THE LANCET Global Health

COMMISSION ON MEDICAL OXYGEN SECURITY

SPOTLIGHT BRIEF

Patient and Caregiver Testimonials

Introduction

To ensure that the experiences of patients and their caregivers shaped the recommendations of ***The Lancet Global Health* Commission on Medical Oxygen Security**, the Commission recorded the testimonies of 25 patients, caregivers, and healthcare workers. Patients included COVID-19 survivors and others with acute and/or chronic needs for medical oxygen in the last five years. Caregivers included family members of deceased and surviving patients, and healthcare workers had recent, direct experience of providing medical oxygen in low-resource settings across Africa, Asia, Europe, and Latin America. All individuals provided written consent for their testimonies to be shared upon publication of the Commission report. Quotations from these testimonies are included throughout the Commission report and are provided in more detail below.

Patients

Woman who survived COVID-19, South Africa

- *I was sitting in the emergency room for close to two hours with no help, struggling to breathe. While waiting for a doctor to come I saw that I was blueish in my face and so I thought let me connect myself to the oxygen cylinder. I gave myself 80% oxygen. I sat on a chair until I felt relief and then I stood up and left the room and shouted for help. If I wasn't a nurse who knew how to use oxygen, I would have died at that moment. During my time of COVID, if I didn't have that oxygen, I really don't think I would have made it. I stayed in the ICU for two weeks on oxygen. I will never forget. Most COVID patients in South Africa never actually got to a hospital to get oxygen. They died at home.*

Woman who survived COVID-19, Nigeria

- *I was on oxygen for two days when I was finally diagnosed with COVID and they took me to an isolation ward. Being on oxygen was a terrible experience for me which I will never forget because I was all alone. Nobody helped. If I wanted to relieve myself I had to remove the oxygen mask and the infusion and hold on to walk to the toilet. I did this for 10 days. One evening the oxygen pipe had a problem. I was hungry for air. I was crying for help.*

COMMISSION ON MEDICAL OXYGEN SECURITY

- *Nobody came. Lucky for me there was a cleaner who came to clean the room. I shouted at him and said please take my phone, call my people that I am dying. I started crying because I had no oxygen supply, I was dying, I couldn't talk. The guy ran to the office and called them. And they found a standby oxygen cylinder and I helped myself. The oxygen concentrator was not effective for me so they brought a cylinder to my bedside. I would have lost my life without oxygen. It really helped me.*

Woman who survived COVID-19, Kenya

- *By the time I was taken to the public hospital my oxygen levels were very, very, very low, but there were 84 people ahead of me in the queue and there was only one doctor. And they could not see me. My family took me to a private hospital and they suspected COVID and asked for US$3,000 before they touched me. But we didn't have it. Then we went to a faith-based hospital and they asked for US$1,500. We didn't have that but my family asked them to diagnose me and that's the first time I was diagnosed with COVID. My breathing was very bad at that moment but they couldn't admit me because they didn't have oxygen. By that time I was losing consciousness. I was finally admitted to another hospital and in the ICU for three weeks and two weeks in the COVID ward. It cost me 1.4 million Kenyan shillings (US$9,800) - and that was with health insurance and a hospital discount. I used to see some people being put off oxygen when they couldn't pay. If I had had a pulse oximeter at home and knew how to use it and what it meant - the different levels of oxygen - then I would have sought care much earlier and it would have been cheaper and maybe I wouldn't have had all these adverse side effects that I am dealing with now.*

Woman with chronic lung condition, Pakistan

- *The government doesn't support oxygen purchases. People have to pay for their own. It cost me 840,000 rupees (US$3,000) for my concentrator. I used to have a little cylinder but it cost 10,000 rupees (US$36) to buy and 400 rupees to refill each week. There was hoarding of oxygen during COVID and a lot of people who needed it couldn't get it. A lot of people are suffering from chronic lung diseases due to climate change and the very bad pollution. That's why they need to make sure oxygen is affordable for everyone.*

Man with chronic lung condition, Pakistan

- *With the hotter temperatures it's harder to breathe and my breathlessness and heart rate increase. I stay indoors and put the air conditioning on and take extra care that I don't strain myself. I don't climb stairs in case I rupture my lungs as this can happen at any time. My treatment cost 5,000,000 rupees (US$18,000) and I had to get 2,000,000 (US$7,000) from my parents, 2,000,000 (US$7,000) in loans from friends and family, and 1,000,000 (US$4,000) from my father's health insurance. It is only families with multiple resources that can afford this type of care. It takes 6-8 hours for me to get oxygen delivered to my home with a doctor's prescription so I need to plan for that.*

COMMISSION ON MEDICAL OXYGEN SECURITY

- *The nearest oxygen shop is 1km away. It closes at 10pm, so if I needed to go quickly at night I would go to the hospital. The delivery of oxygen at home is precarious, especially at night. The second is the cost of oxygen which most people on low incomes can't afford.*

Boy with chronic lung condition, Chile

- *If I didn't have the option to have oxygen, first of all I don't know if I would be here as I was born with this problem. I have one lung and a quarter of the other so I don't know if I'd be standing here. If you leave me for a week without oxygen, I sleep badly, I wake up with more phlegm. My condition would seriously deteriorate. You carry the oxygen like a backpack and so I am able to go to school and get together with my friends, even exercise. I can live a normal life with my illness.*

Woman who survived COVID-19, India

- *Everybody was running around trying to get oxygen. My doctor friends told me, "Don't come to the hospital because if you do you won't come out alive. Stay at home. My family was running around to get oxygen. We got scammed by many people who said they had concentrators and if we paid money - more than 10-15 times the normal price - they would send them. There was no one we could actually rely on for oxygen. It was such a desperate situation. One neighbor offered to lend us their small concentrator for 24 hours with a deposit. Finally we managed to buy a concentrator of our own for 15X the price and I stayed on it for about five days and survived. When you need medical oxygen it's a sinking and very strange feeling - almost like fighting within yourself. Within 10 minutes of getting medical oxygen, I started feeling better. People say oxygen is a lifeline, but you can only truly understand that when you really need it.*

Man with chronic obstructive pulmonary disease (COPD), Chile

- *With oxygen I can live a fairly normal life. There are things I can't do but I can even dance a little. With oxygen, I can take a bath alone because I have the strength to do it. I wash my hair alone. Without oxygen, the exhaustion and lack of energy - especially in my arms - slows me down.*

Families

Son of father who died from COVID-19, Kenya

- *Within the radius of about 50 km of where my dad lived there was no health facility with the capacity to provide oxygen. The hospitals in western Kenya were basically just testing for malaria - they didn't have pulse oximeters or oxygen. We traveled 100km to another hospital which measured my father's oxygen saturation as between 50 and 60, and then we waited as the hospital staff frantically searched for an oxygen cylinder which took another two hours and by that time my father was gasping.*

COMMISSION ON MEDICAL OXYGEN SECURITY

- *When that cylinder ran out there were so many people who needed to be on oxygen there was no more available. I called everybody that I knew for three hours to find another oxygen cylinder and then my brother called me and told me that my father had passed on. That was a very tragic moment. I did not imagine that my dad was going to pass. It was the lapse between one oxygen cylinder and finding another. That's how my dad became one of the statistics of the people who died because of lack of oxygen.*

Nephew whose uncle died, likely from COVID-19, Malawi

- *The nurse told me that my uncle's oxygen saturation was going down and he needed oxygen at a higher flow rate of 15 LPM when the concentrator was only 10LPM. I suggested to the nurse to join two concentrators, a 5LPM and 10LPM model using tee connectors, but the hospital didn't have tee connectors. A cylinder was found but it emptied quickly. The nurse had others lined up already for replacement, however, this required a 28mm spanner to change the flowmeter and the regulator on the cylinder by a technician who stays at the cylinder manifold two minutes away from the ward. But the technician was not there. I went to get the right spanner from my workshop, but when I returned to the hospital I heard cries and I could hear my aunt's voice. I walked through the corridor and saw my other uncle sitting outside crying and he told me, "You have tried your best." I kneeled down with the right spanner in my hand and knew that was the end of it. That's how I lost my beloved uncle. Remember this was Sunday morning when the hospital had very few doctors available.*

Granddaughter whose grandmother died in hospital of unknown causes, Malawi

- *When our grandmother was admitted to hospital it took hours to get an oxygen concentrator. After the concentrator finally arrived, the nurse told us that it was faulty and every time the light flashed red and the alarm went off, we had to switch it on and off quickly. This happened every two minutes. My sister and I and my mother took turns beside our grandmother's bed all night, switching the oxygen concentrator on and off every time it flashed red and the alarm went off. We tried to get a better concentrator but were told we had to pay 20,000 Kwacha (US$12) to a clinician at the hospital who would get one from the ICU. The whole time in the hospital, we don't remember our grandmother ever having her oxygen levels measured by a pulse oximeter.*

Brother of man who survived COVID-19, Nepal

- *Luckily, I had a relative working in the Ministry of Health in a high position who helped get my brother admitted to a government hospital with beds and oxygen therapy available. Once admitted, I noticed the oxygen flowmeter attached to my brother's bed was leaking. There was one nurse in the ward, and she tried her best to reach the maintenance staff. But due to the late hour—around 11pm—she did not get a response. I stayed at my brother's bedside, constantly monitoring the oxygen machine's oxygen concentration, adjusting its flow rate, and adding water to the humidifier chamber.*

COMMISSION ON MEDICAL OXYGEN SECURITY

- *It was a horrible situation. People were dying because of lack of care, lack of medicines, and medical equipment like portable x-ray machines and high-flow nasal cannula devices; as well, oxygen concentrators, ventilators, saturation devices, sensors, and filling stations were scarce.*

Parents of baby who survived COVID-19, Bangladesh

- *The hospital is 80km from home and we could not afford the 3000 taka (US$25) to rent a private bus so we took the public bus which cost 400 taka (US$3) per person each way, but on the way the baby became listless and I was frightened he would die. Our baby was first diagnosed with a lung infection, a blood infection, diarrhea, and malnourishment and then COVID. He was put on oxygen and spent 20 days in the hospital. Initially I was scared about the oxygen for my child but I didn't say anything about it.I slept on a chair beside my baby in the ICU for 20 nights. We have five in our family and it is so difficult to pay for healthcare. The local government hospital is not good but we can't afford the private hospital, so we often stay at home.*

Daughter of woman with chronic lung condition, Pakistan

- *We bought a small oxygen cylinder for home use for my mother. The cylinder would be empty in no time and I would have to go out and fill up twice a week. It's not something that is easily manageable. We have to take the car out and get the cylinder up to the fourth floor. Somebody needs to be there to help my mother set it up and put it on. Oxygen therapy needs to be easier for patients at home to use; so they could be more independent. If the hospitals could deliver oxygen to homes 24/7, that would be great. The cost is a big pain point for most families who cannot afford 12,900 rupees (US$46) per cylinder. It is a Herculean task for a family caring for someone who needs oxygen at home. We are really on our own, with little support from the government.*

Wife of man who survived COVID, Philippines

- *In September 2020 my husband had been sick for 4 days with difficulty breathing and then he fell from a chair. I called my niece, who is a doctor and she advised us to go to her house and get a pulse oximeter. Before this we did not know what a pulse oximeter was. My husband's reading was 73 and so we rushed to the Regional Hospital. There was no oxygen, no doctor, and no medical staff in the ambulance. When we arrived it was very crowded, but they took us in and gave my husband an oxygen mask and big green cylinder. Five to six patients were sharing one cylinder. He had to sit in a wheelchair in a big tent outside the hospital with the oxygen on for 24 hours because there was no bed. After waiting for one week at the hospital, my husband was put into isolation and spent another seven days in emergency where he was finally tested for COVID-19. On Day 18 there was no more oxygen and they tried to wean him off so he could go home. When we got him home he was weak like a child. He couldn't lift his hands and needed help changing his clothes.*

COMMISSION ON MEDICAL OXYGEN SECURITY

Wife of deceased COVID-19 patient, Philippines

- *My husband got sick and had a fever for one week before we tried to take him to the private hospital, but it was full and we were waiting in line, waiting, waiting. So we took a cab to the local government health center to see if we could get faster treatment. They took him in and tested him with a pulse oximeter and his reading was 35 so they got an oxygen cylinder and mask. He was lying in bed and was really struggling to breathe. His oxygen levels went up to 80% and then started coming down again to 60%. They changed the oxygen cylinder four times over a period of 18 hours. The health center had a nurse but no doctor, and my husband was put on the list to be sent to the hospital in the morning. But he didn't make it through the night. My husband was very healthy before COVID. If only the hospital had a bed for him when we first tried, my husband would be alive today.*

Healthcare Workers

Doctor who cared for non-COVID-19 patients, Ethiopia

- *One night, I vividly remember my patient's oxygen saturation dropping below 70 and so we took oxygen away from a patient with an oxygen saturation of 80. We knew we were risking injury to this patient. The whole night was like a gambling game and every 30 to 40 minutes I was checking their oxygen saturation and praying to God that they would make it to the next morning. It was very heartbreaking trying to decide who lives and who dies. One time there was no oxygen for anyone on the whole floor but the ICU always had one or two on backup and so we stole one oxygen cylinder from the ICU. No one from the ICU caught us but this shouldn't have had to happen. I don't want any future generations of doctors having to decide like God who lives and who dies because that is what we had to do when there wasn't enough oxygen.*

Doctor who cared for family members with COVID-19, Bangladesh

- *My father, mother, wife, and three sons all got COVID during lockdown, but as a doctor I was able to treat them at home. I purchased two small cylinders immediately from a private oxygen provider. But they ran out quickly and I had to get two big cylinders from my hospital. At that time oxygen cylinders cost about 20,000 taka (US$180) each and you had to refill every 2-3 hours. It is almost impossible for patients who are not highly paid to afford medical oxygen. It was a vicious cycle - just as one oxygen cylinder was refilling the other was running out. My father was on oxygen for three weeks. I have never seen a patient need as much oxygen as a COVID patient - day after day. I cannot express in language how scared I was for every member of my family. If the oxygen was not there, it's very simple - my father would have died. Even though I am a doctor, I never thought in my life that oxygen security is the mainstay of everything. It should be available every time, everywhere, in every hospital, small or large.*

THE LANCET Global Health

COMMISSION ON MEDICAL OXYGEN SECURITY

Doctor who treated hundreds of COVID-19 patients, Ethiopia

- *As the number of patients started to soar, we were really having a bad time. For example, I remember when all of our oxygen outlets were being used by patients but we had many more coming in. It's not like we could refer them to other facilities, so we started to look for oxygen cylinders for sale. We also looked for patients who were ready for discharge. We pulled patients off oxygen and watched them for about 6 hours. If they were OK we discharged them because we had other patients who needed that oxygen. When we put deteriorating patients on oxygen, most improved clinically. It did not take long - 30 to 45 minutes after starting oxygen. The clinicians were not used to handling mechanical ventilators. We only had one week of training. It was almost guaranteed that if a patient was intubated, they died. In COVID, oxygen meant everything. Oxygen was the mainstay of management - with no substitute - for almost every patient showing clinical symptoms.*

Doctor who treated COVID-19 and other patients, Sierra Leone

- *Prior to COVID, only one public hospital had a functioning oxygen plant in the whole country. A COVID patient used about 4 cylinders per day so we ran out quickly and asked the Health Ministry to send more but they didn't have enough money. We depended quite a lot on donations of relatives of patients who paid to fill the oxygen cylinders with their own money. There were about 8,000 cases of COVID in two and half years, and about 1,000 needed oxygen. Many did not get it. Most of the mortality we had in the hospitals during COVID was related to complications from hypoxemia and not having enough high flow oxygen or mechanical ventilation. When the power went off, patients on the concentrators had to wait for the generator to kick in. Sometimes it took five minutes and we had patients who died in that gap of time. Many patients died waiting to have their cylinders changed. Much of our COVID mortality rate was related to lack of oxygen capacity.*

Nurses who treated sick newborns, Ethiopia

- *I have seen many complications in NICUs from nursing staff who do not know how to operate the oxygen equipment, especially the CPAP. One of Ethiopia's Specialist Hospitals has experienced a big increase in newborns with blindness due to Retinopathy of Prematurity (ROP) caused by oxygen misuse. We typically had just one pulse oximeter per NICU. I saw babies on CPAP in the NICU die due to poor nursing care, typically a lack of monitoring. More than three-quarters of neonatal nurses are not properly trained in safe and appropriate oxygen provision.*

- *In the ICU there are many ventilators we never got to use, oxygen concentrators that are dysfunctional, the manual CPAP machines are made out of plastic water bottles, and the pulse oximeter probes don't fit the newborns. I am still puzzled by how many health care providers didn't quite understand the oxygen targets in the neonates. There is a high rate of ROP. The nursing to patient ratio was so unacceptable and so close monitoring for oxygen titration was impossible.*

THE LANCET Global Health

COMMISSION ON MEDICAL OXYGEN SECURITY

ABOUT THE COMMISSION

Announced in September 2022, *The Lancet Global Health* Commission on Medical Oxygen Security provides a thorough exploration of medical oxygen coverage gaps, with recommendations to ensure that no patient dies for lack of access to this essential medicine, including during public health emergencies like COVID-19.

The Commission was led by 18 Commissioners - multi-disciplinary academics with clinical, economic, engineering, epidemiological, and public policy expertise - representing all regions of the world. Forty Advisors representing United Nations and global health agencies, donors, academic institutions, and non-governmental organizations provided guidance. A large global network of Oxygen Access Collaborators provided constant input to the Commission and included representatives from industry and Ministries of Health. Special consultations were conducted with patients, caregivers, and clinicians to ensure that their voices and experiences shaped the Commission's recommendations.

An Executive Committee coordinated the work of the Commission and included representatives from **Makerere University**, Uganda; **International Centre for Diarrheal Disease Research** (icddr,b), Bangladesh; **Murdoch Children's Research Institute** (MCRI), Australia; **Karolinska Institutet**, Sweden; and **Every Breath Counts Coalition**, USA.

You can find the Commission report here and the advocacy package here, including:

- ***Report with Comments***
- ***Policy Brief (English, French, Spanish, Arabic, Chinese, and Russian)***
- ***Spotlight Brief: Access to Medical Oxygen Scorecard ($ATMO_2S$)***
- ***Spotlight Brief: Patient and Caregiver Testimonials***
- ***Spotlight Brief: 10 Oxygen Coverage Indicators***
- ***Spotlight Brief: 20 Priority Areas for Oxygen Innovation***
- ***Country Case Studies***

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