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Psychosocial Considerations in Managing XLH

Announcer:

Welcome to CME on ReachMD. This episode is part of our MinuteCME curriculum.

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Dr Dawson:

Hi, everyone. I'm Dr. Anne Dawson. I'm a pediatric psychologist at Nationwide Children's Hospital. So what that means is I work with kids who have health conditions and I work typically with patients that are seen by nephrologists. So I'm happy to talk today about the psychosocial considerations in managing XLH. So let's get started.

As a psychologist, what I do when I think about kids in general is just what they're going through in development. And as you all know, as the brain changes and body changes, kids are going through different things and there's different things that are important to them. So if we break it down and chunk it into childhood versus adolescence, we see pretty extreme differences.

So little kids typically think more logically, black and white thinking. They tend to think that what their parents say is true, that their parents are right, and typically look up to their parents as the rule makers. Their friendships tend to be more same gender, same sex, and more play-based around common interests. They're getting improving emotional understanding, so they're able to identify their emotions and what triggers their emotions and have more complex emotions.

And then they're typically starting puberty. So again, when we're thinking about XLH, we want to think about how kids are starting to change and starting to differentiate from our patients. So kids are starting to have stronger muscles, stronger bones, and start puberty. And so they might start differentiating but not quite yet.

And then it's important to talk about the difference in adolescence. So we're thinking about how they think. Adolescents tend to have more abstract and developed thinking. They're starting to question parents a little bit more and be more autonomous and strive for independence. And then friendship is very important. Friends are more relationally intimate, deeper, diverse, and they tend to care more about what their friends think than what their parents think when they're making decisions. So they're engaging in more risky behaviors and engaging in more mature behaviors, one might say. Their emotions are more extreme.

And so we start to think a little bit more about the concerns for anxiety and depression when we're thinking about our adolescent patients, because that's normative. So we really want to look at that when we're thinking about our patients with chronic illness or that are different from their friends. Likewise, their physical growth changes and can be different than their friends. And they're really starting to look at who are they as people, what do they value, what's their identity? So we really want to think about these main areas when we're thinking about supporting our kids.

Who are their friends? What are their goals? What do they want to do in the future? And then also what's fun to them? What do they enjoy? What are their extracurriculars? And these are the things we have to understand about our patients and take it into context when we're thinking about who they are as patients. We have to know who they are first as people.

So when I think about transitioning or supporting our patients, I am always thinking in the background about them and their development and how we can help them and empower them. So when we take this paper that's cited by the [inaudible 00:03:23] in 2022, they describe transition for XLH patients as one, setting the stage, two, moving forward, and three, reaching their goal. When we think about setting the stage, we want to think about how soon we can start that in childhood. When they're thinking more black or white, we want to start introducing them to the topic. At some point, you're going to transition. At some point, this is going to be your responsibility. And we want to introduce that early and often, just like with any big milestone or anything coming up.

For example, homecoming. We want to start thinking about how are we going to pay for the homecoming ticket? Who might be your date? What outfit are you going to wear? Do you know how to dance yet? And kids will start thinking about that probably before their parents. And we want to start doing that with their health too. This is one thing they have to manage in life. And as we do that, we want to make sure that we're providing scaffolding. As providers, we want to scaffold the parents. And as parents, we want to scaffold the patients. We also want to model that anxiety about being ready to manage your care, about having a chronic illness is typical. We expect anxiety. It doesn't mean it's bad. In fact, we can grow more from being anxious and learning than we can from avoiding things. Avoidance tends to increase our risk of being anxious or depressed. So we really want to grow through anxiety.

So as kids are developing, we want to make sure that they have the appropriate ladder set up for them by the adults so that they can do their own climbing, but we're there for them if they need help or they get stuck. And again, we really want to think about in childhood, but even more so as they develop into adolescence, where do their friends come in and how is that important? So as kids are ready for that healthcare transition and we're providing that service, we really want to emphasize scaffolding. How can we help them be advocates, plan for it, organize, be assertive in their medical appointments, ask questions, and how can we empower them to be the patient? We should start modeling this young and continue to do it, always centering on what's important to them as people.

So as we're thinking about their mental health through this process or just through life as a patient with XLH, we want to always be considering their stress, what's stressful to them at what stage they're at. We want to ask them those questions or point out their moods. Think about what resources are available or if they need more to balance out their stress.

And then most importantly, what their values are. What's important to a patient could be their friends, could be sports, could be their computer games, could be their Snapchat Streaks or their TikTok. We want to know what's important to them and how does their health fit into that. We have to first center on what patients and parents care about before we can figure out how to help them manage their health. And then finally, we always want to acknowledge that health, XLH, it affects family going forward and right now and we want to support families in managing healthcare with patients.

And then finally, thinking about a toolkit for transition. There's a lot out there, but we want to know it takes a village to raise a kid. It certainly takes a village of lots of different resources to raise and support a kid with XLH. So we want to think about who their medical team is, who their school team is, who their friendship team is, who their extended family team is. We want to know what kind of support could they need and really develop that ask.

And most importantly, we want to empower kids to ask for help. That's really hard. And as providers, you only know how to help kids and families if they ask. But it's part of our role to tell them and review what's important in your life? Where might your health come into this? When might you take your medicine? And then offer help as they start raising those issues.

And then as they're growing, just developing checklists and records and keeping their records. And social work can often help with this too. But making sure that they're making progress with each medical appointment they're attending, so they're really ready for the next step.

So in summary, we want to think about who kids are as people, what's important to them now, what they can understand, and what they might be going through. We want to make sure that we're supporting them along the way. We're giving them a ladder, but we're expecting them to walk up it. And once they get to the top, they're ready and they feel accomplished being independent. We want to make sure they know that there's a team to support them and there continue to be a team to support them, but they have to know how to ask. Thanks so much for listening and I hope this is helpful.

Announcer:

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