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

Healthcare Transition with XLH

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

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Dr. Diaz-Gonzalez de Ferris:
Good day. My name is Maria Diaz-Gonzalez de Ferris, and I'm a professor and director of the UNC Transition Program at the University of North Carolina Chapel Hill. Today we will be talking about healthcare transition with X link hyperphosphatemia. I am grateful for this invitation. I have worked in this field since 2006 and our group has dedicated the work into learning how to measure healthcare transition and in creating some interventions which are listed in this slide.

We have the TRxANSITION Index, which is a provider administered parenting youth version. We have the STARx Questionnaire, which is self-administered for pediatric patients, and those patients who are already in the adult focus setting and the parent version as well. Our interventions, which I will not discuss very much today, are listed in this slide and are free and available to everyone. We have done this work thanks to the collaborators across the US and several countries such as Mexico, Colombia, Philippines, South Korea, Turkey, Japan, China, Canada, India, and most recently Russia.

Let's just focus a little bit on X-linked hypophosphatemia. We know it is a rare and chronic multisystemic disease that progresses throughout adulthood with worsening muscular skeletal signs and symptoms. burosumab doses change in adulthood from four times to twice a month. This condition requires lifelong multidisciplinary care involving physicians, physiotherapists, surgeons, psychologists, dentists, social workers, and nurses. So what is healthcare transition? It is defined as the process of moving from child to an adult model of healthcare with or without transfer to a new clinician. That is, if you are in family practice, you'll stay with your clinician, but then you'll have to learn how to manage your health. It involves adolescents, young adults, their parents and their health providers. But the question is how do we take patients from this age group to this age group successfully, and what happens if we don't prepare our patients? In many studies across the world and across several conditions, we know that transplant rejection occurs, death of the patient or graft loss can happen, higher disease activity or higher hemoglobin A1c.

In the work that we've done, not just our group but other groups, there have been several publications of what are barriers for healthcare transition. We know that from the adolescent or young part, low literacy, younger age or younger age at diagnosis, being a person that is not white, not doing chores at home and losing the locus of control or having depression, those are considered barriers or have been shown to be barriers for healthcare transition preparation. What about the caregiver?

If your child is from a single parent household, comes from a low socioeconomic status, or in the US having public insurance, coming from a non cohesive family has been known not just in the US but in China and in South Korea or having a parent role overload, those are caregiver barriers or demonstrated as not facilitators for healthcare transition. Let me mention that there are several healthcare transition readiness questionnaires that have been published.

There are three kinds of transition readiness questionnaires, self-report such as ours, the STARx Questionnaire, other groups such as

TRAQ, RTQ, Good2Go, TRS and TRANSIT. There are only a few that have parent proxy report for healthcare transition readiness. That is the STARx Parent, CRTQ or TRS. And lastly, we are the only group that has a provider confirmed tool called the TRxANSITION Index. The word transition has 10 letters. There are 10 domains that are tested, and the TRxANSITION Index has both a parent and a child version. When we were creating the parent version of the TRxANSITION Index, we actually discovered that parents themselves did not know very much about their child's diagnosis. So we changed the questions to learn about parent's own knowledge of the child's disease, plus the caregiver procession of their child's healthcare transition readiness.

What we tell providers is that we must talk about healthcare transition as early as possible at the time of diagnosis. We need to let the parents know that their children will have great survival and that they need to learn to manage their disease without the parent's help. So even in prenatal visits, when some patients in the kidney realm are diagnosed, even at that time we tell parents, "You have to raise your child as he was a child, as normal as possible because your child will become an adult who needs to manage their diseases." So we optimize also the parent's health, because if the parents have mood disorders, then it's difficult for them to be effective parents. We also try to detect the parent learning style. So does the parent like to learn from visual methods or does the parent like to read?

We also have to reeducate parents because we spend a lot of time at the time of diagnosis with them, but when the years pass, they forget. And most importantly, if the children were at diagnosed at a very young age, we need to educate the adolescents about their diagnosis. Why is this important? We have learned that adolescents prefer to learn about their health condition from their parents, followed by providers. This is very, very important because we have to prepare parents to be helping their children manage and learn about their health. We know that if parents are the preferred method for learning, then the patients seem to be more adherent. But if the patients learn to prefer from providers, those patients can manage their disease more efficaciously and are more prepared for healthcare transition to adult services.

If parents have an authoritarian style, there's more success in the child in academic performance. If the parents have greater education, certainly but if the mothers are more educated, patients seem to have lower healthcare transition readiness in a couple of our studies. We're not too sure why. We hypothesized that mothers may be more concerned about the consequences of their children not being well, not managing their disease well. And if that is the case, they don't readily let go of the managing of their child's health. And certainly if the parent is depressed or high anxiety, this can be also reported in their children, as reported in various studies. In 2022 we published an expert consensus on HLX regarding how to support services of healthcare transition for patients. We identified four domains, the patient domain, the parent domain, the pediatric care provider domain, and the adult focus provider domain.

And as you can see in this Venn diagram, which I won't spend a lot of time describing, engaging to disease education and resources, collaborating, ensuring a multidisciplinary approach to transition and coordinating transition seemed to be key for us to have a successful healthcare transition to adult services. In fact, in that expert consensus, we published that certain activities need to happen at certain ages. For example, the 12 to 14-year-olds need to have readiness measurements and early discussions about becoming an adult With HLX. The 17 to 18 year-olds-may be closer to transfer to adult focus services, so we certainly need to measure readiness and we need to start transition planning.

In the 18 to 26-year-old patients, they may or may not be transferred at this age, but certainly if they transfer, after they transfer, we need to make sure that the transfer are successful and that the patients continue to do well in the adult focused services. In a study that we published in 2017 and in 2018, we have measured longitudinal transition scores in 862 adolescents and young adults with different health conditions at UNC Chapel Hill. What I want to mention in this particular slide is that self-management, which is the top blue pentagram, self-management and knowledge about insurance, it's really only acquired after the age of 20, whereas 12-year-olds can manage adherence and learning about ongoing support.

I have this slide to discuss with you that at a, this is Rebecca Ferris when she was 15, and look at the difference between my daughter and her 15-year-old cohorts in her 15th party. It's not that I want to show her off, although I do want to show up my daughter and my son, the 12-year-old Alex on the right side, it's that I want to tell you that at age 15, patients learn about self-management in an exponential fashion. So if you cannot start a program at age 12, don't worry. At age 15, patients are just about ready to start learning about managing their health.

It is important when we have healthcare transition preparation to have interactions with both the parent and the patient at a universal literacy level. If I have a PhD physicist, that person does not speak my language, does not speak medical terms, so we most use plain language. We must speak slowly. If possible, we use a teach back method in a non-threatening fashion. I usually ask my patients, "What are you going to tell your younger sibling you learned today about the visit?" And if you have after-visit summaries, have the patients read to you the after-visit summary. You will learn about their literacy level just by having them read that summary to you.

I am so pleased you invited me to come and discuss healthcare transition preparation. I invite you to read about the consensus that we published on HLX in transition, and I welcome your questions.

Announcer:
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