strong pretreatment psychosocial foundation, plan proactively for continuity of care posttreatment, maintain structured and regular check-ins aligned with patient recovery and adaptation, ensure clear role delineation and communication among clinical teams, and then tailor the monitoring to address evolving psychosocial needs.

So the big takeaway from our preliminary guidelines is the importance of integrating mental health support throughout the gene therapy process and post-gene therapy by conducting brief ongoing assessments of psychosocial health to direct personalized support strategies. So we're hoping that there is increased recognition of the psychosocial supports needed during and after gene therapy and that institutions can incorporate more comprehensive care by adding mental health supports where they might not currently exist.

It's a really exciting time with the expansion of treatment options for sickle cell disease, and it's tempting to focus solely on the transformative nature of the therapy and the tremendous physical improvements that are possible. But it's also important to consider that a major change is a major change, and there's an associated impact to that change, whether it be positive or negative. So I would just encourage healthcare institutions, policymakers, industry, and clinicians to truly understand and address the psychosocial aspects related to gene therapy before, during, and after to best meet individual needs.

Announcer:

That was Dr. Victoria Coleman-Cowger sharing insights on psychosocial needs during and after gene therapy in patients with sickle cell

disease. To access this and other episodes in our series, visit *Project Oncology* on ReachMD.com, where you can Be Part of the Knowledge. Thanks for listening!