Interview with Shahed Alam and Edith Elliott (Noora Health)

Jessica Kantor
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Jessica Kantor: Could you start by describing the problem that you are addressing and how you're responding to it?

Edith Elliott: The problem that we're addressing is one that is common across all health systems, but specifically we work in India and Bangladesh and now Indonesia, where we see that there's a huge disparity between the healthcare that doctors and nurses want to provide and deliver to patients and the quality of care on the other side. The original problem we started off trying to solve when we were starting Noora was that healthcare systems in these regions are completely oversaturated and overburdened. You have doctors and nurses who are doing their best to provide the highest quality of care to patients, but unfortunately because of time constraints and because of a variety of factors, they're very often unable to provide adequate aftercare instructions to patients. What that means is people will leave facilities after having some sort of medical treatment without the proper knowledge and skills that they need to take care of themselves or be taken care of once they return home.

Very often they might not even understand what their condition is. Then on the other side, you have families who accompany patients to facilities and are there with them throughout the duration of their stay and outside of visiting hours are not engaged in the care of their loved one in any formal way. Then they're expected to be the primary caregiver for the patient once they return home. On the one side you have an overburdened, oversaturated health system, and we have a lot of statistics that we could share about what that then means on the other side. Very often what that means is that a patient will end up suffering from a complication or have some serious issue that otherwise could have been prevented. And then you have family members who outside of visiting hours are left to wait and pray. What we found was that, if you are able to engage the family member in the care of their loved one and provide them with formal skills training at the point of care, they're able to be an extra set of eyes and ears and hands and an advocate for the patient. That in turn improves outcomes on the other side.

Jessica Kantor: How exactly are you engaging with those communities?

Shahed Alam: What we try to do is provide a holistic solution for health systems that we partner with so that they can support family members of patients in the way that Edith described, to give them the confidence and the knowledge that they need to care for their loved ones when they're in the facility and at home. The way that we do this is we identify primarily government health systems that are responsible for taking care of the vast portions of the population in the regions that we work. We get into a partnership with them and we support them in implementing a program that trains the family members of the patients within the process of care delivery.

We identify what exactly the family members should learn and need to know, what are the things that are essential for family members to actually perform at home, and of course the patients themselves. Then we develop regionally appropriate, culturally appropriate content that is, of course, in the right language and using the right imagery that's interesting, exciting, and really well designed. [The content] takes those practices and tells it with a story, whether it's a piece of paper someone takes home or a flip chart that a nurse or a counselor might use to train a family member or videos that you can watch over your phones or in any areas of our hospital. The second thing we do is create content and train healthcare workers who are government employees. They're the people who are already there in the healthcare facilities, they're part of the staff within the hospitals and the clinics that we work. We train them on how to deliver this content effectively. A part of it is the medical topics, it is ensuring that the healthcare workers have that basic understanding of the medical side of what they're explaining, the clinical side, why this is important. But more importantly, and where the gap really lies, is how do you actually communicate this information effectively? How do you teach adults how to learn and practice skills in a short span of time and how do you do it in a way that makes sense for those healthcare workers? They're so busy, that was one of the original problems that we saw, that the system was so overburdened. So how do we train them in a way that helps them understand and use this as a part of their toolkit to actually help them in their roles?

That's what the training of the trainers is, where we train healthcare workers. The last piece is everything that I described so far gets the family prepared while they're in the healthcare facility by a healthcare worker using the content that we've created and the overall system that we've designed. The final piece of it is once they go home, the family member and the patient get an opportunity to sign up for a service where they get all of this content again over time as reminders over their phones. Typically in India we use the WhatsApp platform, in other contexts we use other things, but basically it sends reminders, messages, content, videos, and also gives them opportunity for families to ask questions in case they have any once they go home.

We figure out what it is that the families need to know, then we create content around it, we train the healthcare workers and continue to support them while they're at home. Again, all of this is not done in a silo by Noora Health, but really in deep proximity and partnership with local leaders within the healthcare system and the government to have this be baked into what is the standard of care. It's not dependent on Noora Health delivering this day in and day out, but rather the healthcare workers who are there every day and then they see this as a tool that supports the better care of their patients.

Jessica Kantor: How are you measuring success?

Edith Elliott: There's several things that we look at, it really depends on the condition area that we're working in. We work across maternal and newborn care. We have a general medical and surgical care program. Between those two, we are able to cover the majority of patients in an average district hospital, people coming in to have babies and then people coming in for one of many other reasons. We also have tuberculosis as a condition area, oncology, and of course COVID-19 was one of our large focus areas over the last couple of years because families were playing such a critical role in the care of their loved ones. Depending on the condition area, there are a number of factors that we can measure. In terms of outputs, we will look at how many people have been trained, how many hospitals we are working in, how many nurses, just the basic things that you would anticipate us keeping track of and having an understanding of from a program delivery perspective.

We also have a very robust internal monitoring and evaluation function and research function that looks at a number of factors. Readmissions being one that's an indicator of success of the program, whether or not the program is reducing complications. Of course, one of the ultimate metrics would be a reduction in mortality. That's very difficult to measure for a number of reasons, but we have multiple studies that we've done. We just finished our 2022 annual report that will give you an idea of some of the high level metrics that we've been able to study, but all through rigorous evaluation. For example, in cardiology and cardiac surgery, we have a study that showed a 71% reduction in post-surgical complications. Similar studies have been conducted in maternal and newborn care. One of the key indicators that we've measured is a reduction in newborn readmissions. We saw a 56% reduction in newborn readmissions in this quasi experimental study that was conducted there. There was another study that showed a 54% reduction. So anywhere from that 54 to 56%, there's a big noise in the background.

Shahed Alam: As Edith mentioned, what we try to look at is, what are the things that we are having family members understand, learn and do? How does that actually pan out at home? What are the actual practices of those behaviors? And the reason why we chose those behaviors in the

first place is because we know that they're linked to some outcomes that happen at home that are negative, so we try to measure those. Then the final one is we do hope that at least some of the mortality, some of the death that's happening out there we know is preventable through these practices, so can we actually reduce that? With our research, we have shown progress and good signals on each of the steps in what is our theory of change.

We do see improved practice of healthy behaviors, like Edith was mentioning, in terms of improvement in things like skin to skin, thermal care - it's often referred to as kangaroo mother care - by a significant amount, same with a really important practice, which is dry umbilical cord care, which is the standard of care here in India. We also see some measures in more confidently being able to practice behaviors at home. Those are some measures to see when we're training people through this method, are they actually doing the things that we're training them to do? The metric that Edith mentioned, readmissions, is one that we look at because it helps us club a lot of bad things that can potentially happen to a patient that we're trying to prevent. What we see, as Edith mentioned, is a 54% reduction in readmissions for maternal and newborn care, and in the cardiac space, we saw about a 23% reduction.

It's something that we see across different types of patients, in huge sample sizes in this research study that we've done. For COVID care, we actually saw something similar but that one's a little different in terms of the delivery of the program. But similarly, in the middle of the pandemic we saw that the simple training actually brought down hospitalizations by almost 50%. The last piece that we look at is mortality. That one's of course much more difficult to measure because you need a specific type of research apparatus, but we do have initial indicators that we do reduce newborn mortality by as much as 18%, almost 20%, and that is research that hopefully will be published a bit later this year. We see across different patient populations and types of facilities and regions that this program, just the simple sharing of messages at the right time in the right way, can actually improve health outcomes and potentially save lives.

Edith Elliott: There are also the less scientific, less measurable outcomes in terms of health systems becoming more compassionate, nurse satisfaction increasing, patient satisfaction, family member satisfaction, and trust in the health system increasing and improving. And to us, those are equally important because, of course we have to know whether or not the clinical outcomes are being achieved on the other side, otherwise is it worthwhile and beneficial from a broader perspective? We also are very interested in some of the emotional and psychological effects because so much of your healing as a patient is determined by your mental wellbeing and health. Seeing levels of compassion increase and seeing that reflected through things like patient satisfaction or nurse satisfaction is of equal importance.

Jessica Kantor: Is that what makes your approach distinctive? Or is there anything else that makes your approach distinctive?

Shahed Alam: The few things that come to mind are riffs off of what Edith was saying. First, when you walk into any of the facilities that we work with, this is probably the first thing that you'll feel that there's just so many people within the system. Who are they? They're family members. And what are they doing? They're caring for the patient. And again, unanimously, no matter who you ask within the system, whether it's a family member themselves or a patient or a doctor or a nurse or the security guard who's managing everything in the wards, they'll talk about the importance of family. Within the healthcare system, it is something that gets missed, so I think the uniqueness really starts with a very specific focus on this issue, public health and health systems and providing this service in low resource settings.

This is something that understandably gets left out in many health systems no matter how well resourced it is. I think that where it starts again, is the very specific and comprehensive focus on this one particular issue. It does have a lot of other downstream effects. I think the core change that you visibly see before and after our program, apart from the numbers, is how our healthcare providers interact with patients. Anecdotally, they share that before we started to do this program, all we would do is have our head down making sure we finish our clinical duty, filling out the registers, the administrative part especially, and just go from bed to bed and do our best. Now we actually get a chance to take a step back and connect as humans with the patients and families.

We hear time and time again that it's a refreshing way, it's what they want to do in terms of providing that care, and it provides that connection. All of those things add up to trust and a better connection between the provider and the patients and the families. We're tapping into these resources. We know healthcare and hospitals are such intense and vulnerable environments, this is a little bit more humane and a little bit more connected, just to get people to acknowledge one another and talk to one another and express empathy, give some time to do that. Of course that can always happen, but really giving time to do that and focusing on that, I think that's where a lot of the uniqueness comes in.

Edith Elliott: One other piece is that there are so many efforts within our healthcare system to educate families, but typically, you're handed a piece of paper in the settings where we work, and you may or may not be able to read or understand it. Or you'll be sent links to a bunch of videos that you're expected to watch. But typically those are for liability. They've been designed and created so the hospital can say, yes, we sent Jessica the information and so if something happens, we're not liable any longer. Typically patient education is not framed in a way that is one, based on skills training instead of just blanket information exchange. And two, in a way that is,

especially in the environments where we work, that is high quality design and created through the lens of thinking about adult education principles and framed in a way that is empathetic and that is meant to provide the patient or the family member with information at the right time and in the right way so that they can absorb and understand it.

It's not just as simple as making sure it's in the right language, it's framing it in a way that is, as Shahed mentioned earlier, culturally contextualized. And that it is something that sticks, something you'll remember in the moment when there's a warning sign that you start to recognize in your loved one or whatever it might be. To me that's part of what makes this unique because many hospitals will say, "Oh, well, we do patient education, we're already doing this," but then when you really peel back the layers, one, they're not engaging the community that surrounds the patient who really is going to be responsible for taking care of the patient once they return home. And two, it's typically done in a way that's very rushed, very hurried, and doesn't make sure that the patient or the family is getting actual tangible skills training so that they can take action on the information versus it just being a blanket information exchange.

Jessica Kantor: How did you decide on those strategies specifically? One that you identified that family members needed more intensive post-discharge care training, but then also that it needed to be formatted in a very specific way?

Edith Elliott: When Shahed and I met, we were learning about something called design thinking or human centered design, which is a way of solving problems that uses a specific methodology that starts with deep empathy where you try to deeply understand instead of jumping to a solution, you first try to deeply understand the problem that someone is experiencing. In our case, we spent endless hours in hospitals in India, different types of hospitals, talking to and just trying to learn and absorb and understand what patients, family members, hospital administrators, everyone from the folks who are figuring out where patients are physically located within the hospital to the folks who are cleaning the wards to across the board, just taking a step back and trying to understand what really is the problem here.

Trying to find patterns within that information and saying, okay, this is what the patient is really experiencing. This is what the family is really experiencing, and what we saw time and time again was that family members were scared and anxious and confused and frustrated. Very often they didn't truly understand what was happening with the patient. Patients were spending the majority of their time alone for the most part, outside of when the family member could be there, or the very brief interactions with a doctor or nurse. In India, you're lucky if you get two and a half minutes with a healthcare professional during your average stay, and so these are very rushed

interactions. We were able to not come up with an aha moment, but instead just put puzzle pieces together and try to solve some of the problems that nurses are having and some of the problems that patients and their families were having and look at things in a more holistic manner.

It was very clear that in a family member, you have this incredibly compassionate and willing untapped resource who's capable and excited to do whatever they can to help their loved one heal and, in the case of maternal and newborn care, do whatever they can for the new mother or the new baby if they're given the right information, in the right way and at the right time. There are so many myths and misconceptions, especially in the case of maternal and newborn care, about what a mom or baby should or can need in those critical first 30 days post delivery. Understanding what those myths and misconceptions are, and then using our creative muscle to take the complex medical information, put it through our creative filters, and develop materials and content and a training schedule that works within nurses schedule, and actually saves them time and tries to alleviate the burden on them instead of adding onto to their already very busy workday. It was all in the design, and we are using this idea of human-centered design, which we still continuously are iterating on and rethinking how the program is delivered and operates.

Jessica Kantor: Can you share a little bit about some of the things that didn't work in the beginning? Some of the lessons that you learned that maybe other innovators can learn from your story.

Shahed Alam: There's one challenge that we still face, but which was a greater resistance initially. I'll share two angles to it. One is that healthcare providers are so busy and so constrained in a low resource environment, how do you bring in something new? Even if it's a good idea or even if the idea is something that those healthcare providers themselves feel is important, the challenge was, and still is, how do you actually introduce something effectively in that type of environment?

The second part of that is introducing something into the process of a very complex and oftentimes chaotic system, which is a healthcare system. It has so many moving pieces and so many people to consider. One of our first prototypes of trying to get this training to happen, over a decade ago, and we had the buy-in of everyone within the hospital from the director of the hospital to all of the key healthcare workers, but even then the first day the training the family members weren't let in to the training hall and were told to leave by one of the security guards. And so we were like, oh gosh, we thought we trained all the security guards, but it looks like we missed someone.

There's just a small anecdote of how you change something within a complex environment and a system and really effectively integrate it. Before we used to use more training and more

information sharing and more engagement as our only tool, but now we lean more heavily on this concept of co-creation. What we're trying to do is not necessarily implement something very specific and stringent in terms of a program, but rather help the local healthcare system work on an idea together, so the framing of that is different. Our trainings, for example, with nurses who are there and delivering the vast majority of this training day in and day out, does not start with these are all the things that you have to do and now we're going to spend the rest of the time learning about them, and then we're going to test you about them.

Rather, we take a step back and try to learn from them about what is happening in their system. What do they think about this idea? How do they imagine that this idea might be incorporated within their facility? What are the things that are dos and don'ts for them in terms of making this happen? Starting with making sure that this, from the start, from its inception within that local system, it's something that they want and need and it incorporates those specific elements. We of course come in with tools, we have content, we have technology, we have a lot of things to support that. But those things are built and iterated from what we hear, what healthcare providers would like to be able to support this from happening. Those challenges that I imagine would be there for any system, not just health care that is complex, and also working with frontline workers who are just incredibly busy and need to be convinced effectively of a program or a system's effectiveness.

Edith Elliott: One other piece to double down on, just in terms of one of the big meta lessons versus specific examples, it's really about making sure that you are solving a problem for a set of individuals or for a system and not presuming the answer and the solution. Instead, really listening deeply and not becoming too precious about your idea or too wedded to your idea. Anytime we've done that, that's where we start to falter and make mistakes, but instead really listen to the needs of the community that you're acting in service to and the individuals that you're acting in service to and develop from there, for them and with them, not what you presume to be the solution that is best.

Jessica Kantor: Do you have any limitations that you're still facing?

Edith Elliott: Absolutely. Our dream state, our ideal, our long-term vision is for this to be the standard of care so any hospital that you walk into, anywhere in the world, family member training and engagement, or let's say you're not showing up with a family member, but it's a friend or even you as the patient, that you're given adequate skills training so that you are prepared, so that you can be an agent of your own health and recovery and you're prepared and understand deeply what you're going to need to do post-surgery or whatever it might be, and feel supported by the health system on the other side.

In our ideal world this is the standard of care globally, and that's not something Noora can do alone. We can light a spark and we can hopefully show that this model can be absorbed by some of the most resource constrained healthcare settings in the world. It is cost effective, and from a healthcare outcomes perspective it is extremely beneficial. But one of the major limitations that we have is we can't convince every health system in the world to do this. One of our big challenges is really an advocacy challenge and making sure that we're gathering the right evidence, talking about this work in the right forums into the right people so that other health systems can feel inspired and packaging it in the right way so that other health systems can feel inspired to pick this up and carry it forward.

For us to go from health system to health system, that's going to take forever. We face challenges every time we enter into a new health system, there are bureaucratic challenges, there are a number of things at the macro level or the micro level. The promotion of this as a bigger solution, if you're familiar with say the healthcare worker model and bringing healthcare to the last mile, that's a model that a few organizations did in a compelling way. Now you have so many governments and healthcare systems and NGOs that are built on that premise. Our dream would be for Noora to light a spark but not be the ones that are doing it everywhere.

Jessica Kantor: What do you think is needed from other actors in that realm in order for there to be systems level change?

Edith Elliott: I think an openness and willingness to innovate and to try new things, because very often with these health systems, it's very difficult to make changes, even if they're like micro level changes. Typically in the US for example, it's so expensive and there's so many legal and bureaucratic hurdles that one has to jump through to innovate in the healthcare space. So one would be loosening some of that stringency.

Shahed Alam: I'll address two levels of how to unlock some potential for this idea. Related to what Edith was saying, which is I think the much grander vision,, we are trying to work with government, partners across the regions that we work with now to expand this pretty rapidly. In the next five years, we're trying to reach 70 million family caregivers and across four countries, and expanding very rapidly our work in India, for example, to be saturating the majority of states here, Indonesia as well, and across the country in Bangladesh, and identifying one more country to be able to work in. That's a very lofty ambition in some ways, but we're confident because of the data and experience that we have in these health systems to be able to do that.

But to really be able to get to that next stage, to be able to do this a bit more rapidly, what we find is that there's a lot of interventions that happen with healthcare workers or within the public health system. One hope that we have is that some of these things could be a bit better coordinated to provide the best possible experience for the end user, the patients and the families. More coordination of all of the actors in terms of improving things and working on things to be able to provide something more holistic. One of the challenges that we face in order to do that is in healthcare, a lot of interventions are very vertical and program driven and oftentimes this follows specific patient populations.

You'll have N number of programs in maternal newborn care, but then very little for let's say oncology or surgical or medical types of patients. Of course that makes sense in terms of the foundations of the health system, but what that also causes is not having these interventions and these experiences be system wide. It creates a challenge of actually doing something that benefits the entire system and not just one narrow part of it. The issue then for us is, how do we support health systems to do this in an integrated way across the depth and breadth of what a health system is and not just focusing narrowly on one element of it. The other part of that is working better with other actors and including government programs themselves to make sure that all of these interventions are well connected.

There is progress in this way. We do see our government partners trying to do this effectively, but this is a big area of focus for us. How do we unlock that potential even in the regions that we're currently working to scale what we're doing? The bigger picture idea of having this spread to become a movement, having this to spread beyond what Noora Health can possibly do in the regions that we work, I agree with what Edith said, there's oftentimes a lot of resistance in healthcare, especially to these simple ideas. Perhaps just a little bit more openness and willingness to try these things out, a more collaborative way in addressing it where we can share our experiences and provide toolkits for other healthcare systems that want to try this out. I'm sure there's other organizations out there who would want to do something similar.

Jessica Kantor: You spoke a little bit about some goals and things that you want to achieve in the next five years, but how do you see your work evolving over the next five years?

Shahed Alam: We need to continue pushing on how we're scaling this work within the places that we work. So one is geographic expansion and we continue to do that. The second is being able to work with more levels of the healthcare system. While we described our work, it's still not even in the states that we're working with across every single healthcare facility or every single healthcare worker. Providing models to be able to do that across different levels of the healthcare system. In other words, there's big facilities that provide certain types of care, smaller community clinics and

community health workers, and so being able to work across that whole breadth and do something for different types of patients. Those three things put together are how we are looking to scale. Those are the vectors of our scale. Being able to do that will require a lot of focused efforts in innovating in each of those ways.

We're also trying to continue to iterate on our model in a way that lends itself to what Edith was talking about earlier, which is how can we package what we do so that it's not always on Noora Health to support the implementation of it, but how do we package what we do through these learnings that other healthcare systems can take it on? Over these next five years, we hope to, with our experience of working across more geographies, more types of patients, more types of facilities, be able to translate that to a toolkit or something like a set of processes or guidelines on how to do this most effectively. Hopefully that sets us up for the five or 10 or infinite amount of years after that.

Jessica Kantor: Do you have anything that you feel is important to share in this conversation that we didn't cover for anybody who's looking to learn about your model?

Edith Elliott: One final piece that maybe we didn't emphasize even in that first question, what is the problem, the majority of us, if not all of us, have been in the position of being a patient or taking care of someone we love, and those feelings of helplessness and confusion and fear when something does start to go wrong, let's say you're experiencing a complication or something scary is happening with a new baby, whatever it might be, it happens very quick and it can be very scary. Creating a health system, this one seemingly simple and small tweak can have such a massive impact. Not just on the clinical side, but also emotionally in supporting patients and families and supporting the health system on the other side. And I think helping people bring themselves back to that moment and realize that what they needed in that moment was the right information. We think we've figured out a way to get people information in the right way and at the right time, and that can have this massive domino impact on the other side. Tying it back to the universality of this, it is not just for patients who are in a very under-resourced government hospital in the middle of India, this is for you or me or any of us who were in the middle of one of these significant healthcare moments.

Shahed Alam: What we've found to be the most useful way to scale in some ways and how to grow this idea is by listening. Every time we go to a new context, whether it's a big new context like a new country or a new hospital or to the ward where we talk to a nurse or another healthcare provider, at every level of the system that we're trying to grow in and scale to, what we find the most effective way to actually start off is just by listening and understanding what is already happening in this space, what are the key challenges, what are the key ideas that are there?

Starting there, rather than starting with, "we have this amazing thing that's worked in so many places, let's try to visualize it for this setting".

Humbleness really helps in what we've seen in getting the right type of buy-in from the start, to be able to effectively work and actually do something that has the right type of ownership or contextualization within the systems that we're working with. Noora Health should not be the one who's most excited about this idea or concept in those facilities or in that government that we're working with. It should be coming from within and owned by those local stakeholders. And again, the only way we've seen that happening is if we truly take a step back and open up, allowing that to lead into whatever else might come. Sometimes it might be that this is not a priority or this is maybe not the right time for it. Being open to hearing that as well, of course, just some reflection. This came out for me most prominently in our expansion of the work to Indonesia, in expanding in India for example, we did have a little bit of a prototype and template in mind of taking what we do and taking it to new states. But here it was, we really did need to take a step back and understand would this be something that works or would this be something even of interest. Doing that allowed us to get that buy-in and now is supporting us in actually building the program.

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** This interview has been edited and condensed.*