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Bulletin de la Dialyse à Domicile

A dialysis doctor's memories with COVID-19 disease

(Souvenirs d'un néphrologue malade de la Covid-19)

Guy Rostoker

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Section testimony

Résumé (Note de la rédaction)

Ce témoignage est celui d'un néphrologue contaminé au tout début de la pandémie, en France, alors qu'il soignait ses patients. Le 8 avril 2020 alors qu'il terminait la visite de ses patients, il a ressenti myalgie, dyspnée, frissons et fièvre. Après avoir tenté deux jours de rester à son domicile, il est devenu nécessaire de l'hospitaliser en soins intensifs afin d'assurer un traitement adapté et une oxygénothérapie suffisante. Il décrit au cours de ce témoignage son propre vécu de médecin malade, l'efficacité des traitements reçus, l'empathie de ses confrères et des soignants qui l'ont pris en charge, tout au long d'un journal tenu au jour le jour. Une longue période de rééducation fera suite au cours de laquelle il écrira un plaidoyer pour favoriser les méthodes de dialyse à domicile afin de limiter les contaminations des insuffisants rénaux dialysés.
La rédaction a jugé utile de publier ce témoignage médical plein d'humanité, rédigé avec pudeur et la volonté d'apporter soutien et espoir à ceux brutalement victimes de la maladie COVID.

Mots clés : COVID-19, SARS-CoV-2, témoignage patient

Summary (Editor's note)

This is the testimony of a nephrologist who was infected at the very beginning of the pandemic, in France, while treating his patients. On April 8, 2020, as he was finishing visiting his patients, he experienced myalgia, dyspnea, chills and fever. After two days of trying to stay at home, it became necessary to admit him to the intensive care unit to ensure proper treatment and sufficient oxygen therapy. In this testimony, he describes his own experience as a sick doctor, the effectiveness of the treatments he received, the empathy of his colleagues and the caregivers who took care of him, in a diary kept from day to day. This was followed by a long period of rehabilitation during which he wrote a plea to promote home dialysis methods in order to limit the contamination of end-stage kidney disease patients on dialysis.
The editorial staff has deemed it useful to publish this medical testimony full of humanity, written with modesty and the will to bring support and hope to those brutally victimized by the COVID-19 disease.

Keywords : COVID-19, SARS-CoV-2, patient's testimony

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March 23, 2020

I felt an immense sense of relief today as our personal protective equipment has arrived at last. We will now be able to ensure that our dialysis staff members and 135 dialysis patients in Claude Galien hospital (CGH) have adequate levels of protection given their high risk of catching SARS-CoV-2 and the fear that dialysis patients will develop severe COVID-19 due to their frailty.

Last week, when the virus had begun to spread in the Greater Paris area of France, we had our first five cases of COVID-19, which were easily managed in either the CGH (three cases) or in the district's reference COVID hospital (CHSF, Evry) (two cases). At that time, all of the dialysis doctors and nurses had serious concerns about the lack of appropriate PPE and felt like soldiers being sent to the front without weapons.

Since I was afraid of taking the SARS-CoV-2 virus home with me, I decided on March 23rd at the start of the first COVID-19 peak in France, to protect my wife using strict social distancing at home (and when not possible with face masks) with separate bedrooms, bathrooms and meals. This was also the choice of most of the doctors and members of the dialysis staff with regard to their families.

April 8, 2020

Whilst on medical duty at the dialysis centre of CGH, I suddenly developed shivers, mild fever, generalised myalgia and slight dyspnoea just after my afternoon rounds, making a diagnosis of COVID-19 highly likely.

I therefore called the two other senior nephrologists to announce my intention to quarantine at home and the need to find another clinician to replace me. One of my colleagues arrived at the end of the afternoon to finish my dialysis duties whilst I returned home.

I spent most of the following 2 days (April 9th and 10th) at home in bed with a severe flu-like illness, without any appetite and with paracetamol as my sole medication. On Saturday (April 11th) in the morning, I began to experience moderate shortness of breath and sent my wife to the neighbouring pharmacy to buy an oximeter (this was unsuccessful due to a shortage) and with a prescription for an oxygen compressor which would be delivered to our home at midday. As my breathing felt far more comfortable with 5 L/min nasal oxygen, I set about calculating the wages of the doctors, nephrology secretaries and clinical research technicians for April and performed all ongoing administrative duties owing to the possible need for me to be hospitalised over the next few days.

My wife (who is an anaesthesiologist) tried unsuccessfully to convince me to go to hospital but I was irrationally scared about a lack of beds in the ICU due to the epidemic peak and of a possible barrier of age, since I was 64-years-old. Moreover, I was in a denial of the severity of my COVID-19 disease embedded by wrong and reassuring medical ways of thinking.

April 12, 2020

I woke up very late in the morning, exhausted and with difficulty breathing. I was unable to walk

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from my bed to the bathroom, a distance of only 3 metres, without gasping for air. I therefore agreed with my wife that I should to go to hospital. The Paris emergency medical service (SAMU 75) advised us to go to Ambroise Paré University hospital (APHP) in Boulogne, close to our residence in the west of Paris.

In the early afternoon, my wife drove me to the COVID emergency room, which was fortunately empty but waiting. Before entering, Catherine my wife was unable to hide a frightened glance, summing up the severity of my clinical situation. The emergency doctors and nurses worked very fast and efficiently, and with great kindness; I now had more difficulty breathing, even at rest, which translated into a reduced peripheral oxygen saturation in ambient air of 84%, leading to immediate radial arterial cannulation for blood gases (confirming substantial hypoxemia with a PaO2 of 50 mmHg). I was fitted with an oxygen mask at a flow rate of 15 L/min with immediate clinical improvement. Venous blood samples were taken and a nasopharyngeal swab was performed for molecular confirmation of the diagnosis of COVID-19. I could speak again under high oxygen therapy and answered the medical staff's questions on my recent professional exposure to COVID-19 patients in our dialysis centre and summarised my past medical history.

The senior intensive care doctor on duty came to my bedside and performed an echocardiogram to rule out acute left ventricular failure. He calmly explained that I probably had a severe form of COVID-19 but that he also suspected a pulmonary embolism, which had recently been described in a high percentage of COVID patients in intensive care units (ICUs).

Within 10 min, the emergency staff took me for a computed tomography (CT) scan where I underwent pulmonary CT angiography; they then transferred me back to the emergency room. The senior intensive care doctor arrived shortly after with the results of the CT scan confirming the presence of several bilateral segmental emboli complicating typical severe COVID-19 pneumonia. Due to my acute hypoxemic respiratory failure he proposed my admission to the ICU but wanted my agreement to trial non-invasive ventilation with high-flow nasal oxygen together with a curative dose of low-molecular weight heparin; if my pulmonary condition worsened, intubation with mechanical ventilation would be necessary. I agreed to his proposal without the slightest hesitation.

After a discussion with the senior intensive care doctor, I understood that I might not survive this severe COVID-19 disease. For the second time in my life, I was facing my own death as I had 10 years ago while participating in a deep technical Trimix (mixture of air, oxygen and helium) diving course in Ajaccio, Corsica, where I experienced air failure at a depth of 30 metres. I had my first dive at a depth of 100 metres with my teacher. Unfortunately, I did not take into account for my calculations an overconsumption of Trimix due to anxiety. At the level of 30 metres, I was already breathing on the reserve of my Trimix bottle. The rule in deep technical diving (contrary to usual air bottle dive) is that divers must manage them-self alone for air consumption without any help of the others due to scarcity of Trimix. Normally, I should have done a fast ascent without security levels from 30 metres with a very high probability of severe brain damage or death. Fortunately, my teacher was a «dolphin man» with a Trimix bottle only one-third empty and he shared with me his air-mixture, thus allowing my safe dive ascent.

I also knew that my fears concerning the lack of ICU beds and the disadvantage of my age were completely unfounded. Paradoxically, the diagnosis of severe COVID complicated by pulmonary

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embolism put my mind at ease and I felt that it would be possible to avoid intubation thanks to anticoagulation therapy. I was rapidly transported to a private ICU room where two nasal cannulas (OPTIFLOW™) were inserted by the nurses with an oxygen flow of 30 L/min; the first subcutaneous injection of 8000 IU enoxaparin was performed concomitantly. I had total confidence in my treatment and was not in any pain.

My respiratory condition improved rapidly over the next few days and my inspired oxygen fraction (FiO2) was successfully reduced from 80% to 60% on April 14th and OPTIFLOW™ was replaced by standard nasal oxygen with a mask on April 20th.

The ICU and COVID unit staff (doctors, nurses and care assistants) were not only highly efficient but also carried out repeated acts of kindness and had sincere empathy for their patients and their families. While most French hospitals (as abroad) did not allow any visitors, Ambroise Paré ICU and COVID unit teams, full of kindness and understanding to the families of hospitalised patients, allowed one visit per day for one relative. Thus, each day I was happy to see my wife for about 2 hours (usually after my prone positioning session) and she was no longer frightened but confident about my recovery. Moreover, she had fortunately tested negative for SARS-CoV-2 (by PCR and serology). She told me that she was also grateful to the ICU doctors who called her daily each morning for about 30 min until April 20th to give her detailed updates on my health.

During my hospital stay my mobile phone became my lifeline to my tribe (family, friends and the dialysis staff of CGH) and I was able to send (and receive) emails and to communicate by text. I also received touching emails and text messages from my medical colleagues and the surgeons of CGH. Moreover, each day, dialysis nurses sent me either a photograph or a short video in the spirit of Tik-Tok as affectionate encouragement.

I left Ambroise Paré hospital on April 25th and consider myself very lucky to have survived severe COVID-19 even though I know that I have a long rehabilitation pathway ahead before being able to work as a doctor again.

May 25, 2020

Today is a very important day because pneumologists in Antoine Béclère hospital have validated, in a morning web conference, my definitive oxygen therapy withdrawal, which had been performed cautiously and progressively since my hospitalisation by my “angel” doctor from the COVIDOM platform (devoted to the follow-up of severe COVID cases hospitalised in Paris area hospitals). Since my hospitalisation, I had also performed a progressive self-rehabilitation program for normal activities at home and had a morning sleep-in to compensate for sleep loss during my hospital stay. I also had a huge appetite as a healthy compensatory mechanism for my weight loss, eating at least 5 meals per day.

This afternoon, I had my first appointment with Loriane, a physiotherapist who will guide all my rehabilitation; her initial clinical examination diagnosed general amyotrophy predominating on the paravertebral muscles, buttocks and pectorals (I had lost 10 kg during my hospital stay (off a usual weight of 78.5 kg for 1.73 m)).

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June 24, 2020

My physical condition has greatly improved thanks to my rehabilitation program organised by Loriane. I have had 2 sessions a week at the physiotherapist's office devoted to treating my proprioceptive problems and various muscle-development exercises, created by Loriane. These exercises have been performed each day for 2 hours on my terrace together with 3 hours of walking in the streets of my district in Paris. Today was devoted to my chest evaluation: pulmonary CT angiography was normalised but pulmonary function tests revealed a restrictive pulmonary disorder (quantified at minus 23%) without any anomaly of diffusion capacity for carbon monoxide explaining my shortness of breath at effort. My lung specialist therefore prescribed pulmonary and effort rehabilitation for 6 months and completed files for COVID professional disease and prolongation of work stoppage until the end of the year; this was possible financially because in the case of severe COVID disease, health professionals received financial compensation by the French government together with the help of a doctors' contingency fund.

July in Paris

I was fortunate to be able to temporarily replace my fitness program by swimming 3 times a week since swimming-pools had reopened after the first lockdown in France. I progressively increased my endurance and performance and by the last week of July was able to swim 4 km (2 km of breaststroke and 2 km of backstroke) in 4 hours.

August at Ajaccio, Corsica

A morning sleep-in was still the only way for me to overcome my exhaustion as an after-effect of COVID-19. I wrote each day in the afternoon both a piece of an opinion column on the paramount role of home dialysis in the "post-COVID-19 world" (with three nephrologists and friends involved since years in the development of peritoneal dialysis and home haemodialysis in France) and my memories of my COVID-19 disease. Every day, the end of the afternoon and early evening (except Sunday) were devoted to 2 hours of fitness exercises followed by 1 hour of bike training with increasing strength on my terrace.

September 23, 2020

My pulmonary function tests revealed a stabilization in my restrictive pulmonary disorder (quantified at minus 22%) and my pneumologist advised me to intensify pulmonary and effort rehabilitation until the end of the year. Under the guidance of my physiotherapist, I performed fractionated efforts each day, during either the 4 km of swimming or the hour of bike training.

January 2, 2021

This is my first day of work again as a doctor. Throughout the whole day I had duties with 3 dialysis sessions to supervise. Because of the New Year, dialysis teams had been scaled back. During my rounds, I could see and speak at length with my own patients who welcome me back with deep affection like the homecoming of the prodigal son.

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February 12, 2021

I have now resumed a good rhythm of working by reducing the number of days that I am on dialysis duty (1 per week instead of 2 previously) and my mandatory once weekly swimming pool and fitness sessions to avoid a weak and rusty body and to have a comfortable breathing. Today, I received a single dose of the Pfizer vaccine as advocated by the French High Health Authority for patients with previous COVID-19 disease (with the aims of avoiding excessive vaccine reactions and sparing precious vaccine doses). Through my own vaccination, I hope to convince my dialysis nurses who are deeply reluctant to be vaccinated against COVID-19.

March 11, 2021

I am so happy with my three co-authors and friends: our opinion column called "Promote treatment at home of dialysis patients in the time of COVID-19 pandemic" appeared on the Le Monde newspaper's web site today. This opinion column was endorsed few days after, on March 14th, 2021, by the two French CKD patient associations.

From my severe COVID-19 disease and my long rehabilitation, I have learnt about the devotion of doctors, nurses, care assistants and physiotherapists to their patients through their empathy with them, and also the paramount importance of physiotherapy (probably underused) to overcome the after-effects of severe diseases requiring ICU care (including those related to SARS-CoV-2) and probably also numerous moderate cases of COVID-19. I have learnt about the vulnerability of doctor's white coat and the physical and mental suffering of illness.

In terms of my professional life, I understand that the time for hyperactivity has ceased with the need to reduce the number of dialysis duty days and to redirect my activities to home dialysis management and the follow-up of out-patients with chronic renal failure. I am still keen to pursue my clinical research on iron metabolism and toxicity in dialysis patients.

My blunt discussions with hospital doctors on the interest of direct anticoagulant therapy instead of warfarin (thanks to thrombosis in all veins in my arms and forearms except one in the ICU) and the potential medical value of pulmonary function tests besides CT scans, have convinced me that there is still a huge gap between doctors and their patients in terms of shared medical decisions in our country (and probably also abroad). Thus, I wish to work more closely with patients' associations.

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This essay is dedicated to the doctors, nurses and care assistants of the emergency room and ICU of Ambroise Paré hospital (Assistance Publique-Hôpitaux de Paris) who saved my life and to Loriane A., the physiotherapist who guided my rehabilitation.

AUTHOR DETAILS

Guy Rostoker has been head of the division of Nephrology and Dialysis at Claude Galien hospital-Ramsay Santé (Quincy-sous-Sénart, France) since 1999 and Associate Professor at the Collège de Médecine des Hôpitaux de Paris since 2017; he was a past full member with tenure (from

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2013 to 2018) of the French Committee for Drug Reimbursement (Commission de la Transparence) at the French National Authority for Health (HAS).

CONFLICTS OF INTEREST

The author declares no conflicts of interest in this paper.

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