

# COVID-19: A Patient's Perspective

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## Abstract

COVID-19 has been an illness like no other, spreading across nations, sparing none, and claimed so many lives. The following are narratives of two patients who suffered from COVID-19: The first is a consultant nephrologist who developed hypoxia due to COVID-19, required high-flow oxygen therapy, and awake proning but was fortunate to recover from that stage without mechanical ventilation. The second is a biomedical engineer in the Middle East who developed severe COVID-19, was intubated and ventilated, needed a tracheostomy, and then recovered slowly back to health. This invited article includes a narrative of their experiences and personal perspectives.

**Keywords:** CoV-19, patient's perspective, personal experience

## NARRATIVE 1

This narrative is by Dr. Ravi Andrews, Consultant Nephrologist, Apollo Health City, Hyderabad, Telangana State, India.

Humankind is currently fighting the third world war. It is Man v/s Micro-organism... Homo sapiens v/s COVID-19 virus. I too am fighting my own personal war against this virus. Initially, as a frontline warrior (COV-warrior), as a nephrologist, I was taking care of infected patients with kidney disease. Later, as a patient, I was infected by the virus (COV-ictim). Now, I am a victor (COV-ictor), debunking the various myths and falsehoods on COVID-19 on social media. The enemy may be invisible but certainly not invincible.

My story began on the March 22, 2020, when Prime Minister Modi declared a nation-wide lockdown. Closer to home, the Telangana State Government permitted only two state-run hospitals and one private hospital, Apollo Hospital, to admit and treat COVID-19 patients. Since I work as a full-time nephrology consultant at Apollo Hospitals, I knew that I was soon going to be treating plenty of COVID-19 cases.

From March 2020 to mid-June 2020, I continued to work daily, seeing COVID-19 patients, following all the precautions of social distancing, face mask, handwashing, PPE when indicated, etc. Although my colleagues and I have personally fought SARS in 2002, MERS in 2012, H1N1 (swine flu) in 2015, and Nipah in 2018, apart from the usual infective diseases such as TB and influenza, this time it was different.

COVID-19 is an extremely infective virus. Although the risk of death from COVID-19 is just 2%–3% among the general public, it rises to 10% among health-care personnel due to the higher viral loads they are exposed to. It also can lead to long-term complications of the heart, lungs, and kidneys. To top it all, the state government was very stringent on testing for COVID-19. We were sailing blind through the stormy COVID sea!

Even though I had no comorbidities or risk factors, I was worried, more for my family rather than myself. I took utmost care. When I got back home, I would leave my shoes, stethoscope, pen, wallet, and belt outside the door. Go straight to the bathroom, have a shower, wash my clothes separately, change into fresh clothes, and only then meet my family members but still keeping them at a distance as much as possible.

By mid-June, 2020, the Telangana State Government relaxed the stringent restrictions on COVID-19 testing, allowing corporate hospitals and some private laboratories to do reverse transcription–polymerase chain reaction (RT-PCR) nasal swab testing. This led to aggressive testing and an avalanche of new

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cases which had been masked earlier by inadequate testing. I tested some of my symptomatic patients and to my shock, I found that 9 of the 35 patients I was seeing at the time tested positive for COVID-19! I had been treating these patients for the last 3–4 days, blissfully unaware that I was being bombarded with high viral loads!

On Sunday, June 21, 2020, I developed mild sore throat and body ache. I completed my hospital rounds quickly and rested at home. By Monday, 22<sup>nd</sup>, I had high fever, body ache, sore throat, cough, red eyes, loose motions, loss of taste, and loss of smell...all classic symptoms of COVID-19 infection. I immediately isolated myself in a separate room with my laptop, mobile phone, and a few books. I packed a suitcase for 14 days. My family was banned from meeting me. Food was left outside the door followed by a code knock! On Tuesday, 23<sup>rd</sup>, I gave my nasal swab for RT-PCR testing. I also gave routine blood samples for dengue and malaria, hoping it was one of those! On Thursday, 25<sup>th</sup>, the report came as positive for COVID-19.

In collusion, with my infectious diseases (IDs) colleagues, I decided to continue home isolation. I self-monitored my pulse, blood pressure, respiratory rate, and oxygen saturation. For a week, my symptoms continued unabated. On Tuesday, the June 30, 2020, I developed a new symptom – chest pain on taking a deep breath. I initially attributed it to the prolonged coughing for a week but by evening I was feeling breathless on minimal activity. My oxygen levels started dropping. I knew it was time to get hospitalized. I called up my ID colleague and he instructed me to get admitted to the COVID ICU immediately.

As I was leaving home, I bid goodbye to all my family members. Inside I was thinking, “Is this the end? Will I ever make it back home again? Will I come back alive?.” As a doctor, I knew I was in trouble. COVID-19 has no validated treatment, most of it is experimental. I was definitely in a cytokine storm (which classically develops after the 8<sup>th</sup> day of symptoms). With my level of breathlessness, I was headed for oxygen and possibly even a ventilator! These thoughts were spinning in my head as I was taken to the hospital.

In the ICU, it was found that my oxygen saturation on room air was critically low at 80% (as compared to the norm of 96%–99%). I was put on oxygen, steroids, remdesivir, tocilizumab, antibiotics, and enoxaparin. Blood sugar and blood pressure were optimized. The existing COVID-19 therapeutic manual was thrown at me!

The night of June 30, 2020, was the worst night of my life. I was lying on my back, staring at the ceiling... helpless and gasping for breath. Even the slightest of movement such as turning to one side brought on a coughing fit and a bout of breathlessness. I was sure I was going to die that night, alone and isolated, away from my loved ones. There was no one to hold my hand as I passed away into oblivion. My wife would be a single parent and my 16-year-old daughter would experience life-long trauma as a child with just one parent.

They would always struggle financially and never be able to enjoy the lifestyle they were used to when I was alive. My own discomfort from the bright intensive care unit (ICU) lights which were searing into my eyeballs, paled in front of these thoughts.

If the night of June 30, 2020, was the worst night of my life, then the day of July 1, 2020, was the worst day of my life! All the earlier “worst days of my life” were superseded by this particular day. There was no improvement in my medical condition at all. I was still gasping. Getting breathless with minimal movement and all the other symptoms of COVID-19 persisted. My wife kept in touch via video call. Even though I had not improved, I kept reassuring her that I had. However, she understood I was faking it when a single, big, fat tear rolled down my left cheek while I was talking to her. Her suspicions were confirmed when I gave all my account details to her. She understood that I was tying up all loose ends in case of my demise! She asked my treating physician, “so what do we do next?.” His answer was short and direct, “just pray!”

For 2 days, I continued to be sick and hypoxic. I realized that there was a real possibility of death. Those 48 h were the worst and scariest of my entire life! By the evening of the July 1, 2020, I still had not improved. I was lying on my back, staring at the ceiling with the bright lights seemingly streaming across my eyes. Like the streetlights whiz past your eyes when you lie down in the back seat of a car and look out of the window as someone takes you on a long night drive. Multiply the brightness of the lights a 100-fold and the speed of the car by 10-fold... and that is how I felt. At this time, one thought, a terribly clichéd one, kept repetitively going through my mind for no reason at all, ‘it is always darkest before the dawn’.

Late evening, I was lying on my stomach-this is supposedly the best position to adopt when you have COVID-19 with breathing problems. This position is called “awake proning”. So I was awake proning and feeling very, very sorry for myself indeed and I was asking, “Why me? Why, God? Why me?” Then I heard a voice inside me say: “Don’t be a quitter... buck up and go fight this out!!”

That changed things. Suddenly, my body gave a massive jerk, like I was trying to shake a large weight off my back. I clearly visualized a huge, bull-like creature jumping off my back and running away! I recollect its appearance distinctly: It was the size and appearance of those automated rodeo bulls we ride in childrens’ amusement parks, with a time limit for staying on. The one that keeps rotating and rocking and rolling till you fall off it? It had reddish-brown and silvery plates all over it, reminiscent of Iron Man’s costume. After it jumped off my back and galloped away, I immediately started feeling much better as if I had got rid of my very own “COVID Bull”! My breathing became easier, my chest pain reduced, and I began to believe that I was going to survive. I showed steady improvement that night and had a reasonably good sleep after 3 days. As a doctor, I have often heard critically ill patients narrate near-death experiences and vivid visions.

I had always been skeptical about them, dismissing them as unscientific. Now, I was experiencing it myself. I was seeing the other side of medicine and healing. It was an eye-opener, a humbling experience.

I continued to improve. My oxygen requirement reduced, my symptoms got relieved, and I was feeling better. Just as I was beginning to relax, I got another shock. On Thursday, July 2, my wife video-called me saying she was admitted in the same COVID ICU with cough, significant lung injury on her CT scan, and a positive COVID-19 test! I was shocked and demoralized. "What about our daughter? She is alone at home! How will she manage?" was my immediate reaction. "Don't worry, I've made all arrangements at home" she said. Later on, my colleague who was on ICU duty that night told me "This is the first COVID-19 ICU patient I've seen that is *happy and thrilled* to be admitted!". Subsequently, my wife told me "when you were admitted and isolated from all of us and were fighting for your life all alone, I had just one goal in my life. To go to the hospital, get you cured and bring you back home to us. God answered my prayers and sent me to the ICU myself so that I could accomplish my goal."

She was given the same treatment as me (except for tocilizumab). We continued to improve symptomatically, though slowly; COVID-19 is a stubborn disease and invariably leaves long-term sequelae. Our focus was on how our daughter was coping all alone at home. We kept in close touch with her and our maid looking after our daughter via video calls. On the July 7, 2020, we got to know that the maid too had tested positive for COVID-19. This new blow almost brought us to our knees. We got ourselves discharged prematurely from the hospital, promising the doctors we would continue treatment at home and be obsessively careful. We rushed back home to handle this new crisis. Luckily our maid had very mild symptoms and had no breathlessness and her oxygen levels were normal, I decided to treat her at home itself. She began responding well to the treatment.

Our routines continued, with a lot more medications added to both our armamentarium. Our dark cloud continued because both our CT Scans showed severe lung damage and we were now focused on limiting the lung damage so that we did not become lung cripples in future. We continued our isolation as our daughter awaited her 10<sup>th</sup> class final examination results. To our delight, she had performed extremely well. Our dark cloud had disappeared and the dawn was shining brightly! The only thing that remained of our dark cloud was the silver lining!!

We are all much better now and improving rapidly. COVID-19 has a long memory and we will need at least a month to completely overcome it. We will surely do it. It needs grit, courage, belief, God's blessings, goodwill of people, and good luck to do it. *Hum honge kamyab!* We shall overcome!!

## NARRATIVE 2

It was a CoV-19 personal experience of 48-year-old Binoj, Abu Dhabi, United Arab Emirates.

### Onset of symptoms

I am a 48-year-old biomedical engineer working in a private hospital in Abu Dhabi. My ordeal with CoV-19 started as continuous fever and lethargy that had lasted more than a week. I took paracetamol and the fever subsided, only to return once the effect of paracetamol wore off. Since these symptoms persisted for more than a week, I consulted a doctor on an outpatient basis. He prescribed antibiotics for 5 days. I developed cough and shortness of breath and I decided to visit the emergency room (ER) of a private hospital in Abu Dhabi. By that time, my wife who is a nurse was tested CoV-19 positive at her hospital routine check. Later, my younger son aged 6 years and I tested positive.

### Admission to emergency room

In the ER, I was connected to the monitor. The reading on the pulse oximeter at that time was 90% and I was put on high-flow oxygen therapy. My oxygen saturation improved and was maintained within safe limits. A computed tomography (CT) of the chest was ordered by the ER physician. The CT scan confirmed changes in my lung consistent with the disease. The ER physician suggested an immediate transfer to the ICU. Due to the unavailability of beds in the ICU, I was treated in the ER for a while before shifting to the ICU for further management. The oxygen saturation was maintained with high flow oxygen therapy for the first 2 days. Fever continued. Antibiotics and antiviral treatment were started simultaneously. Due to breathlessness and further deterioration of chest X-ray, noninvasive ventilation was commenced. However, I was unable to breathe even with the noninvasive ventilator. I was told that I would need invasive ventilation. I was told that I was then intubated and put on ventilator (this was the 4<sup>th</sup> day). Apparently, I was sedated and paralyzed. As the fever continued and progressive deterioration in the chest X-ray was noted, I was transferred to one of the government hospital in Abu Dhabi for advanced treatment.

A few days passed with me oblivious to what happened to me and around me. I woke up with the breathing tube, tracheostomy tube, in my throat. Later, I would know that my health deteriorated so much and my oxygen level dipped so low that they had to turn me over and ventilate.

Initially, I was kept under total sedation. Once I was weaned off sedation, I woke up extremely thirsty. All I wanted at that point was to go home. I experienced profuse sweating at that time. I remember vaguely trying to get out of the bed and attempting to remove the lines sticking out of me. I also wanted to go to the toilet. During my time in the ICU, I experienced some fearful nightmares. There was some unusual feeling in the neck because of the tracheostomy. I had a strong fear that I will lose my speaking ability. I communicated with gestures and pen and paper at that point. Since I had the tracheostomy and was bedridden

for many days, I was afraid that the tracheostomy tube will stay lifelong. I also feared that I may not be able to speak and if ever I did speak, whether it would be normal speech. I worried if I would be able to walk and whether I would regain my muscle power.

I was told that whenever they tried to wean me off the ventilator, I became agitated and restless. As per the medical staff, roughly a little more than a month was required to get me off ventilator and was one of the most difficult cases that they worked on until then. I was weaned to high-flow oxygen therapy via tracheostomy and later weaned off the same as well. I do not have clear recollection of when the ventilator was removed. When the RT said that there is no ventilator anymore is when I realized that it had been removed.

The physiotherapists worked on me briefly. They mobilized me in the room and said that the muscle power is good. I was moved subsequently to a private rehabilitation center in Abu Dhabi.

### **Recovery**

Recovery thereafter was quick. I was transferred to the rehabilitation center on a tracheal mask. In the rehabilitation center, a speaking valve was attached and I was able to speak. I was ambulated in the room with support, later walked in the hallway and climbed the steps without support. The tracheostomy tube was removed on the 7<sup>th</sup> day at the rehabilitation center, after downsizing the tube once. The feeding tube in my nose was removed after the swallowing test.

### **Discharge**

I got discharged on the 10<sup>th</sup> day from the rehabilitation center. I was able to speak, eat, and perform activities of daily living with minimal support. First of all, I never thought I would be intubated. When the doctor informed me that my chest X-ray is deteriorating and they have to intubate me as a part of the treatment, I gave the consent after discussing it with my wife who is a nurse. I thought that I will be extubated after a few days and never expected that it would take these many days to be out of the ventilator. Since my family members were home quarantined, they could not visit me in the hospital and my condition was deteriorating day by day. They were really tense and emotionally upset. They could not accept what was happening to me. My relatives in India were also worried about my condition as they could not talk to me and visit me. In those days, the death rate also was high.

All glory to God, and thanks to the medical team, nursing team, respiratory therapists, physiotherapists, and paramedics who tirelessly worked to bring me back, I am able to share my experience with you all.

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There are no conflicts of interest.