Stories from a pandemic: A Podcast by It's OK To Talk
Episode 5: Inside a COVID-19 Ward

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Episode Contributors:
Mirai Chatterjee, Sangita Maurya, Dr Evita Taneja, Dr Vimal Sangam, Dr Sumedha Tiwari and Padma Hedoo

CONTRIBUTORS

1. **Ms Mirai Chatterjee** is the Director of the Social Security Unit at Self-Employed Women's Association, (SEWA), a union that helps almost 2 million members in India obtain work and income security, financial services and primary health care. She joined the organization in 1984. She is also Managing Trustee of the Lok Swasthya SEWA Trust and responsible for SEWA's Health Care, Child Care and Insurance programmes. She is currently Chairperson of the National Insurance VimoSEWA Cooperative Ltd and actively involved with the Lok Swasthya Health Cooperative, of which she is a founder.
2. **Sangita Maurya, SEWA** Sangitaben is a migrant worker, originally from Uttar Pradesh and then migrated to Surat city with her husband in search of work opportunity. She has been through various hardships that informal workers in India face on a daily basis. She has been working with SEWA since the last 16 years and passionately helping other informal workers like her, through various programs and grassroot activities.
3. **Dr Evita Taneja** is an anaesthetist and a critical care specialist. She has been actively involved in treating patients with covid from the beginning of the pandemic. Earlier, she was working at PGIMER Chandigarh, presently she is at GMCH, 32 Chandigarh. She describes the journey as "a roller coaster ride physically and mentally." Apart from work, Evita likes to de-stress by going for long runs, regular workouts and decorating her home.
4. **Dr Vimal Sangam** is doing her residency for MD Dermatology from GMC Baroda. She loves deciphering the space between heartbeats, figuratively and literally. She finds her sanity in writing.
5. **Dr Sumedha Tiwari** is a Consultant Psychiatrist based in Mumbai, currently practising at Navicare Clinic (Andheri West) and Nimai Healthcare (BKC). She is also a Senior Registrar at the BMC-run Rajawadi Hospital in Ghatkopar. After completing her MBBS from the prestigious Armed Forces Medical College, Pune, she did her MD (Psychiatry) from Grant Medical College and Sir JJ Group of Hospitals, Mumbai, with an impeccable academic record. Apart from treating common psychiatric ailments, she also provides psychotherapy. She is the official mental health consultant at a firm based in Mumbai and LA. She is also a member of the Internal Complaints Committee of a Mumbai based firm. She was an on-set Child Psychiatrist for a Hindi feature film shot in 2017. Since March 2020, in addition to her role as a Psychiatrist, she has been working with Covid patients and treating them not just medically but also attending to the psychological aspects of the illness.
6. **Padma Hedoo, SEWA** Padmaben is one of the second-generation leaders in SEWA. She is a daughter of SEWA's leader who herself was an Incense stick worker. Being a daughter of an informal worker, she grew up seeing the problems of informal workers since childhood and also got inspired from her mother and her work with SEWA. She started working with SEWA in 1991 as a surveyor in an occupational health program designed for Beedi workers. Since then, she has been working in various health and Child care programs, Padmaben's journey is an inspiration to all the

women coming from such backgrounds. She now is a manager of Sangini Cooperative which runs 11 child care centers across Ahmedabad city.

Host

Pattie Gonsalves works in the areas of public engagement and digital interventions to improve adolescent and youth mental health. She is currently a Project Director at Sangath (India) with the PRIDE research programme where she leads the design and evaluation of a digital intervention for school-going adolescents in low resource settings. Pattie also leads It's Ok To Talk (www.itsoktotalk.in), a national anti-stigma campaign for young people's mental health. As part of this initiative, Pattie currently leads a new Wellcome Trust funded project, "Mann Mela", that is setting up awareness-building immersive media museums for youth mental health in five cities across India. Pattie holds an MSc in Global Health from the University of Oxford and is completing her PhD from the University of Sussex.

Transcript

Sangita: At that time there were so many cases so it was very difficult to get a call with 108 (ambulance). There was a 3-day waiting period so if I called today on a Friday, my turn will come on Sunday so you can understand what my condition would be till Sunday. If my oxygen level is down or if my disease has worsened a lot - you know what the symptoms are - so at that time what will I do at home for 2 days? What can we do? We can drink hot water or do some ayurvedic remedies like taking lemon water and I can take the medicines that the MD has given me at home but at that time I need oxygen, I need a ventilator so I didn't get that so many times, in these cases, there were deaths at home. Those who got ventilators and oxygen after going to the hospital, even they have died and many people died after being in the hospital for 20 days. If we talk about hospitals, some hospitals were giving very good service and with other hospitals, our communities have had very bad experiences. Government had put up wards but they didn't have staff there. There were 100 beds in one line and 100 beds in another line but there were mostly no staff doing rounds there. Patients are shouting that my oxygen is over, sister my oxygen is over, nurse, this is happening to me, doctor, I have this problem but no one was coming there to see them.

Evita: In a COVID ICU, there were certain patients who were on the ventilator and there were certain patients who were still able to talk, and were conscious. To prevent them from getting depressed by looking at the sicker patients, we just make an effort to talk to them whenever possible, you know, encourage them that you will go home, just be positive so when you're talking to them you get to know a little about their history, about how many children do they have, are they married, and then when you hear that she's a single mom already with 2 kids and then when you see her death summary on the group, it just hits you very hard.

Vimal: That 6 hours between the point where you come to know what is going to happen and the point where it actually happens, that is the most excruciating part because see, you know that that person might not live and you've to still keep telling their relatives and you've to keep telling the patient itself that keep hope, that you've to be strong while on the inside you're constantly feeling like shit because you know you're lying so that is a very horrible feeling and repeatedly I had to go through it because there were so many people dying and you cannot tell a patient that he's going to die.

Sumedha: There were patients who were sitting there with oxygen cylinders, we'd given them oxygen cylinders because we did not have beds so there were no beds at all in the whole of Bombay and the war room people told us madam there are no beds, just keep them on oxygen, we can't really do much about this situation and there were people that day who died right in front of my eyes and his wife and his daughter just started accusing me that what were you doing, you were doing nothing, you were busy talking on the phone and now what do I tell them that I was trying to find a bed for your patient? I mean, it's pointless.

Pattie: Over the last year as we have continued to face the COVID-19 pandemic, many battles of life and death have been fought inside COVID-19 wards, especially in cities and during the second wave in India. Medical staff including doctors, nurses and a range of healthcare workers have been caring for what seems like an ever increasing number of patients while coping with limited medical resources and evolving disease and also constantly evolving science on its treatments. It is easy to forget that our health workers are also just people too with loved ones of their own, worries, dreams and lives outside the hospitals. The burden on them to save lives is unprecedented and it comes at a serious cost to their own health, mental health and wellbeing. The second wave has tested the healthcare system in India to the point of collapse and has shed light on many glaring and worrying gaps that need urgent attention if we are to survive yet another wave. Welcome to Stories from a Pandemic, Inside a COVID Ward and I'm your host Pattie Gonsalves. Over this episode, we listen to the stories of 5 health workers – Evita, an anesthesiologist from Chandigarh, Sumedha, a psychologist from Mumbai, Vimal, a young resident doctor from Baroda, Sangeeta from the Self Employed Women's Association of SEWA team in Surat and Padma from the SEWA team in Ahmedabad. They recount some of their experiences at the front lines. In today's episode, we are in conversation with Mirai Chatterjee. Mirai is the director of the social security unit at the Self Employed Women's Association or SEWA that helps almost 2 million members in India obtain work and income security, financial services and primary healthcare. She's also the chairperson of the SEWA cooperative federation of 106 women's primary cooperatives and serves on the boards of several organizations including the Public Health Foundation of India, Save the Children and PRADAN. Welcome Mirai. We are really privileged to have you with us. My first question for you is about how the media has largely focused its coverage of COVID as you just heard in the bites just now on cities' context but what's really happening outside of big cities and much of your work through SEWA is focused on these contexts so could you tell our listeners what the situation is like there?

Mirai: Thanks Pattie. Two-thirds of SEWA's membership in 18 states of India is indeed in the villages of our country. I heard what our sisters said about the urban situation and I'm sorry to say the rural situation is even more dire, has been even more serious and troubling and disturbing. What we saw in the rural areas first of all is that people felt that they would not be affected by COVID-19 because in the first wave they were not much affected. Many of the remote, rural districts, internal districts, even not-so-internal districts of our country were not that badly affected the first time round so first, people were not mentally or emotionally prepared for the pandemic to hit them and their own village, their families, their communities. Second, what we saw was that there was very little service and infrastructure. Gujarat is one of the better off states and I have to say that our local public health authorities did try their best but in a situation as we heard in the cities of shortage of beds and oxygen, I can only say that the situation was much worse in the rural areas. Our frontline workers or agewans like Sangeeta behen and Padma behen did their level best. They provided health education, awareness, they told people what the virus was all about, simple do's and don'ts and also because we had almost 50 years of working closely with the public health authorities, we were able to quickly help with referral care, but refer where and for what if there was no oxygen, if there

were no beds available, if the staff was overworked or if there was shortage of staff and that's exactly what the situation was in the rural areas so as a result most of our sisters and brothers said no, we are going to remain at home, if we are to get sick and die, better to die at home with our families than be in hospital, in fact, they didn't even want to get themselves tested. Of course, RTPCR tests were not easily available but even if they were, they were not willing to be tested because they said the moment we're tested, we'll be moved out of our home far from our loved ones, we'll be put in some COVID center or some hospital and that will be the end of us. Somehow from the first wave and even in the second wave this continued. There was a feeling, a perception among people that going to a hospital is a death warrant so they refused and the families then did their best for home management. There was no question of following central government or state government guidelines because those guidelines never reached them but Sangeeta behen, Padma behen, Aisha behen, all our SEWA sisters and also thousands of other self-help group leaders from civil society and also the government's livelihood programs across the country did their level best to support, to serve, to provide solace to our rural families in a time when there was very public health outreach to them. As I said, Gujarat was one of the better off states but when we hear of our sisters' plight in Bihar and other places, we understand the scale of the problem that our public health infrastructure fell woefully short.

Pattie: Thanks Mirai. We move to the first segment now where we'll be talking about the context of the problem through health workers' accounts and we'll first hear from Evita Taneja, an anesthesiologist and an intensive care provider. She is a senior resident in a government medical college based in Chandigarh. When the pandemic began last year, Evita described it almost like a holiday for some doctors because they were working alternate weeks; one week in the ward and the next week in isolation; however the onset of the second wave meant the increasing number of cases and a limited number of doctors, the time for isolation wasn't an option and she and her colleagues were still working alternate weeks but it was one in the COVID ward and the next outside the COVID ward. She has been doing 12-hour shifts. Let's hear from Evita about her role in the COVID ICU.

Evita: So as an anesthetist I would be posted in a COVID ICU because I would be dealing with putting patients on ventilators, assisting in their breathing, putting tubes; I would be dealing with very critical cases of COVID so I would have 17 patients under me at a time. It was an added stress drenched in that PPE, not being able to even see around 500 meters because of the goggles getting fogged each time. Earlier even the air conditioners weren't supposed to be switched on in the ICUs and in the COVID wards because people felt that cold air is going to circulate the virus and one week we were under so much stress of continuously seeing those patients and even in the next week because it was very initial and we just thought that you shouldn't meet your loved ones, you should stay in isolation, even though we would turn out to be negative or we would test negative, but still that fear was really to a different extent so it started feeling like a punishment.

Pattie: Let's now go to Vimal in Baroda. Vimal just finished her undergraduate degree in medicine in 2020 and has taken up dermatology for her residency. The residency began with the pandemic. She is based in Baroda in Gujarat. Vimal's first ever placement ended up being inside a COVID ICU. Let's hear about her experience.

Vimal: In September I had my first duty in the ICU and I think that was one of the life-changing moments that I had in my life because ICUs have got a lot of critical and intensive things going on and as a medical student I wasn't equipped to see all that. People just lose lives like that. There are so many things that have

to be done and it's still not enough. The college I work at has 2 branches so we used to get posted in both the branches and you have an anesthetist and you have a medicine guy with you but for them to help you out and for you to do your own thing are two separate things right? So if you know your stuff and if you're confident of how to treat the patient, you'll be able to do better but I being the junior most being posted in an ICU, I couldn't figure out a lot of stuff for myself at first and that actually gave me a lot of anxiety because the worst part or I don't know how to say, the unfortunate part of being in this profession is that your mistakes come at the cost of someone's life, especially in a setting like an ICU, you cannot say that oh no, I'm so sorry I forgot this, you cannot say that right? People are dying and that one decision that you take can make the difference between someone's wellbeing and their eventual passing away so that gave me a lot of anxiety because I used to feel so much responsibility that I had to be at my mark all the time and I used to stay awake all night because even if one monitor was beeping, I used to feel why is this monitor constantly beeping, I have to do something about this.

Pattie: Let's now go to Sumedha in Mumbai. Sumedha is a psychiatrist who works at a BMC hospital called The Rajawadi Hospital in Mumbai. Sumedha has been doubling up on the COVID ward as well as working as a psychiatrist. Let's listen as Sumedha tells us what an average day in the COVID ward can be like.

Sumedha: I've heard a lot of patients complain that the doctor doesn't come to take rounds and I keep telling them no, in every shift there are doctors; it's an 8 hour or 10 hour shift whatever; so in every shift doctors come and take rounds. It's just that it's so hard to talk to them because it's so hot and you're wearing that double mask, you literally are screaming and shouting, it just takes that energy. I remember there have been times when I have almost fainted because I've spent so much time in the ward because you're sweating all the time and you're talking to patients and you're measuring their saturation and blood pressure and what not so yes, I personally have; I think twice I remember; almost fainted, I had to hold on to something and then stand there for a while and then come out of the ward.

Pattie: And finally, let's hear from Padma who works as a manager at SEWA's children's cooperative program in Ahmedabad. She offers us an example of a phone based intervention by lay workers providing health information including mental health support.

Padma: Our sisters who are in the field, our agewan sisters who were at their locations, we were in contact with them over the phone continuously so we would talk to them that this is happening in this location and she doesn't have food. People are getting sick and going to hospitals so at that time, we were thinking what we can do for our members as an organization like Sangita behen said so we did whatever we could do. We sent groceries to our member sisters and we were continuously talking about mental health. We have a health and childcare team so at that time, we developed some material on mental health with some help from doctors and experts and we did a conference call with all our members. We have an agewan team and a sevika team and a health worker team. We gave them training and then we gave all our sisters training on mental health, we gave them some education and we continuously explained to them over the phone how to be strong in this situation.

Pattie: Padma just talked about SEWA's intervention to support health and mental health by non-specialists. Mirai, could you comment on what SEWA did as well as other strategies drawing from Evita, Vimal, Sumedha's experiences too that you think would be helpful in tackling the crisis in our healthcare system during the second wave?

Mirai: Well, I think first of all what held us in good stead is almost 50 years of organizing informal women workers at the grassroot level Pattie. Organizing means bringing them together, building their solidarity and sisterhood and by the way, that in itself is a huge mental health intervention so building this sisterhood, solidarity, unity of women and through them their families across caste, class, community, religion and so on so I think, as I said, this strong base held us in good stead because when the pandemic hit, quickly we could swing into action and immediately our grassroot women leaders like Sangeeta behen and Padma behen did indeed spring into action and ours was a holistic approach which means first of all, obviously, doing their best to tackle the health emergency, providing health education and awareness door to door where possible, through digital tools like WhatsApp which they used very effectively especially during the first wave; they learned how to use digital tools so they put both into use in the second wave. Then second and most importantly, also linking up with public health authorities so that when they screened or found early cases of COVID or cases getting out of hand at home, they were quickly able to refer. Importantly, we provided training on use of thermometer and oximeter. These women had never seen an oximeter in their lives but they quickly learned how to use it and monitor people's oxygen levels and then refer speedily when required. Very importantly, both the COVID patients, non-COVID patients and their families needed a lot of support. You heard about the helpline that we had developed. It was both for COVID, for mental health, for non-COVID conditions because one of the things we did experience is that the healthcare was so overwhelmed with the pandemic that the other conditions like pregnant women reaching hospitals on time, patients getting their tuberculosis medicines on time, all those were falling by the wayside so it was important for us to also focus on that while the health emergency of the pandemic was also obviously paramount for us. The third thing we did was making sure that all our frontline workers had some measure of security by insuring all of them. Fortunately, SEWA has its own insurance cooperative, a national level cooperative called VimoSEWA and we worked quickly during the first wave with the insurance companies to develop an appropriate and affordable product which provided coverage both when you were being treated at home and in hospitals so that gave some measure of security for our frontline workers. Then importantly, livelihoods, for informal workers, today you work and earn and today you eat, if you don't earn then you can't eat and feed your families, it's as simple and stark as that and so it was important to have some lifeline of livelihood. Fortunately, many of our sisters were organized into their cooperatives and the SEWA cooperative federation with whom I work managed to get some working capital from donors both in India and abroad and that working capital went a long way into providing work and livelihood for women because that was also very much needed. All the time focusing on COVID, they said our mental health and the anxiety levels and the stress levels are going up but if at least we have work, then we can survive and they said our mind is on other things like feeding our children, doing some work, earning something, so it was really this kind of holistic approach that we had to take at the grassroot level; as I said, both combating the health emergency at hand and doing what we could, although in very tough conditions particularly in the rural areas where beds, oxygen and other support services were not available but also tackling the humanitarian and livelihood crisis that was staring in the face of all of us and particularly our members. Listening to Evita and Vimal and Sumedha, I was thinking perhaps what one can do; of course it's easy to be prescriptive with hindsight; but perhaps what one could have done for young doctors in the COVID ward was to set up support groups. The physical discomfort of PPE, there's not much one can do about but at the end of the day if there was a support group of perhaps their cohort of doctors or other senior doctors to support them first to debrief so they could share their grief, their anxieties as we heard and then have a regular support group where they could share openly with people who are closer to their age, their cohort as I said; that perhaps would be of great comfort to them and support to them for the future. I think what we've learnt through this pandemic is that constant contact is fruitful as you heard Padma behen say, whether face to face, whether on the phone, it was important for patients who are suffering from COVID,

who are not suffering from COVID but other diseases, their families, families who were bereaved and faced tragic loss to have this constant contact and our sisters became not only service providers but they became solace providers so I think those are some of the lessons we can take as we prepare for what is expected to be the third wave.

Pattie: Thanks Mirai. I think that's a really amazing example, especially I think the way that you highlighted the holistic approach you mentioned; I think one of the things that really stood out to me was at the start when you mentioned solidarity and how that in itself might be something that's quite important in the role that it plays in also helping to cope better with a crisis and a couple of other things I think very practical and useful examples that hopefully some of our listeners can take away as well such as the use of simple digital tools like WhatsApp or even the example that you gave of insurance which is something that I think is so critical and so important but so often overlooked and finally I think the point on support groups, we've seen actually interestingly quite a burgeoning of a lot of different kinds of particularly online support groups in the last 2-3 months, many of which are also targeting frontline workers so I think that's a really excellent example as well. We'll be talking more about especially the point on solidarity through challenges that healthcare workers highlighted and we'll come back to this point in our next segment. All of the medical personnel that we interviewed talked about a serious shortage of medical staff but the healthcare workers also highlighted that they felt continuously stretched beyond their capacities and we will hear now from Vimal, Sumedha and Evita on what they were seeing during the crisis.

Vimal: I think one of the major challenges or roadblocks I would say, which was there even during the last year September, October, November phase and now is the dearth of not even doctors, let's say dearth of doctors, nurses, everyone in the healthcare system. There are not enough people for enough patients. Right now in the ward I'm posted, we have 120 patients in one ward and we are 3 doctors and there are 4 nurses and other class IV workers so the thing is even if let's say what, 40 patients have one doctor to take care of them, even if two patients start crashing together, I will be out of support.

Evita: You know, it's like a post-traumatic stress disorder that all of us are going through. It is so tough. During the day, the number of times we write in Hindi that we are explaining to you in your language that the condition of your patient is so and so or giving the bad news that when you come back home and you are sleeping, even in your sleep, it's like you're writing the same thing. You know, I did not know the extent this disease would continue to. I still didn't believe that it could be such a killer. The past few weeks have been very depressing because you were there in the COVID ICU for a week and then the next week when you're posted in the non-COVID, another team comes and takes over but you are still on the same group and you see the patients who were there who were absolutely fine or were in an improving trend, young female like 35 years having two boys and suddenly the next week you see on the group that there's a death summary of the same patient so those days particularly become unforgettable. You sink to the bottom. I did not see so many mortalities last year. Even if I did witness people passing away, they were mostly elderly patients who were already suffering from other diseases and probably COVID was just another hit that accelerated the process but this year it's totally different. It's been what, 2 months of the new wave and every day I have seen 4, 3 patients die each day in my shift.

Evita:: I think if the outcomes started becoming better, at least we would feel that we are doing something in helping people out. Right now, even if we are there, it's like mechanically you are there because you are overworked, you are overburdened.

Sumedha: For doctors, I think they don't have an option to grieve right now, there's no time to grieve. You just can't think about yourself or your emotions because if you do that then there's no way that you can treat these people properly and you can't keep going on for that long. Just recently in my last COVID duty, the last COVID duty I did, it started at 8 am, 8.15 I get a call from my best friend that her father passed away and her father-in-law also passed away and her mother and her mother-in-law both are in the ICU and I had just started with my COVID duty, I didn't know what to say, I tried to tell her a few things and after that I had to tell her that listen, I'm on duty, I'll call you once I'm done with my duty. I almost cried and after that I went back to doing my duty because sadly there's nothing that I could have done, I cannot afford to take time off because I've already started my duty.

Pattie: Vimal, Sumedha and Evita tell us about witnessing death on a daily basis and in an unprecedented manner. Many medical staff are now serving 12-hour shifts in blistering PPE suits for weeks on end, some with up to 40+ patients to attend to daily. They speak of serious anxiety and self-doubt when they invariably lose patients and also carry with them a constant everyday fear for their own physical health and that of their loved ones lest they carry the virus home with them. When we were speaking with doctors as part of our interview, something that struck us when we were interviewing them was that asking for help is something that was definitely not encouraged and in fact it was something that was almost frowned upon and could you tell us more about the difficulties faces especially by community workers during COVID and do you have any insights on what we can do to support the mental wellbeing of health workers and frontline workers especially as we prepare for future waves and not just as a means of making sense of these last 2-3 months and this last one year?

Mirai: Pattie, first and foremost, as Evita, Vimal and Sumedha said, I think the time has come to heavily invest in human resources for help. We need many more health personnel from doctors and nurses and technicians right up to grassroot frontline workers like Sangeeta behen and Padma behen. Many of us have been saying this for decades. The High-Level Expert Group on Universal Health Coverage which I was privileged to serve on made a very strong case for this both for strengthening public health infrastructure and services and also providing livelihoods to people in our country which is critical but we have still done precious little and we have heard from them the kind of pressure, the kind of anxiety that they had to go through and it's not really dissimilar from what our sisters at the grassroots level had to go through – Sangeeta behen, Aisha behen, Mehrunissa, all of them. The saving grace perhaps was that they belonged to a movement, the SEWA movement. As I mentioned, the sisterhood, the solidarity, the unity I believe came in handy, was some support to them as they themselves say; often our sisters say, SEWA to hamara peer hai, SEWA is our mother's home, which says it all for Indian women, the safe haven where they can grieve, where they're not afraid to cry, where they can let down their hair, they can share their worries, their anxieties which is different perhaps from what doctors in the COVID ward had to go through and my heart goes out to them. It's heartbreaking listening to these stories. I wish that there was more compassion; I wish that we were able to set up support groups for these young doctors and have them feel the solidarity and sisterhood that my sisters were able to feel at this time, which doesn't mean that it wasn't hard for Sangeeta behen, Padma behen and the others but all of us remained in constant touch with each other, we had periodic debriefing sessions, in fact, just last week we had a session and I was so touched that almost everybody had faced loss. Not only they're serving others but they themselves have faced personal loss of family members, of a close friend, of a neighbor, of someone in their community. Their family said, "Don't go out to work," and yet they went out and served others selflessly with commitment. People trusted them, they were trustworthy, they were agile, they were low-cost in their approach so really I think there are so many lessons for us from the second wave and even the first wave but more so the

second wave. I completely agree with our young doctor friends that the death toll has been much more than any of us had imagined and also what the official figures show. Many times our grassroot sisters would report that in such and such villages the official figures say that there were just 2 deaths but 20 people lost their lives and in a small village where they have 1000 or 2000 people, that's a lot. I remember Pisawada village, it even came later in the news where at the time the Block Health Officer said there were just 75 cases whereas our sisters were able to authentically report that there were 200-300 cases in this large village of families affected by COVID so the situation on the ground and what people have gone through, it really defies description. I would say this is by and large the biggest challenge that we as a nation, as Indians have faced since the partition of India and what hurts is that much of this is preventable. These deaths could have been prevented if we were better prepared.

Pattie: Thank you Mirai. I think you raise a very important point, one that has interestingly come up in the episodes before as well about how having these enabling and safe spaces to make sense of our experiences is something that is extremely important, how important it is to be able to talk about and express yourself and finally, I think a point that you've been making since the start of this interview which is on the value and the important of service not just as a means of healing but as a means of helping others and very importantly, helping ourselves as well. We move to the third segment of our interview which is around managing and making sense of information and misinformation through the pandemic. We will first hear from Evita on managing patients and their families' expectations through COVID.

Evita: So if a patient is normal, sitting by himself, conscious, he will be searching on his phone, Googling things, they would Google their own treatment, they would have questions for us that why aren't you giving us Tocilizumab, why aren't you giving us plasma?

Pattie: One of the disturbing features of the pandemic in India has been misinformation related to making important health decisions and choices whether it is to take a vaccine or which medications to take if you get COVID, when you need hospitalization and so on. In the second wave in particular, we saw or participated in a frenzy of requests being shared especially on social media, on WhatsApp for many weeks; desperate patients and families searching for hospital beds or oxygen or other medical resources many of which were not part of health protocols and also many instances of extortion and false scarcity of medicines and oxygen. This information gap arguably cost us many lives and caused a great deal of distress. Information and maybe more importantly misinformation has arguably played a devastating role in our effective management of the pandemic and has been a huge contributing factor to causing wide-spread panic. This has had implications for vulnerable groups, particularly children who have received the least attention through the pandemic and as rumors now circulate that COVID may disproportionately impact children in future waves, this may be another important point for health policy makers to tackle in their messaging. We now hear from Sangeeta from Surat about her young child's experience.

Sangita: I have my mother-in-law at home who is 67 years old so my daughter felt that my grandmother will also die due to corona. There were many corona patients in the neighborhood and SMC people used to put up a board and go. No one in our house had got the disease, we were fine but she was so tense that since it is there in their house, no one from our house should get it because we used to keep scolding that don't go out otherwise corona will come to our house as well so she was very tense that my grandmother will also die and she used to cry a lot and say that give me something so that I can do something. She used to say, "Do something mummy so that nothing happens to my grandmother and you and me and my father and nothing should happen to those who are in quarantine" She used to think about others too.

Pattie: Evita's account tells us that even doctors did not have all the answers and Sangita's experience highlights the profound and adverse impacts on children. Mirai, firstly, what would you consider good messaging to the public and also for children or young people and what forms do you think that this messaging can take so that we avoid mistakes that we've made especially in these last few months?

Mirai: Thanks Pattie. I think the first thing that we all need to acknowledge is that this is a novel virus. We did not have all the answers. I think we have to be honest about that. We do not have the answers; we still don't have the answers even after the second wave; the virus keeps outwitting us and mutating and there's new situations all the time so we need to be honest about this with people whether urban middle class or rural grassroots communities. Second, I think that we have to make the information available through trusted sources available at the very doorsteps of people either through digital tools or where possible face to face, house to house. As you know, our country is still a country that appreciates the aural tradition – people coming face to face, that kind of contact - so where possible it has been very useful when our frontline workers, agewans, have explained to people and explained in simple local language do's and don'ts, what kinds of precautions and preventive action needs to be taken right from mask, hand washing, use of sanitizer if possible, social distancing and so on, all of that to also monitoring signs when things are beginning to go wrong whether it's oxygen levels or fever not coming down and where quick referral is required. So I think the messaging has to be simple, it has to be in local language and we found with minimum of text. In fact, we were able to develop a number of videos, some of which are on YouTube in six different languages with more visuals and few words because most of our people still have difficulty reading too much text and that too in a time when they're anyway anxious and not in the mood to read lengthy things. So I think those kinds of tools through WhatsApp are very effective. I think we're finding now that in addition to WhatsApp because of course internet is not available everywhere, it's spotty in rural areas, I remember our sisters in Nagaland right on the border with Myanmar said that they don't even get internet so in those kinds of situations, we use posters, we use wall paintings on the Panchayat walls and so on so those kinds of things can also be very effective but the point is the message has to be clear, simple, in local language and delivered by trusted people. I think one of the biggest issues that we have faced in this pandemic is the trust deficit. Who do you trust? You are bombarded with information from all sides; the infodemic that others have also spoken about in the past and that we keep hearing about in the media so what are you supposed to do when your doctor tells you you've to take doxycycline, remdesivir and a whole cocktail of medicines and you can't even get them and when your loved ones are suffering, you'll do anything so I think clear messaging from trusted sources and it's okay to say that these are evolving things, for example vaccination, first we were told 6-8 weeks, now we are told 12 weeks so we can say that as the science develops there will be a tweaking of these messages but I think honesty in the messaging, scientific approach; there's been so much non-science or nonsense if I may say so also that this remedy will work and that remedy will work, I think people have to understand that there are local foods which are immune boosters but we do not have treatment for COVID, that message has to be said loud and clear and in a simple manner and in a scientific approach so I think taking science to people but in a simple manner, demystifying science, medicine in the messages is all very important and of course, as I keep saying, the mental health support system is critical.

Pattie: Thanks Mirai. I think you've summed it up really clearly and I think we cannot underestimate the importance of being honest. You make it sound simple but I do wonder what that would translate to in terms of actual messaging but I think you raise another really important point also that it's not necessarily a one-size-fits-all communication strategy but the guiding principles you're shared, I think they're extremely

useful for people designing these kinds of communications or messages to take away. We move to the final section and the last segment of today's episode which is thinking through both short term and long term solutions. We first hear from Sumedha.

Sumedha: I have accepted the fact that this is happening, there's no point cribbing about it or crying about it. I know the healthcare system is a mess but we can't immediately do anything about it. Yes, we do complain to our administration about things that we would like them to fix which can be fixed at this point of time but in the long run, I think this has to be like a long-term investment for the government and all. We can't really fix things at this point of time so I have made my peace with the fact that I am going to do the best from my side with the limited resources that we have at hand. The reality is that this is how it is. You have to deal with the situation right now. I know that these are the shortcomings but I also know that tomorrow I'll have to get up, wear my clothes and go back on duty again but this is the person that I am. I know a lot of people are getting affected by it because it is a very hopeless kind of a situation. So we know how the whole political system works, right now we can't really ourselves get affected by it but in the long run, I think we need to remember that this happened, we can't just forgive and forget because healthcare has been neglected for so long in our country and I think it's about time and I hope that people realize after this pandemic that how important their healthcare is.

Pattie: There has been a lot of emphasis on laying aside differences for now, for the time being, staying positive now and so on but these views have also been met with a lot of criticism. In your experience, how do we build now so that we're actually preparing for the future?

Mirai: I think there are several things that we need to do immediately, especially as we are told that we are staring at a possible third wave in the face. The first is to support our doctor friends Evita, Vimal, Sumedha and so many others who've been working tirelessly and selflessly in the COVID ward. We need to provide them mental health support; the kind of support groups I spoke of; the kind of debriefing that perhaps they would like to share their experiences, their feelings of helplessness and loss as they watched their patients pass away, that is urgently required because we need to replenish ourselves, our resources, our internal resources as we brace ourselves for the months ahead and those months we know are not going to be easy. Second, I think we have to prepare ourselves in terms of materials. Some people say the next wave will not involve so much oxygen use but whatever, we can't take chances now; we've burnt our fingers horribly the first time round so oxygen supplies, oxygen plants, the whole range of materials that are required to save lives because that is what it's about ultimately but I also think and I agree with our young doctor friends that we need now to invest in human resources. Of course, it will take time to train doctors, to train doctors for our villages and then of course to get them to go and serve in those remote rural areas but we have to start now, and nurses. Let there be a nursing school in every block, taluka of this country. We have been demanding that at SEWA for years and in the High-Level Expert Group as well we said that. We have now young women who are ready to become nurses, doctors and serve and they will serve in their local, decentralized rural areas but they can't get into these schools because there are not enough of them so we need a whole lot of these. Second, we need to invest heavily now in ASHAs and frontline workers like Sangita, Aisha and Padma behen. They are ready; are we ready? We have lots of young people in this country. We keep hearing of the demographic dividend. Why don't we use that dividend? Why don't we train these unemployed, young people who are ready to serve in their own communities whether low income urban mohallas and neighborhoods of our towns and cities or whether in remote rural areas? They are ready. Are we ready? I think we should be. It's high time to put aside all our differences and our doubts and invest in them because they have proved way beyond the call of duty that it is they

who are at the frontlines and they who will do the early detection and screening that would save lives so heavy investment in human resources needs to be done today. In the longer term, people like myself, my organization, and many other public health advocates around the country in India have been pushing for universal health care. How long are we to wait? Are we not going to learn the lessons from this pandemic? Ten years ago the report came out in which we said we need to invest to the tune of 2.5% to 3% of Indian GDP on public health so that people would not pay out of pocket, so that people would not be pauperized, so that we would have a decent public health system but we didn't, we didn't as a nation at a time when we had high GDP growth, 8%, 9% and we had the money to invest and invest in what? One, I've mentioned human resources; I'm not just talking about buildings. Somehow in our country we're very good about putting up buildings, sort of physical infrastructure but I'm talking about human resources, I'm talking about all kinds of other resources and particularly in primary healthcare. What we saw this time was that the hospitals were overwhelmed. They couldn't deal; they did their best and this happened not just in India, in every country so what we need to do is strengthen our primary healthcare system where the grassroot frontline workers do the early screening and early detection and quick referral so that there isn't a clogging of our hospitals as we saw this time and lives, importantly, are saved. So these are some of the things that I think are very important but as I would like to stress again, I think it's very important right now to focus on mental health. We are staring at a huge mental health crisis in this country, not just doctors in the COVID ward but citizens, common citizens of this country who overnight have lost their loved ones to a virus that as I said keeps outwitting us all the time. We also need to engage much more as a nation with the private sector. 80% of Indians go to private hospitals and we've heard that they have charged exorbitant rates; unfortunately even at this tragic time they have been exploitative so we have to enter into partnerships and engage with them and perhaps develop standard treatment protocols not just for COVID but for other diseases, for mental health and so on so I think we have our work cut out but we have to start today.

Pattie: Thank you Mirai. Finally, what are some lessons we learned from inside the ward that apply to the healthcare system at large and what can we as ordinary people and ordinary citizens do to contribute?

Mirai: I think first and foremost as citizens, we need to equip ourselves; I know it's not easy; but with proper information, scientific information so that we make correct decisions to save the lives of not only our loved ones, our family members but our communities, our neighbors and other citizens. We need to take that responsibility and of course the state, the government, state government and central government has to enable that, make it possible, has to play that stewardship role but we as citizens have to take charge of our own health and in a way, this second wave and even the first wave have shown that we are capable of doing that. In a situation where we were left to our own devices, we did the best we could as citizens and also helped our fellow citizens. There was a tremendous amount of compassion; let us not forget that; which the citizens of this country whether they were well-healed or whether they were poor showed to each other and I think that is a tremendous hope for all of us for facing future health emergencies and other crises so first and foremost, equip ourselves with information, be more aware, a scientific approach; second of all, I think that we need to invest more in frontline workers so that the load is not on those who are serving in the COVID ward. We've heard from the doctors inside the ward; they need much more mental health support, counseling, support groups than have been provided to them at the present time and of course this support is needed all down the line – nurses, lab technicians and grassroot workers as well. So I think these are some of the key lessons. I think another lesson is don't hide the facts; there are deaths happening and it is important for people to know what is happening and where. I think the trust deficit that we faced as a nation is because there's been a tendency to cover up, to not share data, to not be honest about the messaging, so all of these have to be taken head on as part of our lessons and our

learning as we reflect, as we emerge hopefully from the second wave and prepare ourselves for the days ahead.

Pattie: Thank you Mirai. Thank you so much also for sharing your insights especially through the experiences of SEWA. I think that those are extremely valuable examples that apply across all of the themes covered in this episode so thank you very much for bringing that in.

Mirai: I would like to share that I myself have been a COVID patient in this second wave. After my second vaccination, a couple of days after that I developed fever and sore throat and a running nose, some of the symptoms of COVID 19 and I isolated for 14 days in my home. I was lucky to have a mild infection but I felt very anxious because I share my home with my mother who's 90 years old; she also was vaccinated along with me; and my twin daughters who were not vaccinated because their turn to be vaccinated hadn't come yet so that caused me a lot of anxiety as I was isolated in my room for 14 days and I think what really helped me was constant contact not only with my SEWA sisters and trying to contribute from my bed to relief efforts but also having a buddy; I had a fellow public health professional, a close friend but also with a background of public health who would call me daily and we would speak and I would share my worries and she would reassure me; when I needed some medication, she had that delivered because my mother and my daughters were quite at sea with me sick, having never seen me sick. Luckily I had enjoyed good health all these years and I wasn't that sick either but it was a scary prospect for them and also it's scary because you hear all these things about COVID that people start out mild and then things go very wrong so for the first seven days I think everyone was very stressed out, 7-10 days and then we were able to relax after we crossed day 10. The reason for me sharing this is that I think it was very important to have that buddy system and then wider buddies or sisters who I was constantly speaking to during the day and also being able to contribute. I felt frustrated that since I was sick I was not able to be as active as I would have liked to in relief efforts, in reaching health kits and food kits and livelihood support to our members but what I could do from my bed was try raising some funds for all of this and I felt satisfied I was able to do that at least.

Pattie: Thank you Mirai for your insights today and for sharing your personal experience. And thank you to our listeners for tuning in. Healthcare workers are the first line of defence to combat this pandemic. Accounts and stories of health workers over the last year have shed light on how they faced a shortage of protective equipment, high patient volumes, risk of infection, psychological and even physical abuse by patients, and constant exposure to deaths of patients and colleagues. These stressors can manifest in a range of mental health difficulties including anxiety and depression, post traumatic stress and increased difficulties for those who are already experiencing mental health difficulties or mental illness. If this situation is not considered carefully and quickly, the psychosocial consequences of COVID on our health workers are likely to be quite serious. We need to take the time to support our health care workers right now and for the future. If you or someone you know is in need of mental health support, you can visit Sangath's COVID-19 Wellbeing Center on www.sangath.in for helplines, community support and counseling.. Stories from a pandemic is supported by the Wellcome Trust as a part of our Mann Mela project. And thanks to our studio engineer Ishaan Gandhi and producer Faith Gonsalves.

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