SickKids VS Newborn Mortality

Hannah: In northern Pakistan, a woman goes into labor. She's in a rural community, tucked between some of the highest mountains in the world. It's winter, and all roads out of the village are blocked by snow. Even if she could leave, she'd have to travel hours to get to the closest hospital. She has no choice. She must give birth at home.

A traditional birth attendant is there to help. She's delivered babies before, but she doesn't have any formal training. She also doesn't have the means to sanitize the space where mom is giving birth, no clamps or sterile blade to cut the umbilical cord, and no way to get more skilled help if there are any complications.

Still, the baby's coming, so they make do with what they have, and luckily the birth goes okay. But then there are new challenges. There's no scale, so they can't tell if the baby is a healthy weight. The risk of the umbilical stump getting infected is high, but there's no antiseptic on hand. If the baby does get sick, mom doesn't have any way to monitor a fever.

And remember, it's winter. The temperature is below zero, and there's snow on the ground. The home isn't insulated, so it's not easy to keep the baby warm. Newborns in the community have died of hypothermia before.

It's only her baby's first day of life. And already she's worried that her child may not make it until tomorrow.

This mom wants what all parents want, to keep her child healthy and safe. But because of factors beyond her control, she doesn't have access to the health care she needs to do so. Her newborn is at risk of dying from preventable infection and illness.

But one SickKids scientist thinks he can stop that from happening. He's developed an intervention that helps parents take care of their newborn's health, no matter how far away they are from medical care. It isn't some new technology. In fact, it's shockingly low tech. Just seven items packaged in a plastic bag. But though it may seem simple, it has the potential to save newborn lives around the world.

You are listening to SickKids VS, where we take you behind the scenes of big breakthroughs to heal the future. I'm Hannah Bank, and this is SickKids versus Newborn Mortality.

ACT 1

Over the past 30 years, the world has made tremendous progress in preventing child death. In 1990, around 13 million children died before their fifth birthday. But by 2022, the number was down to roughly five million. This decline can be attributed to a few factors. More kids are getting vaccinated. We've gotten better at preventing infections, especially those causing pneumonia and diarrhea. And people around the world have better access to nutritious food and health care. The end result is an almost 60 per cent reduction in child death, a remarkable achievement. But this number doesn't tell the whole story.

Shaun: When we say child mortality in global health, typically what we're referring to is children who die before their fifth birthday.

Hannah: That's Dr. Shaun Morris, Co-Director of the SickKids Centre for Global Child Health.

Shaun: There has been a decrease in infant and newborn deaths as well, but not nearly as quickly as the rate of deaths in older children has gone down. And I think it's not a stretch to say that it may be the single biggest problem in global child health. My work now mainly focuses on newborn mortality. The very first month contributes about half of all of the deaths that happened in the first 60 months of life. And so that's the problem I decided to focus on for a lot of my global health research because it's such a big remaining part of one of the biggest remaining problems, which is still far too many children die.

Hannah: It's a global issue, but all babies aren't equally at risk. Where you're born has a big impact on your chance of survival.

Shaun: In Canada, about four out of 1,000 babies who are born alive, die in the first month of life. In many lower resourced settings in countries around the world, that number may be 10 times higher. So, 40 babies, approximately, out of 1,000 who were born alive will die before they reach the end of that first month of life.

Hannah: The reason these newborns are more at risk isn't biological, it's contextual. Many of the biggest risks to newborn health, being born prematurely, birth complications, infections and congenital conditions, are things SickKids and other Canadian hospitals can prevent or treat. But in many places in the world, this kind of health care just isn't accessible no matter how hard a parent tries.

Shaun: So, I think it's a universal truth that essentially every pregnant person wants their pregnancy to be healthy and wants the delivery of their baby to be safe, but there are many, many challenges and barriers that make it very hard for these women to choose where they would like to have their baby to ensure that those desires are met in terms of safety and health. The facility is just too far. Somebody might not be able to pay, somebody to transport them. Sometimes there are other cultural or social barriers that stop a woman from accessing a facility delivery. The delivery may happen in the home onto a mat or onto a bed or onto the ground and many of the tools that are required to have a clean and safe delivery are not available in that context, nor if there are complications or problems is there a way to easily access the emergent type of care that is needed. That shouldn't happen and there are ways to prevent that from happening.

Hannah: But how do you do that exactly? It's a question Shaun asked himself over a decade ago. He turned to Dr. Zulfiqar Bhutta to figure it out. Dr. Bhutta is a world-renowned expert in maternal, newborn, and child health. Today, he and Shaun are co-directors of the SickKids Centre for Global Child Health, a hub of research, education, and advocacy dedicated to improving kids' health in countries around the world. But ten years ago, they were just two colleagues trying to solve a problem. They knew there were proven ways to address the individual causes of newborn deaths. They wondered if they could bundle all of those solutions into one simple, portable, low-cost package.

Shaun: From those discussions, we developed what we call the Integrated Newborn Care Kit, or iNCK for short, and that is the intervention in its various iterations, because it has changed a little bit over the years, that we've trialed in Pakistan and in Kenya to understand does it work? Can it be implemented?

Hannah: I asked Shaun to take me through the current kit and show me what tried and tested tools made their way into the final product.

Shaun: So, it's a small, sealed Ziploc bag, essentially. And inside of this are all of the different parts of the integrated newborn care kit.

Hannah: There's items to help during labor, like a plastic sheet to give birth on, a sterile blade to cut the umbilical cord, cord clamps, and plastic gloves for delivery. There's a topical antiseptic to keep the umbilical stump clean. There's sunflower oil to massage into the baby's skin, protecting the skin barrier. There's a sticker that changes colour based on the baby's temperature, a made-in-Pakistan fleece blanket, and a click-to-heat warmer, like the kind you use to keep your hands warm when you're out on a cold day. And there's a drug that can reduce the risk of postpartum hemorrhage.

Shaun: We also included what I think is another really important part of the kit that is new in the current version of it, which is a pictorial guide. We engaged a local Pakistani artist to draw out how all of the different parts of the kit are to be used.

Hannah: Even with all those items, the kit is estimated to cost about five American dollars to make.

Shaun: And one of our goals is to start thinking about how we can make it less and less expensive.

Hannah: Now that they had the kit, Shaun and team had to answer another big question. How do you get iNCKs to parents living in some of the most remote, hard to reach places in the world? To figure that out, they would have to overcome some tremendous challenges.

Shaun: Yeah, I think tremendous challenge is to put it lightly.

[Hannah laughs.]

CICB AD

Hannah: SickKids breakthroughs are only possible with the incredible support of our donors. That's why we're proud to recognize CIBC as the premier partner of the SickKids VS podcast. The bank and its team members care about making a difference. CIBC has championed SickKids for over 30 years and is the largest corporate supporter of the SickKids Cancer Sequencing Program. CIBC also generously supports SickKids through CIBC Miracle Day and an active employee giving and volunteer program.

ACT 2

Hannah: To test if the kits could truly save lives, the SickKids team needed to see them in action. As Shaun mentioned, they ran trials in Kenya and southern Pakistan, which helped them finetune the kit. Then they partnered with Aga Khan Health Services and the regional department of health on a multi-year study in northern Pakistan. Pakistan has one of the highest newborn mortality rates in the world, and babies living in rural parts of the country are particularly at risk. The SickKids team focused on the country's northernmost province, Gilgit-Baltistan.

Shaun: So, to describe it, Gilgit-Baltistan, or GB as we often refer it to, is essentially all mountains. So in fact, K2, which is the second highest mountain in the world, is part of GB.

Hannah: The region, which was recently included in the list of the most exciting places to travel in the world, has an incredibly rich history as a trading and cultural crossroads between South, Central, and East Asia and Europe. It's home to 1.7 million people, most of whom live in valleys tucked between the mountains Shaun mentioned. I spoke to

Muhammad Yasin, the project manager for the iNCK study in Pakistan. To understand what barriers this unique geography can create to accessing health care.

Yasin: So, living in high-altitude mountains and harsh weather conditions, there are some areas during the snowfall, they are totally cut off from the main cities, even for months and weeks as well. The area in summers also gets very challenging to people living around. There are mostly challenges regarding to landslides. If the area is totally cut off, then it may take 10 to 15 days to reach to the health-care facility.

Hannah: But there's one vital service that is helping people get the care they need. Lady Health Workers. These frontline facilitators serve even the most remote communities in Gilgit-Baltistan.

Yasin: The prime responsibility of these Lady Health Workers is health education and family planning and timely referral of any high-risk case to the health-care facilities.

Hannah: They're community health workers, a service that exists in many countries. They have some training, but they aren't nurses or doctors. They focus more on preventative care, like educating people about immunization or early childhood nutrition. And they often work in their own communities, so they speak the local dialect, know the customs, and are welcomed in many homes. They were the perfect partners to deliver the kits.

Shaun: One of the really important things that we did in our study is we wanted to, as much as possible, replicate how the real world works. So, we were less interested in trying to understand how well the kit worked in a perfectly controlled situation. And so we used Lady Health Workers in our project to deliver the iNCKs to women when they were still pregnant. And the Lady Health Worker taught the woman, the recipient of the kit, how to use the kit.

Hannah: Lady Health Workers visit 150 to 200 households a month, giving them the perfect opportunity to identify pregnant women who could participate in the study. They'd report back to the iNCK team, who would visit the potential participant during her third trimester, explaining the study and asking for her consent to enroll. To make sure they could measure impact, the team grouped their participants into geographic clusters. Depending on what cluster they were in, moms would receive the kit or the regular support provided by Lady Health Workers. The iNCK team tracked both groups, following up with the families to see how everyone was doing.

Yasin: In our settings, the Lady Health Workers are already in their daily routine. They have to manage their household activities as well, cooking and etc. Some additional other NGOs are also relying on them and working with them. Despite all additional duties assigned to these Lady Health Workers, when we visited these Lady Health Workers and they were very happy with the iNCK kit, and they were saying that this is the thing which we were looking for.

Hannah: Because they live in the same remote communities they serve, where access to technology is limited, we weren't able to speak to a Lady Health Worker. But Yasin and his team saw firsthand how dedicated they were to delivering the kits. One story of a Lady Health Worker from the village of Machulo stands out to Yasin.

Yasin: The scenario was basically in winters when there was limited access to the households. This Lady Health Worker went by foot and covered several miles to just deliver this kit to the family, the potential participant who was enrolled in our study. And

she just not only delivered this kit, she further explained each and every component with the mother.

Hannah: So far, more than 19,000 people across Gilgit-Baltistan have been enrolled in the iNCK study, and almost 99 per cent of those who received the kit have used it, including one mom who was worried about losing another newborn.

Yasin: She said that she had previously babies born that were having some infection prevention issues and she had also lost one of her babies in her last deliveries due to the unavailability and access to the health-care facilities and proper hygienic practices. After using this kit, she said, the infection prevention practices has helped her baby to survive. She has mentioned that this intervention should not stop. This intervention should expand in future for the betterment of the communities and the families.

Hannah: Parents weren't the only people seeing a big benefit from the kit, the team also heard from community midwives who were often given the iNCKs by families to use during delivery. You're going to hear from one of those midwives now. Her name is Maryam.

Maryam [with Jessica reading the English translation]: I was giving my services as a community midwife practicing midwifery alongside my teaching duties. My reason was because of the lack of health facilities in my densely populated area. I was managing normal deliveries at home. However, the initiation of the iNCK project by the Aga Khan Health Service, Pakistan significantly eased my work. This kit almost contains all necessary items for pre- and post-delivery.

Hannah: Testimonials like these showed Shaun and Yasin they were heading in the right direction. But to truly understand if the kits were working, they needed to see if the data lined up with what they were hearing from parents and community health workers.

ACT 3

Hannah: It took a lot of early morning conference calls, all-night text threads, and many, many emails. But those long hours and hard work led to the completion of the iNCK study in 2024. The team had overcome countless hurdles, including the lingering risk of COVID, extreme weather events cutting off access to villages, skyrocketing inflation that skewed all budget predictions, and the daily challenges of conducting a scientific study from over 6,000 miles apart.

Shaun: It was a really, really hard place to do science, and it's really an incredible testament to the amazing team that we had working on this project for over two years to pull this off.

Hannah: Now Shaun and team are analyzing the data from 19,000 participants so they can present their findings to the world. When I spoke to Shaun earlier this spring, he was able to give me a sneak peek of what they were seeing so far.

Shaun: This is, I think, going to be one of the major findings of the study is that almost every single woman who received the kit used it, and used it correctly. And we also collected information about would they use it again? Did they like it? Would they recommend it to their family and friends? And almost 100 per cent of women answered in the affirmative to all of those things.

Hannah: Shaun and team are also optimistic about health outcomes. The early data suggests that the kit is potentially helping to identify temperature irregularities and reduce postpartum hemorrhage and umbilical cord infections.

Shaun: In terms of the newborn mortality outcome, that's the one that we have to really carefully look at the numbers before we make any firm conclusions.

Hannah: The SickKids Center for Global Child Health is leveraging this kind of research to drive meaningful change. And Shaun and team are currently hard at work to turn these findings into health policy.

Shaun: This project, I think, really aligns with SickKids' vision of Healthier Children. A Better World. As part of this project, we built up the capacity, both the research capacity and the Lady Healthcare Worker capacity in this very remote part of the world. And we are now shifting our focus to the knowledge translation aspect of the project.

Hannah: The team has been meeting with members of Gilgit-Baltistan's local government and health-care system to discuss scaling the iNCK project. Next, they're taking it national.

Shaun: That's ultimately the goal is to not just do a study and publish it in scientific journals, but to continue to work on this, to make sure that the information is getting into the hands of people who are making decisions about how to improve the health of the populations that they're looking after. And it's been really probably the biggest honour of my career to have the opportunity to lead this and work with all of the amazing people that have made this happen. And it has truly been a team effort.

SickKids is more than a hospital in downtown Toronto. It's really a globally important child health institute that through clinical care and research and capacity building really projects its influence and the ability to positively impact child health literally to the farthest corners of the earth.

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 Charlotte D’Arcy. Sound design and editing by Quill. Check out our show notes for related links and resources. Until next time.