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Rare Lives: Quest for blood: How COVID-19 pandemic hurt children with thalassaemia

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Hi I'm Maneka Rao the guest host of this podcast of Rare Lives, in this episode we speak about how children with thalassaemia, a rare blood disorder suffered during the lockdown. There are more than a lakh such children in the country. The children depend on regular blood supply for their survival, and this has been hit badly since the lockdown.

Nine year old Rajeshwari suffers from thalassaemia, a blood disorder that causes the blood to have less hemoglobin. She lives in a village, 30 kms from Raichur city in North Karnataka. Her father, Rajshekhar is a farmer. She was travelling every 20 days in an overnight bus to Bengaluru for blood transfusion at a thalassaemia day-care clinic, run by Sankalp Foundation.

Day-care centres are ideal for thalassaemia patients as the entire centre is geared to their needs, including having familiar paramedic staff to set up blood transfusion and getting free medicines, and check ups. It is a kind of one stop shop for thalassaemia children.

This system of reliable blood supply went for a toss during suddenly imposed lockdown this March. Unable to travel to Bengaluru, Rajshekhar took his daughter to a nearby private hospital. He wouldn't have to worry about blood supply before. But this time, he had to take along with a family friend as a donor. This happened 3 times over a period of a few months, but the blood was not adequate for the child. He speaks Kannada.

Raj shekhar: Her face would go white. She said she was weak and would sleep a lot. She would say her legs hurt.

He said that the child's face would become pale, and she would complain of leg pain all day. The nine-year old who is quite active otherwise, slept a lot during that time, he said.

One time, the child got rashes all over her body because of a reaction due to blood transfusion. The parents were not used to it because in day-care they went to earlier, the blood was processed further to avoid such reactions.

In the meanwhile, the Bengaluru centre was also short of blood. Blood donation camps had reduced considerably since the lockdown, and it was hard to arrange for blood for patients. The system of having assured blood supply in the blood bank for these children has been shattered since the lockdown. It continues to be very difficult even now.



The alarm went off as early as the end of February.

Vinay Shetty: Starting from end of February itself, we realize that blood donation camps were getting canceled, or, or people who are telling us that we are going to postpone for these camps. So, the red flag was there towards the end of February itself.

This is Vinay Shetty who founded THINK foundation in Mumbai about two decades ago. The non-profit works with thalassemia children and day care-centres. Shetty explains that blood supply is maintained by organising blood donation camps, usually in colleges, corporate institutes, religious institutions, among others.

Vinay Shetty: A very large percentage of the blood that comes into that, that centers is mainly through blood donation camps. People keep thinking about having a list of donors. That's not how the blood donation scene works, actually. So we need to go to where the donor is. And therefore if we look at what was the situation before the lockdown, and before this attack, pandemic, we were getting almost 30% of the blood through corporate blood donation camps. Another 15% was coming through college blood donation camps. Okay, so by and large, most of the blood that was coming was through camps. So, the minute this pandemic came up, you know, and people started getting alert, and people were told not to do things, you know, which were avoidable. Everybody thinks you know, donating blood is avoidable, because it's not required to be done. Okay? So so all these years, we've been fighting and saying blood donation should be voluntary, there should be no pressure on the patient that is willing to donate blood, all of that has gone for a toss, after the pandemic.

A patient who needs blood should get it through a secure system of blood supply. He or she should not be saddled with the responsibility of looking for a donor, as is commonly believed. When a patient is forced to get a donor, the blood donation is called replacement donation. The system of voluntary blood donation- where blood is collected via blood donation camps or people walking into blood banks -- which was prevalent at least in some parts of the country has been dismantled through the pandemic. This experience was similar in Bengaluru too.

Rajat Agarwal who works with Sankalp Foundation in Bengaluru said that the blood stocks fell during this time. And they had no time to prepare for their patients.

Rajat Agarwal: We saw the blood stocks plummet, we saw the voluntary blood donation plummet, and practically the whole country switched to a replacement driven approach. So while there was stock in the blood banks, it was available only to those who couldn't get a replacement donor, in general.

The blood supply, as all these activists are at pains to explain, are not only for thalassemia children. It is also for people who need them for surgeries, emergency cases such as accidents, for pregnant women delivering babies, among others. While some emergency operations reduced during lockdown-- accidents had reduced-- others such as deliveries and blood for thalassemia children had to continue.

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These organisers tried to get some donors to donate by either organising small camps in residential colonies for instance. During lockdown, the donors also had to be issued travel passes, which were arranged by activists like Shetty and Agarwal. Both Agarwal and Shetty said that they are just about able to collect less than half of what they are usually able to collect. With a huge shortage in blood supply, many children associated with these centres were for the first time asked to get donors.

Though the children were issued travel passes, the biggest barrier for them was lack of public transport. Parents had to hire private cabs who jacked up their rates significantly. Parents often had to spend thousands of rupees for a single cab ride for a blood transfusion.

For instance, Raj Shekhar had to pay Rs 5000 to go from his village to Raichur city three times. The distance in this case was just 30 km.

Atul Gera who works with thalassemia children in Jharkhand said that patients in Ranchi's day care in the government-run Sadar Hospital had to spend a lot of money to come to Ranchi. Of the 600 children registered in this day care centre, only 50-60 are from Ranchi. The children come from different districts in Jharkhand often travelling up to 250 kms. A few children even come from border districts of Bihar, West Bengal and Odisha.

Atul Gera: The serious concern was ke jitne private cabs the, ye sab, they were very badly overcharging, matlab jo unko ek district se doosre district aane me otherwise 50-100, 200 rupay lagte the, now they were charging 5000, 9000, 10,000 so people had stopped moving. To mujhe lagta hai ki ye poore lockdown ke scenario me to do cheezein jo sabse zyada takleef pahouchayi thalassemia ke bachon ko vo tha ki they were not able to reach the daycare in other districts. Jaise vo Ranchi nahi aa paa rahe the.

Translation: the serious concern was that all the private cabs were overcharging badly, moving from one district to another which previously cost about Rs. 50 to 100, they were charging Rs 5000, 9000 or even 10,000 for. So people stopped moving around. I think that the during the entire lockdown scenario what has troubled the children with thalassemia the most is that they were not able to reach the daycare centres in other districts just like he was not able to reach Raachi.

This situation had led to blood hemoglobin of these children falling to levels which are hazardous to their health. The normal hemoglobin levels for children is more than 12 grams per decilitre. This is however, lower for thalassemia children.

Rajat Agarwal: In general, we maintain haemoglobin of around 9.5 before transfusion for these patients, which is considered the safe and healthy limit, we saw that plummeting and that was a very big concern. Now, once it started touching 8, we realised and some of the patients actually when they reached the centre, eventually they had very low haemoglobin Five, six, that kind of thing. So that was a big alarm.

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Sankalp India conducted a study analysing mortality and life expectancy of more than 1000 patients suffering from thalassemia in five day care centres in Karnataka from 2011 to 2018, this is before the lockdown..

One of the findings was that sharp hemoglobin drops had a correlation with the increased mortality among thalassemia patients. The patients whose hemoglobin dropped lower than 2 gm per decilitre had 7.7 times higher risk of dying as compared to children who experienced a smaller drop of hemoglobin of 1 gm per deciliter. This study was published this April. But as Agarwal said, the children experienced severe drop in hemoglobin during the lockdown, and continue to have lower hemoglobin levels.

Rajat Agarwal: And we have to make sure that we prioritise resources towards those who are in greater need. If we had enough blood, we would want to keep everybody at 9.5 and above. But thanks to the situation, we had to do what is called triage, choose the ones who needed more help and direct the resources to them. And that was done for a significant amount of time.

In Sankalp foundation, the children are averaging hemoglobin levels of about 8-8.5.

Rajat Agarwal: Having an average haemoglobin of 8 to 8.5 that we have now, it's not at all ideal. That's not great for the Thalassemia families. However, it's far better not to have few patients get into serious distress than to have all of them really be in a reasonable and though not ideal situation.

Ira Sukheja is a 15-year old resident of Mumbai, she has thalassemia. A few months after the lockdown, the centre where she received blood regularly shut down suddenly. Her mother, Kavita arranged a new place for her and other children from her centre called Samarpan which is linked to Sankalp Foundation. Many children have had to arrange blood near their houses with or without support from organisations such as Sankalp India or Think foundation.

Blood, however, continues to be short. The shortage of blood has played havoc in Ira's life.

Ira Sukheja: My requirement is 1000 ml of blood, I get 250 or 400 ml of blood. So it's like 25 to 40% of my need depending if the blood is there or not. And because the blood is less than a body, we also face many problems, like shortness of breath, I feel weakness, I feel. And that affects my concentration on studies and other physical activities as well. Which if my quantity of blood would have been normal, I wouldn't have faced that. So that is the biggest problem. I feel really weak nowadays when the blood is less than my body. Plus, when I climb the stairs, I realized this, practical because I used to go to school so I had to climb four floors and go to my class. But when I went for a blood transfusion, last time, I could not climb two floors, I was feeling really weakened shortness of breath and little dizzy, I could not climb two floors because the blood I had transfused last time was less and in the body that HB had dropped. And then again I got less blood. Again and again I have to get myself injected also. So that is also a problem because the injection is for eight hours minimum in my vein and so it hurts

there. And if I.. I take two or three bags of blood, then I go after three weeks, but now I have to go weekly for one, one bag.

The process of blood transfusion takes the whole day. Ira used to take her transfusions on her day off. But now, she has to take her online classes during transfusions.

Ira Sukheja: So I leave my house at seven I need to wake up at six leave the house at seven eight ko vaha pahuchna hai Then I join my class and mera yaha IV line prick hota hai blood ata hai, warm hota hai and transfusion chal raha hota hai mere ek haat me phone leke mera class chal raha hota hai aur doosre hath me IV line prick hui hoti hai.

Translation: So I leave my house at seven I need to wake up at six to leave the house at seven, I had to reach there at 8. Then I join my class and while I am being pricked by an IV line, and the warm blood is being transfused I have a phone in my other hand where my class is going on.

Ira takes pride in her school work and is bothered by the disruptions.

Ira Sukheja: So once I was going for my transfusion on a Friday because they can call us any day. And I had a skit to perform that ..an online skit I had to do for my history project, it was 20 marks skit to be counted. And we were informed Thursday night that on Friday morning, early morning, I had to go for a transfusion at eight o'clock I reached there. So that night, then my mother had to call up my class teacher, she talked with her, then we had to send a written message to her, she forwarded it to the coordinators and principal And then my skit had to be postpone and once I had exam also, but that was only MCQ. So I was in my transfusion Center and I give the test that then and there.

Many children are from poor families and depend on these centres for their medicines. The children need a class of drugs called iron chelators. Agarwal explains what iron chelators are.

Rajat Agarwal: So once you give blood, the blood you actually give them a lot of iron, which the body doesn't know how to handle so it keeps accumulating it in the organs. Now once that happens, you need to give them these specialised medicines called chelators, chelating agents, which remove this item from the body and make sure that you don't have long term damage. So the vast majority of the patients who come to sankalp centres anyways, need support for chelation drugs. These medicines start from going by the market price, they start from 40 rupees a day, but they can go up to anywhere to 300-400 rupees a day of cost. And when I say start, that's for a very young kid who just needs a tablet or something like that, for most of the families anyways require support. Now, many of them for this support rely upon not just Sankalp, but also the government. Government does dispense chelators in some states in some hospitals

Many children skipped these medicines for some time after the lockdown. Nine-year old Rajeshwari for instance, skipped her medicines for a month.

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The children also need to be monitored constantly to remain healthy. Vinay Shetty said that these children need to do medical investigations from time to time.

Vinay Shetty: You need to do a liver function test, renal function test, an MRI, a DEXA, and all these things, you know whatever tests were done within the center itself with the hospital, fine, but all the other tests which were to be done outside, we still haven't been able to do that at all. Because we feel that that can be postponed. But can it really be postponed? We don't know.

The children and their parents are now constantly worried about the next transfusion.

Vinay Shetty: So the big challenge for all thalassemia patients was 'where am I going to get the blood from?' In Mumbai, when we are not used to telling the patients to go and organize donors, we never asked them to go and organize donors, the blood is already there in the blood banks. But here it was a reverse equation that there was no blood in the blood banks. So each patient was also told each doctor was told every person we met on the road was to please look at the possibility of organizing of blood donation camp within your residential premises, or any place where you think it's possible for you to do a blood donation camp, exercising all those social distancing measures and all the safety measures, okay. We don't want anybody to take a risk for donating blood. So Thalassemia children were always worried.

Ira Sukheja's mother, Kavita said that they try to arrange donors for the blood bank, but it's very hard.

Kavita Sukheja: It's like daily hunt hamara liye kyuki hum log last moment Pe toh kisiko approach nhi kar sakte kyuki humara experience aisa raha ki mere ek friend hain. Vo har bar every three months me Ira ke liye donate krte they toh jaise COVID start hua maine unhe approach kiya ki mujhe requirement hai toh app apke friends ko bat kar ki donate kara sakte hai toh unhone mujhe seedhe seedhe directly mana kar diya ki jab tak COVID hai tab tak mai nhi krunga na meri family se koi krega na mere friends krenge toh is tarha ke response bhi humko mile toh humne daily basis pe dhoondna try krna shuru kiya.

Translation: It's like a daily hunt for us because we can't approach people last minute. Our experience with one of our friends has been that while he would donate blood once every 3 months, but as soon as COVID began and I approached him that I need blood, and asked him if he could ask his friends to donate, he flatly refused saying that as long as COVID is around neither I, my family or any of my friends will donate blood. So that's the kind of response we've got which is why we started looking for people on a daily basis.

Kavita said that they circulate messages on social media, and sometimes arrange for transport for donors to the site where they can donate.

In Ranchi, Atul Gera said that they have to work much more to get a smaller quantity of blood donated.

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Atul Gera: Is waqt abhi jo hum in baccho ke liye ab jo bacche face kar rahe hai.. that is actually yes blood shortage because bahut sare venues band ho chuke hai camps ke..Kyon ki bade woh spots hai camps ke. It is very difficult to mobilize people now .Because camps chote hai..ab yaha hum 15 camp main kaam lagaya karte the, yaha utna hi energy lagake humain 30 din 30 camp karna padey.

Translation: At this time, what these children are facing is blood shortage because lots of venues to procure blood have been closed, blood camps which were big spots to collect blood have been stopped. It is very difficult to mobilize people now. The camps are now smaller, earlier we used to put up 15 camps now we have to put our energy towards planning 30 camps in 30 days.

Many people continue to feel that blood donation can spread infections such as COVID-19. Shetty said that it's important for government to send across the message that donating blood is safe.

Vinay Shetty: So that's why even now, we are plodding and plodding and telling people, please organize a blood donation camp within your residential premises, you don't have to step out of your comfort zone, we will come to where you are. And you know, we will organize a blood donation camp, if you have a place a covered place within the society premises, we will sanitize the entire place, we will actually, you know register people beforehand, give them time slots, so that there is no crowding, and people can come one after the other and donate blood and go back to their houses. Whatever precautions they're exercising, when they step out of the house to go and buy groceries, the same precautions have to be exercised. In fact, it's safer to donate blood in the blood donation drive within the residential premises than to go to a grocery store. Because a blood bank will exercise all the precautions.

Shetty has been working towards increasing blood transfusions in Mumbai, and Maharashtra for decades now. He was even part of an expert committee of National Blood Transfusion Council. He is simply frustrated with how all the gains they made have been reversed. He spoke of the National Blood policy which pushed for voluntary blood donation. Though there were organisations which were violating the norms, the pandemic has legitimised their practice to some extent.

Vinay Shetty: There are a lot of people who are violating the National blood policy, okay. We say that no, you must not ask for a replacement donation, replacement donation happens, we say that you must not put pressure on the patients related to organize that it happens, okay. And then a lot of people who don't believe in going for blood donation camps. They just feel that, you know, if we go and tell the patients relatives they will move heaven and earth and get the donor to come to our hospital and donate. And those people have got a big fillip actually, you know, because of this, because now people are not questioning them for that. Because they everybody will say no, now there is no blood in the blood bank. So there's no other option but to do this, okay. So they are the ones who are getting away with this, with even more impunity, actually. Whereas most other people, even other centers are now trying to do that now, slowly, saying, see if we can get a donor. There's no compulsion. But that is

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the need of the hour really. Blood should be there in the blood banks. And people are not coming in walking into any place or organizing camps. So where is the blood going to come from?

One of the modalities of COVID-19 treatment was infusing plasma of a recovered COVID -19 patient in the hope that the antibodies would help the patient. Though scientists have found no benefit with this treatment, it still continues in Indian hospitals. Needless to say, plasma donation is almost never voluntary and the patients' relatives have to find donors. The lack of regulation will affect blood donation, Shetty said.

Vinay Shetty: Now, all those gains that we made over the last 15-20-30-40 years of slowly saying that blood donation is a voluntary act, it has to be done by non remunerated, voluntary blood donors, all of that has gone for a toss. And in particular with respect to plasma, when we were trying to say that plasma also should be voluntary, should be non remunerated. No guidelines given. Nobody knows what is happening. It's a complete free for all. So and that's going to impact voluntary blood donation movement on a long term basis it

Shetty emphasizes again that the voluntary blood donation movement is bigger than thalassemia treatment.

Vinay Shetty: I think COVID is here to stay. And we all need to now you know, try and find out what else is possible for us to do to ensure that blood is there in the blood banks. It's not just about thalassemia. It's also about all the others who need blood transfusions, cancer patients need blood transfusions, renal failure patients need blood transfusions, maternity cases need blood transfusions, you know, we need to ensure that all the blood is there in the blood banks. There's a desperate need, because people will die, there will be more people dying for want of blood and because of COVID-19.

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