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The Frightening Reality of Nearly Dying of Covid 19 and My Reflections as a Healthcare Professional

Dr Rani Khatib, FESC, FRPharmS, PhD (DPharm)

Visiting Associate Professor, University of Leeds, UK.
Consultant Pharmacist in Cardiology &Cardiovascular Research, Leeds General Infirmary
National Clinical Champion for Lipid Management, NHS England
Heart Failure Guidelines & Quality Standards Committee Member, NICE
Task force on Cardiology Allied Professions, European Society of Cardiology
Co-Chair of Cardiovascular Group, UK Clinical Pharmacy Association

Correspondence: *R.Khatib@leeds.ac.uk*

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I tested positive for COVID-19 in November 2020, and that was when the story began. It was still quite early in the pandemic, there were no approved vaccines, and we were still learning how to treat the disease. I had no obvious risk factors nor any core morbidities so was not worried. I fully expected to be back at work within a few days in my role as a frontline clinician (consultant cardiovascular pharmacist) at Leeds General Infirmary and as an Academic (Associate Professor at the Leeds Institute of Cardiovascular & Metabolic Medicine) with several national and international roles. The horrors I had seen during the pandemic meant I was eager to get back to treating patients and helping the sick recover.

Quite quickly however, I sensed that it may not be as straight forward as this. My symptoms progressed from fever and a never-ending cough to dizziness and breathlessness. Dizziness was my mark that I needed to visit the hospital and was the first real alarm bell. Whilst I was very ill, I was still well enough to call for an ambulance myself and was admitted. I thought that all I needed was a bit of oxygen and rest. My condition deteriorated, and I was sedated and intubated: the biggest fear. I was unconscious for more than 2 months, learning only later that I had experienced multiple pneumothoracies, multiorgan failure (including kidney failurerequiring dialysis), and cardiac arrests. My survival chances were very slim. My care team did not think I would make it, but my body managed to rally itself: a miracle of sorts. My gratitude and gratefulness are endless to the many good deeds performed,and prayers made to help me recover and the One who made these prayers come true. I have definitely beaten the odds. When I semi- “woke up” in February 2021, it was clear that it was only the beginning. I suffered extensive deconditioning and had multiple morbidities that compelled me to spend many more months in hospital. More than three years on, I am still recovering.

Currently, I am finalising a whole book about my experiences from admission to discharge. Unfortunately, I faced many challenges after returning to work which delayed the publishing of the book. I am sure many will be interested in the detail.I am almost finished with the first book, and it will most likely require a second book to describe my return to work and the challenges I faced since. However, in this short piece, I share some of the lessons that I take, as a health care professional, from being a patient for so long. I will also dedicate a few paragraphs in this particulat article for spiritual reflections, from an Islamic angle.

Lesson 1: The Value of Good Communication

As my condition deteriorated, and I found myself in the intensive care unit (ICU), I dreaded being sedated, not just because I knew I might never come back, but also because of the praiseworthy responsibility it would place on my family. My wife is a teacher and an artist; she is intelligent, educated, and fantastic at what she does, buthas no medical training. Would she be able to make key decisions on my behalf if I were incapacitated? Luckily, some of my medical friends, colleagues from cardiology and other departments rallied around and assured me that they would support her while I was under sedation—and, indeed, they were invaluable for interpreting technical jargon and providing wise counsel. At times they made suggestions and cautiously intervened without offending the team(s) looking after me.

Nonetheless, listening to my wife's stories about my period of unconsciousness was an emotional experience. It made me realize that what we say to patients' families often (eventually) makes it back to the patients themselves. Her stories also drove me to reflect more broadly on what families go through when a loved one is critically ill.

Good communication is so important. Some of the consultants my wife dealt with were fantastic at delivering what was often bad news in a way that remained at least somewhat positive; others were overly pessimistic and caused her significant distress. Obviously, as responsible health care professionals, we cannot give our patients and their relatives false hope. However, we must keep the lines of communication open, make time when necessary, and find compassionate ways of having difficult conversations.

Lesson 2: Shared Decision Making

Losing control, is another great fear that I dreaded when sedated. Up to that point, I had been heavily involved in the choices about my care; I even asked to review my own blood-test results! I was desperate to avoid losing the ability to participate. We often preach the concept of shared decision making with our patients, and I, myself, have written about the benefits of this approach.[1] But how often do we really deliver it in everyday practice? Not enough, I suspect.

Of course, considering my background, I was a relatively informed patient. I was fortunate enough to have the medical knowledge that so many others in my situation would not have. And even when my mind was barely functioning after I first regained consciousness, I wanted to play a role in the decision-making process. But when I look back, it concerns me that some of my care team seemed uncomfortable with that.

Battling the breathlessness when first admitted. I needed CPAP non-stop. I had multiple PEs and my condition was deteriorating before needing to be put into an induced coma on a ventilator.

As clinical practitioners, we should allow patients a degree of reasonable scrutiny of what we do for them. It is not always easy in overstretched daily practice, but we still need to make the effort to answer our patients' questions and engage them in treatment. Their treatment journey is a partnership after all.

The motto"No decision about me without me" is very empowering for patients and needs to be respected and fulfilled by us—healthcare professionals. More listening and humbleness will make shared decision making more a reality than an aspiration.

Lesson 3: Understanding Delirium

During my ICU admission, my wife was warned that even if I survived, there was a big chance that I would be a different person. Brain damage due to hypoxia, cardiac arrests, and severe anaemia, were potential contributing factors. This was terrifying for my family, but they had to wait and see.

I am sure most readers will understand that facing the possibility of death—or the daunting prospect of a lengthy and uncertain rehabilitation—was pretty frightening. Actually, though, the most terrifying aspect was the delirium I suffered as I gradually regained my mental faculties after being sedated.

Delirium is very common in patients in ICUs. It can present in various ways: as agitation and restlessness or, on the flipside, as apathy and decreased responsiveness.[2]

For me, it lasted a couple of months, and I felt like I was losing my mind. It was not just the side effects of the sedating drugs used in ICUs that worried me: I had severe hypoxia for many weeks, and the potential for brain damage was very high. Was it just delirium? Or was my brain damaged? It was terrifying.

Whilst unconscious, I had experienced many different dreams, and those fed into my delirium when I woke up. Thoughout my coma I dreamt and dreamt. In some of the dreams, I was with my family or going about my normal activities, such as seeing patients, giving lectures, and travelling to conferences! Some dreams were very spiritual and related to the challenges I was going through including when I died (cardiac arrest). There was also a third type, which I did not understand, which later seemed to "match" new events that occured. I might elaborate more on this in my book. In the early days of my recovery, I found it very difficult to distinguish the "fiction" of these hallucinations from the fact of being seriously unwell in hospital. Dreams and reality seemed to be mixing themselves together and the confusion this caused me was deeply disorienting.

Thankfully, the wonderful ICU rehabilitation nurses recognized that seeing my family could help me to overcome this confusion and regain a sense of psychological wellbeing. It is well known that involving family and friends can be important in mitigating the impact of ICU delirium[2], but getting access to them was a big challenge during the pandemic.

I am hugely grateful to the nurses who facilitated that for us; I am not sure that ward managers appreciated the importance of this. We have a lot to reflect on with regards to many decisions we made during the pandemic. Based on my experience, I do not think we are good with addressing the psychological well being of our patients and their families.

Unfortunately, the impact of delirium on seriously ill patients is still too often under-recognized. I would encourage practitioners to give greater consideration to alleviating this very frightening manifestation.

Lesson 4: Looking after a healthcare professional patient

I would probably declare that I was not an easy patient, while in a coma and after I woke up. I asked too many questions, I made many suggestions, but at the end of the day I was another human being who wanted to get better and go back to his family. There was no need to feel intimidated that one is looking after a healthcare professional. Yes, I did challenge the things which did not make sense, but isn't that a good thing if we want to get it right?

I did worry about my privacy, as I was known to many (not necessarily a celebrity). This was very concerning to me. I remember the emails sent by Trust senior leaders reminding us that when a celebrity was admitted to hospital to respect their privacy and not to check their records (unless you have a direct caring responsibility) nor share their news. How many respected this aspect of my privacy, I do not know, but I assumed that many would have acted professionally.

I have huge respect to all those who delivered on the mottos and values that we talk about in the NHS. However, I am not sure that we are all on the same page when it comes to implementation. Most of the care I received was excellent and I am very grateful for many. I am also conscious that we are humans; we err.

Another aspect that we should be aware of is treating all of our patients fairly. This, of course, applies to healthcare professional patients as well. However, I would be careful. In my experience, the attempts made by some to not "advantage" me as a healthcare professional, have in fact disadvantaged me. For example, not allowing colleagues to help wheel me down to get fresh air when staff were busy was very unfair and caused me a lot ofunnecessary distress.

I was in hospital for months;I could not walkand all other patients were able to walk down. I felt imprisoned. It took far too long for the healthcare team to respect and acknowledge my need to get out of the ward "prison".I was disadvantaged as a healthcare professional and felt discriminated against, as a person with "disability" (unable to walk)—something to reflect on when we are delivering care for patients with long hospital stays.

Being able to be wheeled down had a huge positive psychological impact on me. My colleagues were forbidden from wheeling me down (a complete illogical decision by managers). I had severe deconditioning and could not walk or mobilise for months.

Lesson 5: The Importance of Family to Long-Term Recovery

As I write this in Nov 2024, I count myself lucky that I have regained much of my physical functioning. For that, I am particularly indebted to some amazing physiotherapists and occupational therapists.

When I began my recovery in hospital, I could not even sit upright, let alone walk. I had to relearn these abilities as if I were a baby. For many months, I needed assistance with even the simplest tasks, such as eating, washing, and going to the toilet. We take these things for granted in normal life, and being incapable was truly humbling. Regaining the capacity to care for myself was a cause for celebration!

Once I was able to walk unassisted, I asked to be discharged early. I was bored and fed up, and the psychological burden was becoming overwhelming. I felt imprisoned, and I felt that going back to my family would hasten my recovery. I still believe it was the right decision. I continued my physiotherapy at home and gradually returned to my work and other activities of daily living.

As practitioners, we need to take a step back and not see the illness but consider the patient too. And we must appreciate that the hospital is not always the best place for them to be. Many like me prefer to recuperate at home and are fortunate enough to have loved ones to support them there. People of faith are taught that maintaining family ties is crucial, and in this instance, their support can play a huge role in ensuring a complete recovery. The healing power of a united family with strong ties should not be forgotten or underestimated. It is one of the biggest blessings that we should cherish and be incredibly grateful for.

Lesson 6: Understanding Patients with Long Term Conditions

I was left with many chronic health conditions as a result of COVID-19, but heart disease is not one of them. Nonetheless, as someone who spends much of his working life interacting with patients with cardiovascular disease (CVD), I now have a lot more empathy and can put myself in my patient's shoes.

Indeed, I have first-hand experience of many of the common symptoms of heart failure, for example, such as breathlessness, extreme fatigue, limited exercise capacity, and peripheral oedema.[3]

Breathlessness was, of course, a key warning sign during the acute phase of COVID-19, and I will never forget the distress of sitting in my hospital bed gasping for air and relying heavily on oxygen. I had multiple pulmonary embolisms, and breathlessness was a huge burden.

I could not even chew my food. Then later, during the long journey to recovery, my lungs were so damaged and my body so deconditioned that breathlessness became an everyday challenge. Similarly, I now understand the extreme fatigue that patients with CVD often report. Even when I regained the strength to walk, I was too exhausted to go very far. It took a long time to get back to work, engage fully with family and friends, and live more normally. My quality of life was greatly damaged. Even now that I have recovered a lot of my functioning, I am still living with the aftermath. I have had to adjust my life to chronic fatigue—pacing myself in everything I do and rationing my energy throughout the day.

I also have to live with various chronic conditions that many patients with CVD would recognize, such as renal disease. My kidneys completely failed while I was sedated, and I needed dialysis. Some of the damage is permanent, and I have had to come to terms with that, which has not been easy emotionally, but perspective is key here, and I am extremely fortunate to still be alive and that I have been able to take steps towards a normal life. I need to remain vigilant however for other issues associated with kidney disease, for example, the increased risk of cardiovascular events.

My experience made me better appreciate the value and importance of the multimorbidity approach or the Cardio-Respiratory-Renal-Metabolic care.

Ultimately, though my experience suffering from Covid in ICU with multiple complications has been difficult, I feel that it has also helped me become a better care provider for my own patients.

I can now see their perspectives more clearly and can better appreciate what they go through every single day. Patients must play a role in their treatment plan and my experience over the past few years has only confirmed this further.

Watch out for my book for a more detailed account of my experience and lessons learned.

Spiritual Reflections

The ordeal I have experienced, and the outcome thereafter, strengthened my belief that Allah is our Rab. Rabis the one who looks after and cares for His creation. He is indeed the one who has ultimate control of all matters. When I woke up, and before I learnt what happened to me in ICU, I was repeatedly made to feel that something very "special" happened to me. "You are a miracle" -many healthcare professionals told me. "How many souls do you have?" - others said. "You definitely beat the odds" - added others.

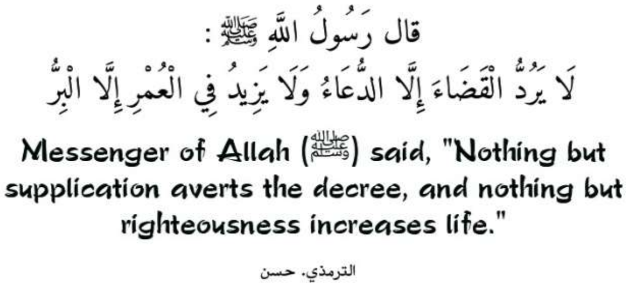
I had no idea how slim my chances of survival were. Humans reached their limit, medicine reached its limit, but the One who is the Rab of this existence destined something else for me. Alhamdulillah. Indeed, "And when I am ill, it is He who cures me" (Surah Al-Shu'ara. Verse 80).

قال الله تعالى:
وَإِذا مَرِضْتُ فَهُوَ يَشْفِينِ

Allah the Almighty says:
"And when I am ill, it is He who cures me"

سورة الشعراء اية 80

One of the multiple dreams I saw in my induced coma had many people praying for me with a lot of detail. It was a very strange dream that I did not understand. Months later, my family started sharing with me the videos, recordings, and messages of people who were praying for me non-stop from all around the world. All faiths. This was a very humbling experience, which made me shed tears. People I knew and many I did not know were guided by the Almighty to remember me in their du'aa and supplications. This was astounding. I instantly saw that this must have been a major reason for my miraculous recovery.Didn't the Prophet ﷺ say: "Nothing but supplication averts the decree, and nothing but righteousness increases life." (Al-Tirmidhi)



قال رَسُولُ اللَّهِ ﷺ :
لَا يَرُدُّ الْقَضَاءَ إِلَّا الدُّعَاءُ وَلَا يَزِيدُ فِي الْعُمْرِ إِلَّا الْبِرُّ

Messenger of Allah (ﷺ) said, "Nothing but supplication averts the decree, and nothing but righteousness increases life."

الترمذي. حسن

The last part of the earlier narration fits well with another potential reason why my destiny was changed. It is the many good people out there who gave charity on my behalf when I was battling. Indeed, this was the last request I made from my family before being sedated - "Please give a lot of charity on my behalf - I sense what I am about to face requires a divine intervention and nothing but a lot of charity is likely to address it." These were my private words to my family. My family were always protective of my privacy and my request for prayers and charity stayed only with them. However, after I woke up 2.5 months later, I was astonished by the endless charities that were given with the intention of Allah granting me healing (shifaa).

Most were not from my family or even from people I know. SubhanAllah and alhamdulillah who facilitated this. I was so humbled and moved by this second gesture by people from all around the world. Indeed, the Prophet ﷺ says: “Cure your ill with charity” (Al-Suyuti).

قال رَسُولُ اللَّهِ ﷺ :
داوُوا مَرضاكُم بالصَّدَقة

Messenger of Allah (ﷺ) said: "Cure your patients with charity"

السيوطي حسن

I have lived experience of many spiritual encounters that I am still learning from. I hope these spiritual experiences and reflections can provide you, as healthcare professionals, and patients out there, hope beyond this materialistic world.

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