

SickKids VS Hardship

COLD OPEN

Hannah Bank: Yuniarti planned to take her 9-year-old daughter to one of the happiest places on earth: Hong Kong Disneyland. They were already visiting family in Indonesia. But then her little girl, Ney, became very ill.

She had a high fever that lasted for days. When Yuniarti took Ney to a local doctor, they prescribed antibiotics, thinking she likely had typhoid fever. Yet Ney didn't respond to the medicine.

Yuniarti and Ney skipped seeing Mickey Mouse and flew back to Canada. Instead of connecting from Toronto to their hometown of Timmins, they took Ney straight to SickKids. At first, doctors thought Ney probably had an infectious disease. But then...her bloodwork came back.

Yuniarti: She has leukemia. And then the treatment is right away the next day. The treatment, it was blur because we didn't understand everything—what kind of treatment, what kind of medication, and everything.

Hannah: I asked Yuniarti how *her life* was affected in that moment.

Yuniarti: Oh, it completely changed, because we just had to stay in Toronto at that time. We didn't even have time to get back to Timmins, because she's right away admitted in SickKids and she has a lot of complication through the chemo. It's hard on her and it is hard on us too, because we didn't know how to make her better at that time.

Hannah: A cancer diagnosis alone is scary and stressful. But it also upends a family's entire daily life, especially when you're figuring out a treatment plan quickly, and in another city. Where do you stay while a child receives treatment? What paperwork do you need to submit? Who do you contact for assistance in different situations?

SickKids staff wanted to help more families, so they started providing additional support and launched a specialized, one-of-a-kind program. You're listening to SickKids VS, where we take you to the frontlines in the fight for child health. I'm Hannah Bank, and this is SickKids VS Hardship.

Act One

Hannah: The Garron Family Cancer Centre at SickKids is the largest paediatric oncology centre in Canada. The Centre sees many patients, with more than 1,400 admissions per year and around 20,000 clinic visits.

In the last two decades, breakthrough research and clinical advances have increased the survival rate to more than 80 per cent for children with cancer. But as Dr. Sarah Alexander has observed, there is a lot more to the cancer experience than just survival.

Sarah is an oncologist and clinical director of the Hematology/Oncology Division at SickKids. She sees some of the sickest patients in the country.

Sarah: I think that the diagnosis of a child with cancer is a catastrophe for that child, but equally a catastrophe for the family. In every way, it absolutely puts that child and that family's world upside down for a period of time. And then I think that there are pragmatic things that are incredibly burdensome to kids and their families, you know, in terms of disruption of school and disruption of work and just the rigor of medical care, the rigor of the number of appointments, or the number of nights in the hospital. So I think that the challenges vary at the beginning and during therapy. They vary by who the child is coming into this. They vary by the specifics of what we're asking them to go through, and then they vary by lots of overlaid logistical factors: How far do you live from here? How many people in the family are there for support? What are their resources and finances?

Hannah: So in 2019, Sarah and Sonia Lucchetta, a Social Worker, came together to redevelop psychosocial care within their program. They aimed to have the best possible program focused on easing the physical, emotional, and psychological impact of a cancer diagnosis on a family.

Their team expanded to include nurses, social workers, psychologists, Child Life specialists, and music therapists. Together, they provide care and practical support to patients and caregivers. But they started hearing from caregivers who needed more help navigating the paperwork, the logistics, and other support. In short: there was a gap in the team, so they brought in resource navigators.

Sarah: We currently have two resource navigators, Dennis and Lisa. They're both absolutely terrific. Their role is really defined around consistently delivering supports for the pragmatic parts of care. They meet every new oncology patient and there are some standard components of the logistics of care and things that I think they talk about with every family—and whether that's around parking or transportation or kids who need access to supports that are available through community or provincial agencies. In addition to just being exquisitely good at doing that component of the job, I think one of the one of the unwritten but incredibly important part of what the resource navigators do is pragmatic problem solving.

Act Two

Dennis: My name is Dennis Maplazi and I'm a resource navigator with the Haematology/Oncology Program here at SickKids. I work with a lot of families when they come to the hospital. The impact of illness and working with chronic illness has leaves, or leaves, a lot of families without any resources. I've seen a lot of people get broke because of the expenses

that they go through every single day and amount of money that's needed with the care. I know what it is like to not have enough money. So I felt like I wanted to be able to figure out ways and how I can help those families in able to save what they could and find other resources that are out there that could be able to assist them.

Lisa: My name is Lisa Berardo, and I have a background in social work. I've been working at SickKids in the role as Resource Navigator.

Hannah: Lisa has a special connection to this field.

Lisa: I, myself, had a child with chronic illness when they were younger. And so I understand firsthand, really, the positive impact that this type of psychosocial care can have on a child and family. And so I really want to use my skills and my expertise to support these families through their challenges and successes.

The impact, I think, of paediatric oncology is psychosocially and physically demanding, and this can be compounded by other factors such as inadequate housing low-income, food insecurity, mental health challenges. Families experience, you know, I think significant worry and distress over these things and then, therefore, are less engaged in the care of the child and even the care of themselves. So before this program, I feel that the psychosocial needs of families really were not adequately being met. Members of the health care team, they do not always have adequate time to address these issues or even an understanding of the impact of some of the psychosocial issues.

Hannah: Lisa and Dennis tell me there's no typical day. They could be meeting with families in the cancer clinic or the inpatient unit, helping secure financial support for equipment they need to leave the hospital, sorting out a parent's employment papers for taking time off work, or finding local accommodations.

Lisa There can be 100 people in clinic on any day. But we probably average anywhere from about 350 to 450 families per month. I think we're really, really good at developing those trusting relationships with families. And that's why oftentimes you'll just see families popping in, have a space safe to share some of the things that they're going through. We help with financial resources through government and community agencies to help address health related-care costs. Managing time away from work, so that might be helping families with any kind of insurance: EI insurance benefits, insurance through their work. Also, maybe insurance coverage for medication. Helping with accommodations—both long-term and short-term stays, hotels, condos. We help with travel: flights, train, housing. Might be connecting a newcomer family with community agency, providing assistance with completing applications and forms, and helping them gather documents for those applications as well.

Dennis: So having someone like me who can sort of like say, hey, don't worry about this type of paperwork—I will take care of it for you. We will work together. Here is what you need. I just need you to sign. I just need you to be able to give me all this paperwork here and take care of

the little one. Don't be stressed out about anything that's on paper, because we can fix that. That's why we're there. And so we're able to remove the burden of worrying about accommodation, remove the barrier needing to know whether your sibling at home, the child at home, is having care because we can find you some funding to be able to help with that or find you a place where you could stay where the rest of your family members can visit on the weekend.

Hannah: It's clear in listening to some of the stories shared by Dennis and Lisa that they have made a huge impact.

Dennis: There's a father that I was working with. The drugs that he was looking to cover was somewhere around \$30,000 or \$40,000 that they had to spend out of pocket. So I was able to help the family apply for a drug benefit program. And then I worked with the family to set up reimbursement. At first, dad didn't believe me, because I had to say to him that it's something that's possible that we could do. He couldn't see that it's something that was possible. So, at the end, when we finished with the program, he was very grateful.

Dennis: One of my biggest wish—or my dream—is that in participating in this program, my hope is that maybe one day someone somewhere is listening, that they can understand the impact of this program and the impact with their decision making and how it influences and impacts the families that we work with.

Hannah: In 2017, before SickKids started providing resource navigation support, Yuniarti and other parents were typically left to manage much of their child's care alone—on top of many logistic demands. Ney underwent many years of challenging treatment. In time, she recovered and returned to school.

Yuniarti: She was in remission. She was done treatment. She rang the bell. Then we thought everything okay. Life again normal.

Hannah: In 2020, however, Yuniarti received some devastating news, which she'll share after this brief break.

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Act Three

Hannah: What news did you receive a few years ago, Yuniarti?

Yuniarti: I diagnosed for breast cancer, and I got lumpectomy and mastectomy one month after. Then they proceed to get the chemo for my breast cancer, stage three.

Hannah: Wow. I'm so sorry to hear that.

Yuniarti: When I get diagnosed, I say, okay, I get diagnosed. But then we have to do what we have to do. Go get chemo and radiation at the time.

Hannah: Just a couple of months into Yuniarti's treatment, her daughter had a high fever—again.

Yuniarti: So we thought, oh, this is only like a coughing or a fever or virus. And then we found out that we have to go to Toronto because the oncologist concerned about it. Then we found out that her cancer was relapsed.

Hannah: Yuniarti flew to her daughter at SickKids and tried to transfer her own cancer treatment to a nearby hospital. Both began therapy, and this time, Yuniarti knocked on Dennis' door for support.

Yuniarti: But because it's happening at the same time with me, so I feel like when I talk to him, I feel some helping in term of somebody listening to you too. So they there is beyond them only helping and funding helping in accommodation or other things, but they try to help. Okay, I have a problem here. What do you think that I should do? And then he can go to find a resource to help me with some of my problem.

Hannah: Dennis and Lisa helped them with both the big and little things.

Yuniarti: I would like say, really thank you and really appreciate they there to help me to navigate most my problem in terms of navigate logistics living in Toronto. I guess without them, it was so confusing. In the beginning we didn't know how to submit our documents and how to submit the funding. But when they there, it was a big help because we only go to see them and then they be able to provide all the other information to provide or submit our form to get funding through them. Instead, we going to different, different person to submit it, find faxing or find email or scanning or printing and everything. I found that navigator office is the best place to look at all the resources because it's just one place to get all the answer with many questions.

Hannah: I ask Sarah how it makes her feel to hear about the impact of Dennis, Lisa and the program overall.

Sarah: I've been doing this a reasonably long time now and remain motivated, impressed, inspired by how kids and how their parents and how their families are able to navigate

sometimes the most difficult situations and sometimes with humor and sometimes with all sorts of different strategies, but you do get the privilege of being sort of forcefully invited into the inner workings of how families pull off things in incredibly distressing situations. And it is often really inspirational about how kids and families pull this off. This program is definitely there in support of helping families do that to the best that they can.

The obligations I see is our responsibility of the use of our unique Foundation funding in some of these programs is to demonstrate impact and demonstrate feasibility with the idea that these may then be sharable. Not only that we would be able to perpetuate them here, but we may be able to share them with other oncology centers in Ontario or Canada or North America or wherever.

Hannah: From SickKids Foundation, this is SickKids VS. Thanks for listening. If you want to support work like this, visit SickKidsFoundation.com/podcast to donate. And if you like this podcast, please subscribe and rate us on Spotify, Apple or Google Podcasts, or wherever you listen to SickKids VS.

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