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Pediatric To Adult Care: A Team Effort

Announcer:

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Dr. Filler:

So that brings me to something else. And I would like to hear from you how your clinics are organized. And what we're seeing is that probably two thirds of the patients are being seen by pediatric endocrinologists, and about one third by pediatric nephrologist. And that they all need a dentist and they all need, at least unless they have been started also up very early, an orthopedic surgeon. So what we have done in our clinic is we have actually organized it in such a way that we have every three months, a phosphate wasting disorder day. And we have the dentist, the orthopedic surgeon, the endocrinologist, and the nephrologist doing it all together.

And it has helped so much with the coordination of everything. We have a very, very large catchment area where patients can be as far as a thousand kilometers away. And to have one-stop shopping is really in my way, the ideal way. And it brings me to the question, how do you do it with the multidisciplinary team, and what should the world be doing for those rare diseases, and who should be leading it? Because it's an endocrinological disease because of the excess FGF23, but the effector is on the kidney.

Dr. Mahan:

Yeah. And in our clinic we have peds endo, peds genetics, peds nephrology. We actually have a complex care physician who's interested in bone health. Our orthopedic surgeon doesn't come to our clinic, but we have two orthopedic surgeons that we only use. So we work closely with the two of them. And their areas of expertise are in limb abnormalities in children. And then, we have a specific dentist who happens to be the head of our dental program that we refer patients to. So I do think we have to think of care of these kids and these families as truly a team effort and no one of us can do it by ourselves.

So I think in terms of who should be the lead, it's perhaps who's interested, who has the devotion to really keep up with the literature and to understand what our best practice is. But at the end of the day, these kids and these families require a multidisciplinary team. We, in fact, have a specific group of adult endocrinologists that we refer these patients to as they transition and that we refer the adults to the parents and some cases grandparents. So I think in my mind, our team includes our adult endocrine bone experts who help in the care of the adults as well.

Dr. Filler:

So the question about this, I agree with the notion that we should be advocating that our patients should be on therapy because of the lifelong implications. And even in a 50-year-old or a 60-year-old, you may improve quality of life substantially. We have been telling those patients when they graduate it in the past that rickets don't occur and therefore it's questionable whether or not they should have therapy. It's sort of evolved over the years because of the quality of life, the chronic pain and so on. But how do we actually repatriate the patients that have been transitioned from our clinics 20, 30 years ago? And how do we get them to be treated? Many of them may not even seek any medical attention.

Dr. Mahan:

That's a wonderful verb, repatriate, because that's what it feels like. And for me, it's a conversation. The first time I bring it up with a parent who has a mental model that she doesn't need treatment and no treatment's going to help her, I feel like the first time I bring it up, they look at me like "Really?" And then we talk a little bit about, there are adult studies that have shown effectiveness.

I do think as they see their child do well and in many most cases do better than they remember doing as a child, that adds. But I always look at it as a process. And I can't think of a single time when a parent took my first question about, do you want to see one of our adult colleagues and jumped and did it? They usually take a little bit of time in thinking and won't bring it up at the next visit. And because we're seeing these kids regularly and three, four times a year, I think that helps. And we still have a few parents that have held off so far, and I just try to gently bring the question up and try to see what questions they may have.

Dr. Filler:

And reimbursement coverage are issues as well. So I think we actually need some kind of consensus guidelines that are given to all the insurances and reimbursement bodies so that there's a harmonization. It can be that you have to do it in Ontario differently than in Alberta or in Ohio. I think that is very important. And another argument also for the multidisciplinary clinics, because when you have a sizable number of these patients, then the whole process of the annual claiming of the coverage, et cetera becomes so much more streamlined. Right?

Dr. Mahan:

Yes. And I think you'd raise a good point that you really are looking for guidelines in what to do with the adults. I mean, in my experience, no one has ever questioned in any length starting a child on this monoclonal antibody treatment. But with adults there is less evidence, because it's not been around that long and because they don't get the deforming rickets, maybe a little less obviousness for folks that are approving therapy.

So, I know transition's another issue, which transition used to be, "Okay, you're done growing, there's really probably no reason for you to stay on therapy." And in my experience, the patients quit the therapy that day the first time we mentioned that, because they didn't enjoy four times a day treatment and the side effects. But now, I'm really orienting myself to think having the conversation early in adolescents like 13, 14, that we reframe this now. We see this as a lifelong disorder.

We know adults suffer. This therapy may be given a little differently as an adult, but you should expect to stay on this treatment because we believe it will be useful to you. And then I also talk to them about the fact that you're not going to be seen in our pediatric clinic forever, even though you might prefer that. So we are going to be talking to you as you hit older teenage years about when's the best time to transition to our adult colleagues. So yeah, it's a very different conversation because in the past, they weren't transitioned because in their mind and in our mind it was not much that was available. Now, there is.

Dr. Filler:

I have been transitioning for probably the past 16 years, and the experience that I had is that upon withdrawal of the therapy, the patients are starting to get more knee pain, shorter walking distance. And yes, they don't bow more, but the quality of life goes down. And so the younger parents that I have been treating, as children have been on ongoing therapy, and it depends also on your adult partner. It happens to be that I was her PhD co-supervisor, so it was a very harmonious collaboration. We published like 50 papers together. And as such, she's very, very open and receptive to this.

And also Paulson, our adult endocrinologist. The only problem is if they live far away, because if they're within a 100 kilometers or 200 kilometers, it's not a big problem. You can centralize them. But if they live in Thunder Bay or north of Thunder Bay, then it becomes really very challenging to coordinate this. And we probably need specialized multidisciplinary adult clinics as well. Now that we have these treatment options.

And we need to figure out a little bit more about, so what should we target during adolescence because of the higher alkaline phosphatase during the pubertal growth spurt? Do they need more? That's an unanswered question. And then we need to figure out, you can't just go on the 18th birthday and cut the dose in half. So there needs to be a tapering approach and maybe prolong the interval. But if they have symptoms, then go no further or something like that. But that whole process is not ironed out.

Dr. Mahan:

So Guido, one of the issues I'm sure we both face is transition. Young kids, young teenagers aren't necessarily that excited about thinking of leaving us. But it is important to have some conversations. We rely on some aids, like the different materials that are available from transition.gov through the NIH, and then also the University of North Carolina has some wonderful transition tools. I wonder, do you feel like your patients are transition-ready when they hit that 18, 20 years of age?

Dr. Filler:

So the Exxon H patients are not too bad. The CKD patients are often not. We have in Ontario a mandate for a fixed transition at a chronological age of 18, which is a concern because it's not chronological, but the developmental age that matters. But yes, we start having conversations about that at age 15. We've also learned from the STARx program how important it's to educate the mother who may not always be affected. If they are, they are obviously much more motivated to help. But we've learned that the adolescents go to their mom for medical information. So we need to also focus on that.

Dr. Mahan:

Yeah, very well put. It's been really enjoyable today, sharing our experience and also just really celebrating the improved outcomes for our kids now and what we hope to see as they move into adulthood. And then the opportunities for adults now to have therapy that really has been shown to be effective. So it's been really great to share these perspectives with you, Guido. And so I'm sure we'll talk some more, but we'll continue to learn together.

Dr. Filler:

No, thank you very much.

Dr. Mahan:

Okay. Thank you.

Announcer:

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