Transcript Details
This is a transcript of an educational program. Details about the program and additional media formats for the program are accessible by visiting: https://reachmd.com/programs/project-oncology/the-transition-from-pediatric-to-adult-care-for-patients-with-sickle-cell-disease/36448/

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The Transition from Pediatric to Adult Care for Patients with Sickle Cell Disease

Announcer:
You're listening to *Project Oncology* on ReachMD. On this episode, we'll hear from Dr. Nidhi Bhatt, who works in the Department of Hematology at St. Jude Children's Hospital in Memphis, Tennessee. She'll be discussing the transition from pediatric to adult care for patients with sickle cell disease.

Dr. Bhatt:
Transition starts at a much younger age than we think. It is not only something that we start discussing with our patients when they're 17 or 18. We start talking to families and the patients from at least 12 years of age when they start understanding. So we start talking to our patients from 12 years and onwards, and we start preparing them for the transitions from 12 years and onwards, and that includes education with our transition nurse or the care coordinator. It includes doing a transition tour of the adult center because a lot of the times, some of the barriers are that the patients don't know the adult providers, there's unfamiliarity, or there's sometimes mistrust or distrust, so we try to remove a lot of those barriers. Knowing how to read your insurance card, knowing how to reach out to your insurance companies if you don't have insurance and are on public aid. So again, we try to provide a lot of these skills, of course to the parents, but also to the patients themselves, to make sure that they have these skills because they're going to have to do it on their own as they're moving to adulthood. And one of the biggest things we try to teach them is to advocate for themselves. So if they know which pain medication works for them, we need our patients to be able to say, "Hey, these are the medications that work for me." They also need to be able to verbalize some of their history, like, "Hey, I have had issues with my heart," or "I have had issues with my kidneys before."

The biggest mistake or a misstep that we make is not listening to our patients. I think our patients know what is needed. Obviously, they've been taking care of their sickle cell disease for a long, long time. The parents have been dealing with a lot of the barriers for a long time, so the biggest advice I would give is to have a patient advisory panel or have a patient advisory group or do a patient focus group and just hear the patient population out and figure out what the barriers would be the first step. Once we know we have surveyed the resources and we have surveyed the barriers, then I think we should go back to the drawing boards and say, "Hey, what can we offer?" And I would highly, highly recommend having a nurse care coordinator or having a transition care coordinator. I think that really makes a big difference, because you really need somebody to have that connector between all the specialists and the patient and the team members who are taking care of the patient. I think that central person really needs to be there.

Announcer:
That was Dr. Nidhi Bhatt talking about transitioning from pediatric to adult care for 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!