Transcript: SickKids VS Fragility

COLD OPEN

Hannah: Roughly 1 in 100 babies a year are born with a heart defect. Most of them will need major surgery to survive. In some cases, their hearts are disassembled and rearranged. Holes are patched, or circulation re-routed. Survival rates today are generally excellent, but many of these kids will need lifelong care and possibly more surgeries as they get older.

And often, there's a lingering sense of fear about what their repaired heart can handle. Families worry about their child playing sports, or even going to gym class. Dr. Barbara Cifra hears this all the time at her exercise clinic, part of the Labatt Family Heart Centre at SickKids.

Barbara: So, one of the reasons why – and we know that from data – children that have a congenital heart disease are not active, there are three main components. Like physicians, we don't spend enough time talking about the importance of physical activity. Then there is the parental over-protection. And you can imagine – my child had heart surgery. I really don't want him to exert himself unless someone says that exercise is beneficial. And then there is also the kid's fear to exercise. I have a heart condition. I had surgery – or even if I didn't have surgery, but I have a heart condition – I don't want to have an event that is negative. I don't want to feel bad. So I actually do not exercise.

Hannah: Decades ago, this *was* the advice for children with heart conditions. The prevailing thought was that their hearts were too easily strained or overloaded. Better to be inactive and safe, rather than risk a major cardiac event. But the consequence of inactivity becomes obvious as these kids grow into adults.

Barbara: They have lower quality of life in terms of higher rate of mental health, especially depression and anxiety. They tend to be overweight. They develop all the cardiovascular diseases that we can develop if we don't do preventative medicine: so, diabetes, high blood pressure, high cholesterol.

Hannah: Barbara did her medical training in Italy and has a background in sports medicine and exercise science. She spent her early years at SickKids using various exercise tests to evaluate young heart patients.

Barbara: So the first things I've done was to adapt this technique called stress echo. You have an exercise test on a bike and we acquire images of your heart with an ultrasound. And then you look at how the heart responds to exercise. Because exercise is a stressor for the heart. It has to work harder. And so when you stress the heart muscle, the heart muscle can give you some information about itself that doesn't show when it’s in resting condition.

Hannah: The data was illuminating and could detect signs of heart dysfunction. But, overall, exercise testing wasn’t being used to its full potential – to help patients *improve* their fitness. For example, if a child’s test showed a low tolerance for exercise, the advice was simply: your child should exercise more. But parents didn’t know how much was healthy or safe.

There were no clear exercise recommendations for this patient group, even though the science had come around. A critical mass of research in the last 10 to 15 years has shown that exercise *is* safe for young heart patients – and beneficial. Even for severe diagnoses. After all, exercise has long been a standard therapy for adults recovering from heart attack or stroke.

Barbara: And if you look at what we do with adults, we have model of cardiac rehabilitation program. So, if me and you, we have a heart event. So, we get surgery, we get medication, we get everything, and then the first thing the cardiologist will tell you is to go to cardiac rehabilitation. And cardiac rehab is exercise. I look at this model of cardiac rehab, and I thought, they’re doing something very valuable for adult patients – why don't we do the same in paediatrics?

Hannah: You’re listening to SickKids VS, where we take you to the frontlines of child health. I’m Hannah Bank and this is SickKids VS Fragility.

ACT 1

Hannah: 28-year-old Aaron is a former SickKids patient. He was born with a serious heart defect in which one side of his heart was severely underdeveloped. He needed a series of major surgeries, starting days after birth.

Aaron: They did four open heart surgeries. The first stage, they kind of enlarged my aorta so that more blood flow can happen and go through the whole body. And then they're connecting the superior vena cava and inferior vena cava –so blood coming above my body and below my body – to the pulmonary artery, so it goes straight to the lungs. And then the last stage is where they're just making sure the blood flow goes entirely through the right side. So in a nutshell, I have half a functioning heart in my body.

Hannah: Aaron is what cardiologists call a single-ventricle or Fontan patient, named after one of the most complex surgeries for one of the most complex heart defects.

He is monitored at Toronto General Hospital, one of the first and largest adult congenital heart disease clinics in the world. It's only in the last few decades that this patient group has survived into adulthood. And this is largely because of surgical advances *like* the Fontan procedure.

Several years ago, when Aaron was 22, his cardiologist told him about an exercise study happening at SickKids in collaboration with Toronto General. Barbara was gathering more data about the effect of exercise for congenital heart disease patients. Would he want to participate?

Aaron: I'm like, exercise? Me? Sure, let's do it. I got there and I said, Hi, I'm Aaron. I'm here for the exercise test, and so they kind of strap me in, get me all set up there with the respirator and everything. And so Dr. Cifra walks in, and then she's just there observing, like, just, just looking at me, like ok...

Barbara: I walk into the room and I see this fit guy, and I'm thinking, they give me the wrong patient. That was my instinct when I saw him. And I went back to the front desk, and I said, is this really my patient today?

Hannah: Aaron was on an exercise bike, chatting easily with staff as they measured his heart function. He had no idea why Dr. Cifra was staring at him in disbelief.

Hannah: Did she ever explain to you why she was so shocked? Was it that made her so surprised?

Aaron: I think it was the fact that I was so, like, nonchalant, casual. And I think it just shocked her because it's like you don't see most Fontan patients as physically active as myself, or at least, especially at my age.

Hannah: Barbara was expecting to see someone who was unfit and struggling on the bike – certainly not carrying on a cheerful conversation while pedalling.

Barbara: We do the test. The test is done. And then I said, may I ask you a question? And I said, I see a lot of patients like you and I was seeing some adults. And I could see already the trend of not being active and the consequences of that. And so he was an outlier. And I said, I'm interested in your story. Can you share with me your story?

Hannah: Aaron was born in 1995, a time when doctors were still wary about exercise for paediatric heart patients. But his doctors told his family to let him play, be a typical kid. But, also, to watch him carefully.

Aaron: So the doctors, from what my mom has told me, is just go play, just be a regular kid, because they wanted to see how I was going to progress. And so every year I would be followed up, or every six months, I'd be followed up at the hospital. I'd be doing the exercise test, the breathing testing, blood work, the echo with the jelly stuff. That's what I remember. And they would constantly like stage by stage, just look at it and see how the blood was flowing. My mom and my uncles, everyone, just encouraging me to just do me, go have fun, play. I didn't really tune into that I had a condition until I was much older, like 11, 12, 13, is when I started to question, okay, what do I need to pay attention to? Why is my scar here on my chest? I do feel something that's different.

Hannah: With the support of his doctors and family, Aaron grew up playing all kinds of sports. In softball, he played first base. He was a goalie in soccer, lacrosse and hockey, which became his focus.

Aaron: I started playing hockey competitively, so I was playing single-A and then I moved up to a double-A team and then I had an opportunity to play hockey in Boston for a junior development program. We did a mixture of like on ice training and CrossFit. And so we were going on the ice almost every single day.

Hannah: Without any structured exercise guidance, Aaron made it up as he went. He did what he liked. He did what *felt* right. He learned to listen to his body and really know his limits. And sometimes he pushed too hard. When his heart felt like it was beating out of his chest, or palpitations continued long after he came off the ice, he knew he needed a long rest.

For Barbara, seeing Aaron in her clinic that day was like a glowing beacon – living proof of her vison for an Exercise Medicine Program. *This* was what exercise could do for heart patients.

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ACT 2

Hannah: In 2016, armed with clinical data and conviction, Barbara met with leaders and colleagues at the Heart Centre to pitch the idea of a structured exercise counselling program for kids with heart conditions.

Barbara: Paediatric cardiology is innovative, but at the same time conservative. So I was doing something that…a little bit thinking outside the box. Do we really need this program? Because the patient seems to do fine. So I had to collect the data to convince that this is a needed program.

Hannah: With seed funding from the Heart Centre and a key donor gift, Barbara launched the Exercise Medicine Program in 2017. It was just her and a physiotherapist named Robin.

The program is a hybrid of on-site and home-based work. Patients come into the clinic for testing, but the exercise happens at home or in their community. This remote structure was helpful during the pandemic, but also for program participation.

Barbara: So I use that model because I think in a city which is big like Toronto and everybody lives in different parts of the city or outside of the city, then I can give the opportunity to more patients to participate in the program. So to me was like, I want to reach as many patients as I can.

Hannah: A patient's first visit to the clinic involves a battery of tests to determine their cardiovascular health and baseline fitness. Then the patient and family sit down with Barbara for at least an hour. Mostly, she asks questions. What are their fears about exercise? What are their attitudes about nutrition and fitness? Do they have any financial constraints? What are the facilities like in their community? This family counselling and personalization is essential, says Barbara.

Barbara: I mean, every patient is unique. And we have to stop protocolizing people. I mean, life is diverse, and we need to shift into personalization. So the only protocol is that we do prescribe aerobic and strength training and flexibility. That's the protocol. Now, "the how" – it's related to the heart condition, the desire of the child, what he likes, what is available to them. Because we see families with different socioeconomic status and belief around movement. And accessibility then becomes very complex if you really dig in.

Hannah: From each patient's clinical and psychosocial profile, Barbara and her team create a highly individualized plan, laying out the type and intensity of exercise, along with direction about sleep, nutrition, and screen-time. But she knows she also has to make it fun.

Barbara: Otherwise for the kid it becomes another doctor telling me what to do, and it's related to my heart condition. And I want them to understand that this is beyond that – it is also for your overall health. And in terms of your life, it's an important component of that.

Hannah: Over six months, patients are assessed regularly to look for changes in their heart health, and to see if they're ready to advance their exercise program.

Barbara: And the ultimate goal is for us, of course, we want to see a benefit from a body perspective, and science and medicine give us the data. But we also want to see improvement in how they perceive their ability to move. And that's the empowerment piece that is very important. So they feel more confident about themselves in terms of: “I can do this, I can participate in the gym class, I don't have to be left out.”

Hannah: One of the program’s first participants was Alex, also a single-ventricle Fontan patient. He was 8 when he came to see Barbara.

Alex: I remember when I heard I was doing the Exercise Medicine Program I was really interested because it wasn't something that I'd heard of before. It was something that was very new to me and just sounded really interesting because unlike a lot of the other things in the hospital, I knew what it meant before I went into it.

Hannah: Like Aaron, Alex (who’s now 13) had several major surgeries to re-route his blood circulation so he could survive with just one functioning ventricle. Alex’s family was told that he was free to exercise and play sports. It was a relief for his family, who are all very active.

Alex grew up playing basketball and baseball, and going to gym class like everyone else. When he got tired, he rested, or played fewer minutes on the court. But despite the doctor’s reassuring advice, Alex’s parents weren’t sure about *how much* to let him do. How would they know if it was *too much*? Here’s his mom, Michelle.

Michelle: We’re active people so we wanted him to be able to be as active as possible and we figured it would give everybody a lot of comfort to know just how much he could do. Alex had his first set of testing, I think he had the exercise tolerance test and a pulmonary test as well, and his results were pretty good, actually. So we were happy to hear that for sure. And then watching him do that exercise tolerance test was just amazing. I thought I had seen his limit. I thought I'd seen how far he could push himself, maybe in a basketball game or something like that, but then watching him on the bike made me realize that he could do so much more than I thought he could. I actually felt really comforted that any time I thought I had seen him hit his maximum, it was not near his maximum, it was maybe halfway.

Hannah: Having parents witness the exercise testing has been a key strategy of the program. Parents are reassured – and so are the kids.

Alex: I thought I had reached my limit too, with basketball. Because I would come off the court really tired. But after that first exercise medicine test where I made it to the top of the hill on the bike, I felt a lot better knowing that this is something that I could actually do. And I'd never felt like this before, but I could do it.

Hannah: Alex told Barbara that he wanted to do CrossFit, a high-intensity workout involving weightlifting and cardio. Both Michelle and Alex's sister were avid CrossFitters and Alex was keen to try it.

Barbara: My jaw almost dropped to the floor because CrossFit is not really the ideal activity that you expect for eight-years-old. So then with my team, we said, okay, let's do the medical evaluation. Let's see all the parameters that we need to understand. And then let's talk about potential modifications, or what that class might be for Alex.

Hannah: Based on Alex's clinical data and the unique constraints of his condition, Barbara and the team suggested some modifications so he could do CrossFit safely.

Michelle: Dr. Cifra let him know what he could and couldn't do. And he couldn't lift so heavy that he'd need to hold his breath. So, lighter weights, but more repetition. It's nice to have the guidance from somebody who's a medical expert and who knows Alex's physiology. So it's not a guessing game. Because we have very knowledgeable and very talented coaches but they don't know about kids with congenital heart disease and they don't know about those challenges. So getting this information specifically from SickKids, from an expert, was just invaluable.

Alex: I felt a lot more confident going into more sports than I wanted to try, but never been able to. Things like karate. I probably would never have started if I hadn't done the Exercise Medicine Program.

Hannah: As Alex worked through his training program with Barbara, he was getting stronger, and so was his heart function.

Michelle: So with every test, there was noticeable improvement – measurable improvement. They were explaining also that a good thing for the heart, especially for kids like Alex, who are functioning on half a heart, is having stronger legs because it helps return blood to the heart. Dr. Cifra was actually using his results at conferences to show the benefit of exercise for kids with congenital heart disease.

Hannah: Alex’s progress confirmed the growing research about the benefits of exercise, especially for Fontan patients, who have a higher risk of morbidities later in life. Exercise training has been shown to be the most effective non-invasive therapy to improve exercise capacity for Fontan patients. And these gains are associated with improved physical and mental-health outcomes.

Barbara: The striking part – we saw Alex changing in the way he was talking about himself. And you can see that in patients sometimes from the beginning, the way they walk into the room, the way they talk to you, the eye contact, the way they see – there’s body language, they're shy, they're not confident. So the confidence really came out of Alex and we measured that. We measured the perception of quality of life and confidence, and we saw that in Alex, but we also saw that in Michelle.

Michelle: It really helped us to not be afraid. And I think in turn, then we weren't putting our fears on Alex. That fear was taken away, then he wasn't afraid and then his coaches weren’t afraid and his teachers. And so it helped everybody be more comfortable with Alex's ability to just participate and do whatever he felt he could do, what he wanted to do.

ACT 3

Hannah: Since the Exercise Medicine Program launched six years ago, the team has grown and so has the scope of patients. Barbara is getting referrals for cancer patients whose hearts have been affected by treatment and the inactivity of a long illness. The program has also expanded to Toronto General Hospital to support adults with congenital heart disease. Barbara has presented all over the world about this pioneering model of exercise counselling, and others are adopting principles of the program.

Barbara: When I started the program, I started to get invited to talk about the program and I could see that across the globe somehow there was *a little bit* of resistance, but not negative resistance. People were skeptical. Is it feasible to create a program like this? And in the paediatric centre where we have volume and we're busy and it needs resources, so how do you actually create it? So it took a lot of work even to advocate outside of SickKids. But I'm very proud to say that right now there is a movement in North America, there is a network that we're building with other centres in the U.S. and some centres in Europe and also the Philippines, and it's going globally. It's all about: we need to create this program in paediatric centres because our patients need this.

Hannah: Aaron, who you heard from earlier, understands this more than anybody. As someone who grew up without the support of exercise counselling, he sees what a life-changer it could be.

Aaron: There was no support growing up, like it was just myself and my family kind of working through things, and it wasn't all sunshine and rainbows. Like we had moments where I had to figure certain things out, right, how hard I could push my body, what I can do, you know, if I felt anxious, like, what do I do then? Setting the limits and doing all these different things, like, I always felt alone. But now that there's this program in place, I know for a fact the future of it, it will just help kids just be more confident in themselves and to know that they have a resource available to them.

I think this is amazing program because it really focuses on the emphasis of physical activity no matter what state of condition that you have, because it also empowers young children to realize that, regardless of where they are in their life, what they want to do, the key thing is maintaining their physical activity and just having a good time. And for children with, you know, especially with my condition or even a more severe condition, if they're able to exercise and say, be part of, you know, a community sport, then they get to interact with other kids and just have that overall sense of feeling that, you know, they're a part of something.

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