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/examining-barriers-and-facilitators-in-pediatric-sickle-cell-disease-care/36235/

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

Examining Barriers and Facilitators in Pediatric Sickle Cell Disease Care

Ashley Baker:
This is *Project Oncology* on ReachMD. I am Ashley Baker, and joining me to discuss their recent research on facilitators and barriers to sickle cell disease care in children are Drs. Alyssa Schlenz and Shannon Phillips. Dr. Schlenz is an Associate Professor of Pediatrics at the University of Colorado School of Medicine.

Dr. Schlenz, thanks for being here today.

Dr. Schlenz:
Yeah, thanks for having me.

Ashley Baker:
And Dr. Phillips is an Associate Professor in the College of Nursing at the Medical University of South Carolina.

Dr. Phillips, welcome to the program.

Dr. Phillips:
Thank you so much. Happy to be here.

Ashley Baker:
So, Dr. Schlenz, I'll start with you for some context. Why did you decide to focus your research on facilitators and barriers to care for children with sickle cell disease?

Dr. Schlenz:
So this particular paper was part of a larger study called DISPLACE, and DISPLACE is a large 28-site consortium led by Dr. Julie Kanter where we were actually interested in a more focused question around why kids with sickle cell disease were not getting screened for stroke risk. And to understand that more specific question, we realized that we needed to understand what was going on more broadly with healthcare for sickle cell disease, so that's why we decided to ask these broader questions of families around what was working well related to their healthcare for sickle cell disease and what were the things that were getting in the way.

Ashley Baker:
Now, Dr. Phillips, I understand your study uses the Conceptual Framework of Access to Care Model, so could you briefly describe this model and why it worked for your research?

Dr. Phillips:
So many access-to-care models focused primarily on patient or individual-level factors related to access to care, with limited consideration of more systems-level factors, and so we were really looking for a model that went beyond availability and uptake of healthcare services and that also included both systems-level and population-level drivers of access. And so this model, the Conceptual Model of Access to Care, does this. It includes systems-level determinants of access that it refers to as supply factors, and patient or population-level determinants that they refer to as demand factors. So in addition to that, the model also places these determinants—the supply factors and the demand factors—on a trajectory from identifying a need for healthcare through obtaining healthcare services.

So in summary, the model defines access as the opportunity to have healthcare needs fulfilled, and it considers the accessibility of providers, organizations, and healthcare systems, along with the ability of populations, individuals and communities to engage with those services. And so the model worked for this study because it gave us what you would call maybe a road map for analyzing our qualitative data and identifying not only the relevant systems, or supply, and population, or demand, barriers and facilitators to access, but also where on that access trajectory of identifying need all the way to obtaining services those barriers and facilitators lie.

Ashley Baker:
Looking at the results, Dr. Schlenz, what were some of the most significant facilitators identified by families?

Dr. Schlenz:
So one of the really interesting things that we found is that families overwhelmingly wanted to talk to us about the positive qualities of their sickle cell provider and care team. So, in particular, they described having this really positive, trusting relationship with their sickle cell specialist, which was typically the child's hematologist. They described that person as being knowledgeable, competent, and able to provide accurate and up-to-date information about sickle cell disease. And they also described this really interesting style of care from their team that was proactive, so that anticipated their child's needs ahead of time, that was responsive, so if they called or left a message, someone was going to be there to answer and help them, that was timely, and also that was comprehensive and coordinated, so care that considered all of the child's needs and that involved providers communicating well with one another. For the healthcare system as a whole, they also talked to us about having easy and flexible scheduling systems, and noted that having reminders and things like that were also useful.

And then I would say, outside of those groups of factors, families also told us about resources both in and outside of the clinic that mattered, with the top one being transportation. They also told us about things like access to social work and child life, family and social supports, and having a background in the medical field or previous knowledge about sickle cell, and then outside of those pieces, having things like an understanding or flexible workplace and high-quality insurance.

Ashley Baker:
For those just tuning in, you're listening to *Project Oncology* on ReachMD. I'm Ashley Baker, and I'm speaking with Dr. Alyssa Schlenz and Dr. Shannon Phillips about how we can improve sickle cell disease treatment in children.

So, Dr. Phillips, if we continue to look at the study's findings, which barriers stood out as most impactful to families navigating care?

Dr. Phillips:
So the barriers that really stand out are very complementary to the facilitators that Dr. Schlenz just talked about. So thinking back to the model or theory again, with the systems and supply side versus the population or the demand side, in terms of the systems or the supply side, some of the key barriers were around concerns of provider competence in caring for sickle cell disease and thoughts around the need for additional provider training in sickle cell disease. In addition, some participants felt like some providers didn't really care about them. This was in their words—quotes—but this was usually described outside of the sickle cell clinic and referred to other providers, not usually their sickle cell providers or sickle cell specialist. Also on the supply side, complex healthcare processes—and this also kind of speaks to what Dr. Schlenz was saying with the facilitators—but the complex healthcare processes were a key barrier. This included things like challenges with scheduling and rescheduling, keeping track of appointments, and facing delays in care or delays in being discharged from the hospital.

And then on the population or the demand side, again, reflecting what Dr. Schlenz was just saying about facilitators, one of the key barriers was transportation difficulties, and so this included things like having issues with the Medicaid transportation system and/or public transportation. Another key barrier on the population or demand side was competing demands, and so those are the things that you think about in your everyday life, so trying to take off of work to go to an appointment, having your child miss school for an appointment, or even having other caregiving responsibilities like caring for other children or an aging parent. And then the third barrier I'd highlight on the population and demand side were insurance challenges. And so this included things like not just getting insurance as a whole, but also having incomplete coverage, copays that weren't affordable, having to reapply annually for your insurance, and also finding providers in the network.

Ashley Baker:
Before we come to the end of our program, I'd like to ask each of you one more question. Starting with you, Dr. Schlenz, how can healthcare providers and systems use these insights to optimize facilitators and overcome barriers?

Dr. Schlenz:
I think one of the things that was really highlighted in this study was the importance of relationships. We know many sickle cell specialists across the country through our work, and all of the day-in, day-out interactions that providers and care team members have with families really do make a difference. I would say for providers who are unfamiliar with sickle cell disease, listening to podcasts like this and educating yourselves will also go a really long way with these families.

For care teams who are interested in identifying other ways to optimize care, this paper does have some great examples in the tables, particularly the supplementary table, that include things like analyzing your style of care as a team. So do you have a proactive or reactive approach to patient care? What are response times like to patient requests and calls? How easy or not is it to get an appointment scheduled within the hospital system? How well are team members communicating with one another? What does your education look like to families, and are there ways to optimize that? I also think from a hospital-systems level, making sure that clinics have access to things like social work, healthcare navigators, and child life. Those were resources that also seemed to make a difference.

And then outside of those pieces, there are certainly policy-level things that could be done particularly around the way that insurance does or doesn't work for families of kids who have chronic and unpredictable conditions. And even things like how work programs like FMLA are functioning, there are certainly some changes that could be made there that would facilitate care and remove some of the barriers that get in the way.

Ashley Baker:
And, Dr. Phillips, to finish up, what do you see as the next critical step or research areas to continue improving care for children with sickle cell disease?

Dr. Phillips:
So sickle cell disease has been underfunded in research and treatment advancements for years or even decades. This has started to improve, and we are seeing new disease-modifying therapies being developed and increases in curative and transformative options, which are things like gene therapy and bone marrow transplant. But in many cases, for children and adolescents to have access to these new treatments and to learn about ongoing research they could participate in, they really need to be under the care of a sickle cell disease provider or specialist. So what I see as a critical next step is to apply what we learned in this study as well as some of the other studies in this area so that we can develop some strategies to ensure that children with sickle cell disease are being linked into disease-specific care.

Ashley Baker:
That's a great way to round out our discussion. I want to thank my guests, Drs. Alyssa Schlenz and Shannon Phillips, for joining me to discuss facilitators and barriers in pediatric sickle cell disease management. Dr. Schlenz, Dr. Phillips, it was great having you both on the program.

Dr. Schlenz:
Thanks.

Dr. Phillips:
My pleasure. Thank you.

Ashley Baker:
For ReachMD, I'm Ashley Baker. 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.