

COVID 19 Times: Experiences and Learnings

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The COVID19 pandemic has led to an unprecedented situation world-wide. Not only has it put people under lock-down, all businesses have come to a grinding halt leading to significant economic losses. It has claimed more than 400,000 lives and has infected as many as 7 million people worldwide.

It has now been almost 2.5 months since our country has been under lock down. With clinics and hospitals closing down due to the viral outbreak, doctors had to stay home. Initial few days of the unexpected break from work seemed to be pleasant. But being used to gruelling work hours, it soon started to get uncomfortable. As doctors we are used to getting adjusted to situations, and thus many of us started getting used to this new routine and began doing things which had been long pending. Many pursued their hobbies during their free time- music, drawing/ painting, cooking etc. Some finished their academic activities which had taken a back seat otherwise.

Patients and their care-givers too had a gruelling time during this lockdown. Most of our patients with rare genetic disorders have special needs. It could be special diets/ supplements for our patients with inborn errors of metabolism (IEMs), therapies/ special training for children with autism and intellectual disability, physiotherapy for our patients with neuromuscular issues etc. When the lock down was announced, many of the parents panicked as they did not know how their children, and they themselves, would be able to cope up with the situation.

Care-givers of our IEM babies panicked as they feared running out of supplies of special diets and medications. This fear did come true. IEM medications being in the non-essential/ supplement category quickly went off the shelf at many places. Some medications that were ordered through online portals too became unavailable.

One of our patients with intracellular cobalamin synthesis defect ran out of hydroxocobalamin injections, and her symptoms started to flare up. Then we got in touch with a pharmacy chain who could find about 5 vials in their stock from all over India. They were kind enough to have these shipped to Mumbai and further on to Solapur for our single patient. These are rare examples of compassion during such stressful situations.

Many of our IEM patients had a low stock of the special medical foods (SMFs). We did advise them to use these sparingly and consider stricter dietary measures instead. But still some of our patients did run out of the food stock. For two such patients we had to arrange the delivery of SMFs up to Mumbai by air through the cargo flights and then had them sent to Kolhapur and Solapur through milk vans which were running under the essential services category. Thus, travelling by air and road, these SMFs could reach our patients in a timely manner.

Parents of our IEM children were also worried if their child would decompensate during this period or worse, would catch the infection. We told them to identify any primary care physician close to their locality and assured them that we will discuss any issues with the doctor through teleconsultation. Fortunately, only 2 of our IEM babies had minor decompensations which were taken care of locally.

Autistic children whose therapies had stopped, started showing more symptoms of distress-they lost toilet training, had an increase in hyperactivity, loss of speech and regression of skills, etc. Parents too got extremely distressed because along-side their office work they had to take care of the children the whole day as their schools and day care facilities had shut down. Such parents had to be counselled on phone and it was suggested to keep the child busy in a specific routine throughout the day.

I know of a hostel for intellectually challenged

girls, which is more like their home, where they spent the day in a specific routine doing many skill-based activities. Because of the fear of COVID19, these girls had to be sent back home and only the orphaned ones could be kept in the institute. This led to significant distress among these girls and their parents as they were so used to the set routine of this special girls' hostel. We have become irritated by the lockdown as we are not being able to go anywhere or do anything of our choice. But spare a thought for these young special ones whose routine itself keeps them going, and a halt to their activities can lead to a bad flare up of behavioural issues.

With no signs of the pandemic abating at the moment, there is fear among the patients and relatives. They do not want to visit the hospitals/clinics personally for the risk of contracting the infection. This is the time when e-consultations have perhaps become both a necessity and a measure of safety both for patients and health care professionals. Initially there was difficulty in accepting this, as I feared that the examination and counselling would lose its personal touch and a rapport may not be established with the patient and relatives. But I soon found out that this apprehension was unwarranted and that it was possible to consider an equally effective history taking, dysmorphology evaluation, basic examinations and counselling session over video

calls. So, this mode of consultation may have to be considered as a new norm and the COVID19 pandemic has taught us this.

Similarly, the concept of webinars has heralded a new era of e-learning, where we get to hear and interact with the many stalwarts in the field without actually having to travel anywhere. This is a great opportunity especially for our trainees and postgraduate students.

Spending so much time with family and especially my little one was unthinkable if this lockdown would not have holed us up in our homes. It was enjoyable to sit with her in her e-learning classes as well and do various activities with her.

While we are busy making a career, and striving to achieve a work-life balance, we forget to pursue our passions and hobbies. Nature photography was one of my unfulfilled hobbies that had taken a back seat all this while. I did get time to pursue this to some extent, though only balcony photography was possible. All things may have come to a standstill, but nature is still the same and will continue to be so. It is we who perhaps need to change our outlook.

This COVID19 pandemic lockdown has taught us so many important lessons and given us varied experiences both as individuals and health care professionals!