**SickKids VS Mechanical Hearts**

**Hannah:** In December 2021, four-year-old Harper was at the end of the road. She was back in the hospital after a harrowing eight months. She'd had two major heart surgeries. She'd survived cardiac arrest. She'd been on dialysis, a heart-lung machine, and a respirator. A few times, she'd been well enough to go home, only to be rushed back to SickKids by her terrified parents. Here's her dad, Andrew.

**Andrew:** Physically, Harper had deteriorated to a point that... It was really scary. She was really, really thin and she had no strength and she could hardly walk and eating was a struggle.

**Hannah:** Harper was in severe heart failure. Attempts to treat her condition had been unsuccessful and riddled with complications. Her last hope was a transplant. But they had no idea how long that could take and her medical team worried that she would continue to deteriorate. They told Andrew and his wife, Hsin, about a technology they could offer Harper: a Ventricular Assist Device, or a VAD. It's a machine that pumps blood throughout the body. It would ease the burden on Harper's ailing heart, allowing her to rest and get stronger while she waited for a transplant.

**Andrew:** The conversation around going to a VAD was basically, it was kind of put to us that if we want to get to transplant, this is the way to get there. And the way you get there in a healthy manner. And the team did a great job in explaining to us that kids that have the opportunity to use a VAD really have the best chances at survival. And at that point, we had seen the deterioration and how quickly things can go to the negative. And we decided that that was absolutely going to be the best path forward for Harper.

**Hannah:** Harper would need surgery to implant two silicone tubes into her heart. They would stick out just below her rib cage, carrying blood in and out of her body from a small pump that dangled below her groin. The pump was powered by a large air compressor on wheels. The machine was nearly as big as Harper, and it would be at her side constantly while she ate, slept, and walked the halls. Because of its bulk and power requirements, Harper wouldn't be able to leave the hospital, and she would have to stay on the VAD until a donor heart became available. That could take weeks, months, possibly a year.

**Andrew:** Not knowing is the really scary part because you're just left in no man's land just trying to figure out life and you're taking day by day and eventually that was the attitude. Eventually we just got to a point where you accept that you don't know when it's going to happen and you just gotta take every day as it comes and live the best you could every day.

**Hannah:** Globally, in the past few decades VADs have saved thousands of children with severe heart failure, most often by supporting them until transplant. VADS can hugely improve physical health, but the experience can take a psychological toll. The encumbrance, the loss of freedom, the isolation, which can seem secondary when talking about a life-saving treatment. But a unique new study at SickKids is shining light on this aspect of VADs. And not just from the patient's perspective, but the entire family's. How does it feel to be stuck in the hospital indefinitely? What does daily life look like? What is the toll on everyone? You're listening to SickKids VS, where we take you behind the scenes of big breakthroughs to help heal the future. I'm Hannah Bank, and this is SickKids VS Mechanical Hearts.

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ACT 1

**Hannah**: There are several types of VADs used at SickKids, depending on the patient's condition, age, and size. Some VADs are short-term and don't require open-heart surgery. Some VADs are compact and fit in a backpack, allowing kids to go home. And then there's the original clunkier design, the kind Harper had. Andrew calls it the V8 engine of VADs – tough, reliable, and made to last.

**Andrew:** I want you to picture a two-drawer steel filing cabinet. It's basically that on four wheels with a push-bar handle and then there's a laptop above it that is controlling all the settings based on Harper's requirements.

**Hannah:** This filing cabinet VAD was one of the first to be designed for babies and children. It was developed by a German company and first implanted in a child in 1990 at the German Heart Institute. SickKids was one the first hospitals in North America to implant this VAD back in 2004. Today, SickKids has the only paediatric VAD program in Ontario and one of largest in the country. Since inception, the program has treated more than 100 patients. The majority of them, like Harper, require it as a bridge to transplant. Andrew recalls how he and Hsin explain the need for a VAD and yet another surgery to their four-year-old, who'd already been through more surgeries and scares than most of us will in a lifetime.

**Andrew:** Harper is a special kid. I always joked around, even in her lead-up appointments, that Harper is the perfect patient. She was a little kid that trusted her parents. And anything we told her – we told her the good, bad, and ugly. We told her what was going to happen. We were very…not overly descriptive to scare a kid, but we made sure she understood the severity and what kind of things were taking place. This is going to give you a fighting chance. This is going to allow you to feel better.

**Hannah:** Patients generally do very well on VADs. At SickKids, roughly 90 per cent of patients either receive a heart transplant or, less commonly, go on to recover their heart function. A major international study led by SickKids in 2018 found that widespread VAD use had drastically extended survival until transplantation. Between 1993 and 2015, waitlist mortality rates had dropped by an astonishing 50 per cent. Today, paediatric VAD use continues to grow, and patients are staying on them longer thanks to advances in technology and clinical practice.

Though VAD survival and outcomes have been well documented, there's been very little analysis of the psychosocial impact. Yes, many of these patients are surviving and even thriving physically, but how is their quality of life? Dr. Samantha Anthony is hoping to find out. She's been a social worker in SickKids Transplant and Regenerative Medicine Centre for 25 years. She's also a health clinician-scientist, a rare breed of researcher whose studies originate directly from their clinical practice. Samantha's also Canada's first and only health clinician-scientist in the field of social work. Over the years, she has witnessed the remarkable advancements in heart transplantations and VADs, alongside a shift in medical research to consider quality of life.

**Samantha:** So I began my career working in solid organ transplantation, which is a field (in particular in heart transplant) that began in the early 1980s. So at that point in time we were really trying to think about survival and medical management. It wasn't until we children started living longer that the field really shifted to thinking about a more holistic definition of health and looking at quality-of-life implications.

**Hannah:** Samantha was at SickKids when the first VAD was implanted, and she wanted to formally investigate what she and other clinicians had been hearing from children and families living with a VAD. So, she recently launched a first-ever Canadian study to explore their lived experience and eventually use these findings to improve clinical practice.

**Samantha:** And this goal is achieved in two ways. First, by engaging patients meaningfully. So, by focusing on patient-identified priorities. And second, capturing the patient's voice by exploring the illness experience from the perspective of those who live it and create meaning from it. And while most research tends to be quantitative in nature, so using numbers and statistics, our team specializes in qualitative research methodologies. We listen to participants' voices, learn how they construct their world. And understanding the meaning participants ascribe to their experience.

**Hannah:** Uniquely, the study involves all family members, including dads and siblings, who are often underrepresented, but whose experiences are just as profound.

**Samantha:** As a clinician, as well as a scientist, it's very interesting because for most of these parents, with such a profound experience, the memories remain quite vivid and strong. So, families can still remember the smell, the sounds when their child was in the critical care unit. So, for some of these families, a year or two may have passed. For many of them, it feels like it was just yesterday.

ACT 2

**Hannah:** Harper's VAD surgery was on December 22nd, 2021, just four days after she'd been readmitted. She woke up in a nest of tubes and monitors.

**Andrew:** Immediately after surgery, she would have had the cannulas coming out of her body. There would have been a catheter. There would've been multiple IV ports, probably on both arms. She had a breathing tube, a feeding tube. And, and then actually after the surgery, there was drainage tubes too, so that they could get rid of some of the excess fluid. So, one, two, three, four. Five, six, seven? Seven tubes connected to her, plus all the wires and everything else that would be monitoring her heart. So, yeah, it was hard to find space on her body that wasn't covered in something.

**Hannah:** Harper would be in the ICU for several weeks to recover and slowly shed the tubes while her body adjusted to the VAD. Some of her early outings were cumbersome, to say the least.

**Andrew:** We were connected to both the IV pole and the machine. And she was in a wheelchair at that time because she didn't have the strength to be able to go without it. So, we would go for walks and you just had to kind of learn to maneuver everything all at once and it would always be two people. It would either be my wife and I who both had to go through training to be able take Harper on our own – emergency training – being able to operate a pump if the machine stopped working, all these kind of little procedures we had to through.

**Hannah:** Harper quickly made friends with her medical equipment. She named her IV pole Ivy, and the VAD was called Ike. They dressed Ike in various shades of pink vinyl wrapping and unicorn stickers. Harper came to know Ike's specific smell, and she would give it hugs and kisses. This was at the height of COVID. Hospital restrictions meant that Harper couldn't play with other kids. In the beginning, she could only be with one parent at a time. And her older brother Oliver wasn't allowed to see her at all, which was crushing for both of them.

**Andrew:** I was able to work with our physio team. And I said, you know, look like how much better she does at physio and how much more active she is when her brother's here, I said he's, he's her biggest fan. And he is her huge supporter and he's her opportunity is still feel like a kid. Eventually we were allowed that he had every privilege that we had. He could come and go as he pleased with us and be there with her a lot. And I think that was one of the biggest things that elevated her care.

**Hannah:** It didn't take long for Harper to feel better on the VAD. The changes in her were obvious. She had more colour, she had more energy now that her heart didn't have to work so hard. The VAD boosted her blood flow and the delivery of oxygen to her organs and tissues. She was putting on weight for the first time since Andrew could remember.

**Andrew:** And that was the real magical part about her being on a VAD was that it allowed her, even though essentially tethered to something and being connected to something, and she was able to exercise, she was able to go to physio, she was able to, within the confines of living in a hospital, live a relatively normal life.

**Hannah:** Being in hospital meant that there wasn't a lot of outdoor time, except for quick trips to the rooftop patio. But they could never be too far from an electrical outlet.

**Andrew:** Our older style of device only had about a half-hour of battery life. So, if you wanted to go for a walk, you had to get to an outlet really quickly. And then some outlets didn't work or you'd plug into one that you thought connected. And then all of a sudden the alarm goes off that you're almost out of battery. And we had a couple of really scary moments when the machine almost shut off on us. And yeah, it was, and you know, you get carried away being a parent sometimes too, right? You're not just a medical parent, but you're also a parent. So sometimes we're playing around and being silly. And, you know, you don't realize, oh, gosh, we lost track of time. And now we need to get somewhere. Now we're stuck here waiting for a charge before we can get back to the room.

**Hannah:** Sleeping could also be complicated and didn't always offer much reprieve.

**Andrew:** She's a kid that tosses and turns. So if she were to twist in the wrong way and something kinks and there's a disturbance in the medicine being given to her or the tube that kinks and now isn't allowing the air pressure to pump the VAD…you're laying there sleeping and alarms are going off like all hell's breaking loose, so, lucky kid, she slept through most of it. I would jump out of bed and nurses would fly into the room and we'd turn her and twist her and she's usually still out of it, but sometimes it would wake her up and scare her and let me just kind of lay down with her and talk her back to sleep and she was really remarkable about it.

**Hannah:** Maybe because she was so young or because three years have now passed. But today, Harper doesn't remember much about the hard times. What's stuck with her are the fun moments.

**Hannah:** Were there ever times that were a little bit hard for you?

**Harper:** I kind of forget that.

**Hannah**: And your dad told me you got to ride a bike. Do you remember?

**Harper:** Oh yeah!

**Hannah:** Tell me. Can you tell me about that?

**Harper:** Like it was, um, I think a pink bike and I rode on it and it was fun, um, with a little basket, I think.

**Hannah:** Listener, imagine Harper rolling down the hallway, her dad beside her pushing the VAD, and trying to keep the tubes from kinking.

**Hannah**: That sounds really fun. And I bet you it was really fun to be able to ride a bike inside in the hospital. That's really cool. But you were in the hospital for a long time. What was it like to be in the hospital for so long?

**Harper:** I started kind of getting used to stuff there and not used to things at my house. So, I was more used to there than I was at my house.

**Hannah:** Her family was probably starting to feel that way, too. Their house was a two-hour drive from SickKids, so they'd been living at the Ronald McDonald House just down the street. Both Andrew and Hsin were no longer working at this point. Even before the VAD surgery, they'd spent the previous eight months in and out of hospital with Harper, and they had no idea how much longer they'd be there. Friends set up an online fundraising campaign to keep them afloat. It was hard to swallow at first, being so vulnerable and dependent, and having zero control over the situation. But the family clung to small pleasures and the big picture.

**Andrew:** I got to spend a phenomenal amount with my daughter that I never would have got to spend. We got to spend a phenomenal time as a family, a lot of one-on-one time. Like, man, we come back to life and life gets busy and all of a sudden it's work, it's school, it's extracurriculars. And this whole experience has taught me how precious life really is and the value of time.

**Hannah:** In their interviews with families, Samantha and her team have been hearing similar sentiments and contradicting emotions. Caregivers have described the VAD experience as terrifying, torture, hellish. But they've also acknowledged it can be a hopeful, peaceful, and even beautiful time. A mix of awful and amazing, terror and gratitude.

**Andrew:** When you've seen your child in the worst possible condition they can be in, you know how bad it *can* be. And we had seen the absolute worst. Like we were way too close to losing Harper way too many times. We had the guidance of an incredible team. And... being able to trust and being able to understand that these folks are some of the best in the world and they're not going to lead you astray and that they're going to give you the best option available and to be able to hand over your child in full trust with a medical team is a really difficult and scary thing to do, but this is a place and this is a system and this a mechanism that can really help kids in this situation.

**Hannah:** For Andrew and Hsin, the VAD experience, as hard and uncertain as it was, would be the final obstacle before the final surgery, a heart transplant.

**Andrew:** At that point, she was healthier than she had ever been. And she was so prepared and our team was so prepared that heading into this one, it was like, okay, this is the last hurdle. There was no other way this was gonna go than positive.

ACT 3

**Hannah:** After seven months and six days living with the VAD, Harper went into her last surgery. When hearing that there was a donor heart, the family experienced a swirl of emotions: disbelief, elation, sadness for the family who'd lost their child, and overwhelming gratitude. During the surgery, Andrew spent the night in Harper's room.

**Andrew:** I remember just sitting in this empty room, just staring, cause she had all this artwork everywhere. We would make all these different art projects and all of her rooms would get fully decorated. Like, you could hardly even tell it was a hospital room at a certain point. We had different drapes up and oh man, it was special. I remember sitting there looking at it going, wow, it might actually be over. Like we might be at the finish line.

**Hannah:** Unlike Harper's previous surgery, this one could not have gone smoother. Andrew describes her recovery as breathtaking. Just five days after receiving her new heart, Harper was discharged. She said goodbye to Ivy and Ike and her beloved VAD team, and SickKids, her on-and-off home for more than a year. It was the best possible ending to a long, twisting saga. And of course, not everyone's experience is the same. Though there are common themes among families, the VAD experience can be quite different and nuanced depending on the type of VAD, their level of freedom, if a transplant is required or successful. Capturing these nuances is what makes Samantha's study so important. As a health clinician-scientist, she and the clinical team can directly and immediately apply what she's learned from the research.

**Samantha:** One of the strengths of being clinician scientists is that we continue to practice, we continue be involved in clinical care. So, for me, all the lessons learned from every interview readily translates back into my practice, as well as other team members. We have a multidisciplinary team who are actively engaged in caring for these patients and families. So, we have integrated knowledge translation throughout the research program. So, sharing findings throughout. We don't have that, the siloed information with those 17 years for knowledge to be translated from research to care. It's quite seamless.

**Hannah:** The two-year study launched with seed funding from the Labatt Family Heart Centre Innovation Fund, set up in 2007 to support promising early-stage research.

**Samantha:** I think it's critical to have seed funding in order to conduct exploratory psychosocial pilot studies. Again, innovative questions, smaller patient population, but the impact can be significant across the organization.

**Hannah:** By offering their personal experiences and insights, study participants can improve care and supports for other patients and families. And it can be therapeutic, allowing them to piece through the trauma with the benefit of time and find resilience, growth, and gratitude.

**Andrew:** The first time we were discharged from SickKids, when Harper was going to Holland Bloorview, an ambulance, or our patient transfer vehicle, was taking us. And I said, ‘Harper, look over at that building.’ And she looked out at SickKids and I said ‘say, see you later SickKids.’ And she does it in just the cutest little voice.

**Harper:** See you later, SickKids...

**Andrew:** Every time I see that video, I go, oh man, I was wrong because we had to come back so many times. And this time around, I remember when we left and we were leaving Toronto, I remember it going through my head, like how dare I say anything like that, right? It was just this overwhelming feeling of just thank you. She's safe. We made it through this crazy, crazy scenario. And I'm driving home and I have my wife, my son, my daughter in the vehicle and everybody's safe. And it was just this overwhelming feeling that just, we made it, we just made it. And I always felt like we would.

**Hannah:** From SickKids Foundation, I'm Hannah Bank. Thanks for listening. To support breakthrough research and care at SickKids, please visit sickkidsfoundation.com/podcast. And if you like this episode, subscribe and rate us wherever you listen to podcasts. SickKids VS is produced by me, Liz Surani, Neil Parmar, Jasmine Budak, Charlotte D’Arcy, and Rebecca Ostroff. This episode was written by Jasmine Budak. Sound design and editing by Quill. Check out our show notes for related links and resources. Until next time.