# COVID-19 and extracorporeal membrane oxygenation: experiences as a patient, general practitioner, wife and mother

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## Summary

I contracted SARS-CoV-2 early in the first wave of the COVID-19 pandemic in the UK and, following nine days of mechanical ventilation, was one of the first few patients to be accepted for venovenous extracorporeal membrane oxygenation. I remained in hospital for 150 days, 34 of which I spent with full extracorporeal respiratory support. I have no recollection of my time on extracorporeal membrane oxygenation, but liberation from it was not the end of my story; I had to overcome numerous physical and mental challenges during recovery and rehabilitation. I hope my story is read by others who are recovering from COVID-19 or critical illness more generally, and that it provides hope that the challenges of rehabilitation can be overcome. This reflection is a personal view of my illness as a patient. In it, I focus upon the aspects of my care that I can remember, predominantly around the time I became unwell but also during the recovery and rehabilitation period, which remains ongoing despite my discharge from hospital and subsequent return to work as a general practitioner.

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# Introduction

The COVID-19 pandemic was declared on 11 March 2020 when there were just 456 confirmed cases in the UK [1]. Although I remain uncertain about when and how I became infected with SARS-CoV-2, my role as a frontline healthcare worker no doubt placed me at high risk of exposure [2], at a time when little was known about the virus or what its impact might be. I am a full-time general practitioner, as is my husband, and we have a daughter who, when I became unwell, was 18 months old. I probably contracted SARS-CoV-2 towards the end of March 2020, around two weeks following my 40<sup>th</sup> birthday.

This report is written seven months following my discharge from hospital and, except for the clinicians' perspectives (Table 1), is based on my experiences and information passed on to me by my husband and clinicians who cared for me during my illness. To my knowledge, this manuscript is the first patient perspective of COVID-19 pneumonitis and extracorporeal membrane oxygenation (ECMO) to be reported in the medical literature.

# Report

Following approximately one week of persistent cough, fever and increasing breathlessness, I was admitted to a medical ward at Wythenshawe Hospital on 1 April 2020. I deteriorated clinically in the early hours of 4 April; I became severely breathless and

Table 1 (a) Clinician's perspective: a brief description of events following referral to the extracorporeal membrane oxygenation(ECMO) service and during the course of ECMO. (b) ECMO Director's perspective: a reflection on the challenges facing thosecharged with delivering ECMO for patients with COVID-19 during the pandemic in the context of this case.

#### (a) Clinician's perspective

- A 41-year-old general practitioner of South East Asian ethnicity and a body mass index of 40 kg.m<sup>-2</sup> was referred for VV-ECMO on 8 April 2020. Nasopharyngeal swabs confirmed the presence of SARS-CoV-2 by polymerase chain reaction. Mechanical ventilation via tracheal tube had been commenced on 4 April, following failure of high concentration facemask oxygen therapy. She was known to have mild asthma but was otherwise fit and well. She had poor lung compliance and required a plateau pressure of 32 cmH<sub>2</sub>O to achieve a tidal volume of 365 ml in the supine position. Her PaO<sub>2</sub> was 9.0 kPa with a F<sub>1</sub>O<sub>2</sub> of 0.8, and her PaCO<sub>2</sub> was 8.5 kPa, with a pH of 7.45. She had previously responded to trials of prone positioning.
- The consensus was that she would be a candidate for ECMO, but the treating team agreed to try another trial of prone positioning to which she responded positively. However, on 13 April she developed critical hypoxaemia ( $PaO_2 8.9 \text{ kPa}$  and  $PaCO_2 \text{ of } 14.8 \text{ kPa}$ , despite an  $F_1O_2$  of 1.0; respiratory rate of 30 breaths per min; inspiratory/expiratory pressures of 30/12 cmH<sub>2</sub>O; tidal volume of 300 ml). The treating team were advised to consider a trial of inhaled nitric oxide, and the decision to institute VV-ECMO was made following further deterioration.
- I inserted a 23-Fr drainage cannula in the right femoral vein and a 21-Fr return cannula in the right internal jugular vein, and VV-ECMO was established uneventfully. Echocardiography demonstrated an underfilled left ventricle; mild left ventricular hypertrophy; a dilated right ventricle with mild to moderate impairment; mild tricuspid regurgitation; and no regional wall motion abnormality. Her tidal volume on rest ventilation settings was approximately 30 ml.
- There were a number of problems during and following ECMO. These included: bacteraemia; severe pulmonary hypertension; cytomegalovirus reactivation; hyperinflammation requiring high-dose steroid therapy; respiratory weaning with a tracheostomy; and thromboses of cannulated veins. Furthermore, she suffered a cardiac arrest six days following decannulation from ECMO due to a pulmonary hypertensive crisis during inhaled nitric oxide weaning.
- This case, early in the COVID-19 pandemic, was a source of reflection and learning for my colleagues and I, not only in terms of the clinical management of COVID-19 and ECMO, but also regarding how best to communicate remotely with relatives during a pandemic, and how we can best enable recovery and rehabilitation following a long run of ECMO.

## (b) ECMO Director's perspective

- Deciding who gets ECMO has led to some challenging times over the course of the pandemic. Was this the correct use of what was going to prove to be a limited, precious resource an ECMO bed? Our ECMO runs were proving to be very long months in some cases. Weighed against the average ICU length of stay for urgent, life-saving cardiac surgery of 2–3 days, who should have that ICU bed? More nurses are required for ECMO (1.5 nurses per patient as opposed to the usual 1:1 in ICU). Is this right in a pandemic when resources are stretched already? Extracorporeal membrane oxygenation is an exaggerated microcosm of the everyday decisions that all intensivists face with respect to which patients should have access to a finite resource.
- Candidacy for ECMO support largely hinges on two factors reversibility and disease severity. We can keep someone with severe COVID-19 pneumonitis alive with ECMO but will doing so save a life? Early in the pandemic there was little in the way of disease modifying treatments. So, did we just need to 'keep patients alive' while time did the healing? Yes and no: with very few clinical features to help us distinguish which patients were in which group, some deteriorated very rapidly and did not survive; many just remained on mechanical ventilation, stuck; however, a proportion of patients improved. This is where 'time on a ventilator' plays a role in determining reversibility. Pre-COVID-19, we knew that much more than a week spent receiving mechanical ventilation before initiation of ECMO meant that a patient's chance of weaning was significantly reduced. Was this true of COVID-19 patients too? All ECMO centres had abundant referrals of young patients with single-organ failure, gradually worsening after days of prone positioning. Did they all warrant ECMO? Given that the incidence of ECMO-related intracerebral bleeding appeared to be higher among patients with COVID-19, it seemed unwise to proactively start ECMO for patients who weren't critically hypoxic. But if delaying ECMO simply meant that patients received prolonged ventilation and then became critically hypoxic, what then?
- I used to believe that ECMO was wonderful, and for H1N1 influenza it was—those patients got better. From my perspective however, COVID-19 doesn't feel the same. That may, in part, be because the operational issues around patient access to super-specialist critical care beds are so challenging. After all, there's no such thing as an 'ECMO bed' it's just an ICU bed which could be used for a heart transplant, a lung transplant, urgent cardiac surgery, a patient receiving ECMO, or many other deserving patients. Who gets that bed? Well, on 13 April 2020, our decision was that Anushua Gupta would get ECMO, and we got it right.

experienced visual hallucinations of a black-winged figure everywhere I looked. I remember seeing that my peripheral arterial oxygen saturations were 80%, despite the high concentration of oxygen I was receiving via facemask. I was visited by a critical care consultant soon thereafter and he explained that I needed to be transferred to the intensive care unit (ICU) for tracheal intubation and mechanical ventilation. This would require a medically induced coma and there was a chance that I may not survive.

My worst fears were coming true. I telephoned my husband and asked to see our daughter on a video call as I thought that I would never get to see her again. I feared that I would never get to fulfil the dream that my husband and I had of living into old

age together. However, I had to remain composed for the sake of my husband, who likewise had to be strong for our daughter. I decided to contact a friend who is a consultant anaesthetist in another part of the UK. I hoped she would see my message before I was taken to the ICU and contact my husband to offer support and advice, given her medical knowledge. I asked her if I would survive, which must have been an extremely difficult question to answer. Later that night I was sedated, and I remained so for approximately two months.

Nine days following my ICU admission I deteriorated further. I was referred, accepted for, and placed on venovenous (VV)-ECMO on the night of 13 April 2020. As it happened, the hospital where I was admitted is also the ECMO centre which serves the North West of England, one of five such centres throughout England that work together as a network. However, my case still had to be discussed and assessed by the same criteria as any other case from any hospital in the country. Not everyone is accepted [3], but the doctors decided to give me a chance. I remained on ECMO with my respiratory system completely supported for 34 days. I was one of the first patients in the UK to receive ECMO for COVID-19 pneumonitis. Initially, my doctors had very little hope, if any, that I would survive, and they told my husband that there was little evidence about what strategies could be used against the disease.

From 13 May 2020 onwards, I began to show signs of improvement. On 23 May I had a tracheostomy, and my sedatives were weaned slowly. I received ventilatory support in one form or another for a further eight weeks. I have subsequently been told by many doctors and nurses that it is nothing short of a miracle that I survived.

## Discussion

I was discharged home on 1 September 2020, 150 days after my admission to hospital. Since discharge, my recovery has been exponential. My daughter has been my driving force, underpinning my determination to get better. My husband, who held the fort when I was not there, has continued to support me in every way. I resumed my clinical work in November 2020, though I am only working remotely currently. I suffered several complications of COVID-19 pneumonitis and its management during my



**Figure 1** A collection of personal images documenting my recovery and rehabilitation: (a) my husband and I during the respiratory weaning process when visiting restrictions were relaxed; (b) an image of me and the team who looked after me on the ICU at Wythenshawe Hospital (with consent from the staff members); (c) when I was able to see my daughter in hospital as I neared discharge; (d) enjoying time with my daughter following my discharge home.

hospital stay including pulmonary emboli [4]; pneumothoraces [5]; pulmonary hypertension [6]; secondary sclerosing cholangitis [7]; and liver abscesses [8]. A major challenge was weaning from the ventilator, as my respiratory muscles were weak due to many reasons including the severity of the disease and the long period of ventilatory support that I received.

A prolonged ICU stay goes hand-in-hand with other problems. My generalised muscle atrophy was marked: I had to learn how to sit upright, stand, and be able to walk a few steps, like a baby in their first year of life. I could not feed myself, brush my teeth or hair, wash myself or even hold a pen. I had to be moved by hoist for two months despite being completely awake and alert. Eventually, I mustered the physical and mental strength to be able to pull myself to a standing position using a patient transfer aid; it took a further few weeks for me to progress to taking my first few steps. I learned that one can certainly not underestimate the vital role of physiotherapy following critical care.

When I was weaned from sedation, I was alarmed to find that I had no voice. It was so distressing that I could not communicate. My laryngeal structures were oedematous due to prolonged tracheal intubation [9]. The speech and language therapists provided me with placards to help me communicate simple messages, but this proved difficult as my hands were so weak and I could not point to the correct box. It was frustrating at times not to be able to communicate effectively.

I was initially fed with a nasogastric tube. Once the speech and language therapists determined that my laryngeal oedema had reduced, my ability to swallow was assessed; it was necessary for me to commence oral intake with pureed food initially before gradually progressing to food of normal consistency. I also experienced altered taste and smell, and oversensitivity in my throat which meant that I thought food was getting stuck.

Initially, my voice was merely a whisper which gradually became husky and hoarse. I remember after a long day my throat would often feel sore. I was worried about my voice normalising, especially as my job requires it and also because I feared that I would not be able to sing nursery rhymes with my daughter. My voice is not completely back to normal; it still sounds slightly husky, but it has improved vastly with speech therapy which I have been undertaking remotely as an outpatient.

Psychological input was integral to improving my mental health and played an important role in my rehabilitation. Having gone through the scale of trauma I endured, knowing how close to death I came, not being able to be close to my family and most of all not being able to see and hold my daughter made me anxious and low in mood. I had difficulty sleeping and felt very fearful about my health and recovery which sometimes obstructed my rehabilitation. I learnt about coping mechanisms, different thought pathways when faced with a particular scenario, and meditation.

Seven months following my discharge from hospital, my recovery is by no means complete [10]. I have significant changes to my lungs. It remains unknown whether these changes are reversible. I still get breathless, but this is improving and my exercise tolerance is increasing. I was suffering with significant pains in multiple joints for many months. I feel this may well be what others have described as 'long COVID'. However, this is also improving as I become fitter and more active. My liver function is settling but is not quite normal. My mental health is much better: I try to keep a very positive outlook on life, and I feel like I have been given a second chance.

It has given me immense joy, satisfaction and a sense of achievement to be able to tell the tale of my battle with COVID-19 and to have my story read by others. Writing this marks the one year anniversary of when I became severely unwell. I hope this report will raise awareness and give hope to others that one can have a good outcome despite such critical illness.

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