

LEADERSHIP • CROSS-COLLABORATION • WINNING PRACTICES

ISSN = 1377-7629

VOLUME 20 • ISSUE 5 • 2020 • € 22

Superheroes

Cover Story:



368 Paulo Moll: Fighting the Pandemic in Brazil - Experience of Largest Hospital Network

374 Adaora Okoli: Tragedy of COVID-19

376 Sabine Torgler: Nurses Are Not Soldiers

384 Prof. Jonathan McNulty: Radiographers on the Frontline 386 Valérie Martin: "Not in My Care Home"

392 Elikem Tamaklo: Burning Platform for Change: COVID-19 Experience in Ghana

396 Lloyd Vincent: Traversing the Unknown Frontlines - COVID-19 from a Resource Limited East African Setting

427 Alberto Porciani: Telemedicine in Time of COVID-19

So Not Your Regular Flu

Interviewee: Svetlana Piliavsky | Speech Language Pathologist/Rehabilitation Program Director | Boston (MA) | USA

The COVID-19 pandemic has hit nursing homes around the world particularly hard. With the infection spreading among both staff and residents, the consequences have been horrible. A director of one such facility in the U.S., who has survived the disease herself, talks to HealthManagement.org about this devastating experience and the need to change attitudes in those who still do not take COVID-19 seriously.

I am a speech pathologist and the director of a rehab/ nursing home. In the facility, there are residents and 'short-term' patients that come for rehabilitation. When COVID-19 started, we stopped taking in new patients at some point. If we did take a new patient, they would be in guarantine for two weeks. Unfortunately, there was no proper PPE. I was screaming at the top of my lungs saying that if we didn't protect ourselves and they didn't start screening us for infection, we would be spreading it. Back then there were no directions from the Department of Public Health (DPH) on the use of PPE. We were actually told that was nonsense and PPE was only for our own comfort. We were told that we didn't need the equipment, that we didn't even have any COVID-19 and it was not transmitted the way everybody thought it did. It's just regular flu, don't worry about it - because the President said so. It was all very political.

At the end of March, I refused to allow any of my staff to see any patient without masks because I started to see symptoms. Despite being told that I was spreading panic and that nothing was wrong, eventually we were given regular surgical masks. In a couple of weeks I demanded we have gowns, and at that moment I was pointing out to the patients who I knew were sick. Unfortunately, the gowns were yet to materialise, and unfortunately, all those patients that I pointed out, died. It breaks my heart because I knew most of them and their families for years. They came to us because I worked there, and some were just short-term patients.

Going Through Disease

My husband was concerned about this new virus from day one. We had a small vacation planned for the end of February, to Puerto Rico. We were, of course, worried about having to be in an airplane where it would be the most dangerous. We even took masks with us, but nobody around had any on, so... cruises were still in full swing, and we crossed the street whenever we saw that crowd. The situation continued to worsen, so from 4 March, when we returned, to 24 March, when the stayat-home advisory was introduced, we went to the stores maybe twice, already being very careful.

On 8 April, I suddenly felt like something was squeezing my chest. I couldn't breathe, and the pain was excruciating. The temperature skyrocketed to 100.4°F (38°C), and I immediately had to notify the infection control nurse about my symptoms. She first suggested I pack my things and get out of there as quickly as possible, but then it was arranged for me to get tested. I went to a drive-through clinic and in four days got the results, which were positive.

At home, we were taking all possible precautions and self-isolating. My husband slept in the basement, we used different bathrooms, and so on – but six days later he got sick, too. That was a complete disaster. He had to take care of me because I couldn't move. We couldn't go shopping, couldn't go to the pharmacy. Our son, who is very brave, would bring us groceries without seeing us, leave them at the doorstep, and in about three hours we would disinfect those and then bring them in. That's how we survived.

I was very sick, with terrible pain, no sense of smell, high fever, fatigue, horrible cough and shortness of breath, with oxygen dropping down to about 84-86%. Other symptoms, that are very rare, were rash and hearing loss. Basically, I had everything in the book with this horrible disease.

There is nothing I can compare this to. The fever lasted for about three weeks, during which I would only go to the bathroom a couple of times a day. Brushing my teeth

COVID-19 Superheroes

would take about half an hour because of the shortness of breath, the fatigue, the pain, and so on.

My doctor suggested I go to the hospital, but I decided not to. Being in a hospital meant either being on a ventilator, or having oxygen support. The big question was also, how safe it was – there were not enough oxygen tanks, not enough medication. I would've probably been given one particular drug, heavily pushed by the government, but my doctor said it could be very dangerous for my heart. He was extremely supportive of my decision to stay home as long as I could handle it and do my breathing exercises (in which I specialise professionally). I also took vitamins and drank a lot of water with ginger and lemon – hot water as I couldn't do anything else, even room-temperature would give me chills.

The families of those patients who died were still calling me, at home, to make sure that I was alive. This was the saddest, the most incredible thing. It was giving us strength to survive. And still, there are some awful people who would say, "Ah, it's like regular flu, no problem." No, it's not a regular flu. It's something to which there is no comparison, and nobody knows what to do with it. about 15, we are in very good shape now. I was even able to put my wedding dress on. It was still tight, but I could do it! And we have a new toast now – 'For life!' We're alive, and life is beautiful.

Politics, Policies and Deaths

Early on, the perception among my colleagues varied. Some were very worried. Others were dismissing all my concerns saying it was a flu and we had many other flus before – stop being paranoid. Here, it depends on what news outlets you were following, eg those where the President first said that people died from the regular flu and then – well, even if we get to the point where we lose 100,000, we're doing a great job. Well, he did a much better job because we ended up with many more thousands than a hundred.

Another very interesting point is that only in mid-May the government got the order to test everybody. Before, it would say there was no need. Since March, I tried to get the message through – start testing people, and if anybody was positive, send them home, so that we didn't spread it! The reply I got was, it was all nonsense, there were no orders, and even if people were tested, they

We were actually told that PPE was only for our own comfort

Now, three months later, I can only walk about half a kilometre, taking breaks and being short of breath. Two weeks ago I had to go back to work - my husband, unfortunately, lost his job over the quarantine period. My company allowed me to have a family leave of absence, so there was some job security. They also suggested I try to apply for the workman's compensation, which is about 60% of your salary. At that time it was all very new. Only several states, including Massachusetts, were offering this kind of financial protection to those in the medical field who got infected at work. I had to put a lot of effort into proving that last part, but in the end succeeded because a) since mid-March my husband worked from home and b) the only place that I would go was to work, in my car. As a precaution, we didn't do grocery shopping because we are both over 60 and I have other health issues. When I would come home from work, I would strip everything off, get washed, and only then get inside. Still, that didn't protect us.

The story is very sad. I have never been so sick in my life. The recovery is very painful. But every cloud has a silver lining. As I lost about 10 pounds and my husband

could get infected three days later anyway. In the middle of May they tested the first group. Out of 25 people, seven were positive. With no symptoms, none.

Now, by the order of the DPH, all the facilities are tested on a regular basis. Our facility has zero cases, and we take in patients again, who must be tested first in the hospital with negative results. We also test them upon arrival, and they are kept in a room for 14 days in a separate wing of the facility. After the quarantine they are tested again and, if negative, moved to another wing to a room for two people. In one very recent development, those who underwent the quarantine and are negative, are allowed to see their relatives. They meet outside for about 15-30 minutes keeping the six-feet distance and with masks on. No visitors are allowed inside. The staff arriving for work have their temperature taken, fill out a questionnaire, and don PPE. They are also regularly tested.

That's the story for now, which, I think, would've been wonderful if it happened three months ago – we could've protected ourselves and prevented all these deaths. My facility is 78 beds, 14 deaths. I know of facilities with 120 beds,



70 deaths; 450 beds, 155 deaths. It's disgusting. These elderly people who are most vulnerable – they are dying. But unfortunately, young people are dying too, and being very sick.

If Only...

Since the beginning, different facilities, companies, states had very different opinions about and ways of handling the outbreak. If everybody were on the same page, it would've been much easier. One wise move our company did was to stop people from going between buildings. It was necessary because nursing assistants, who are the least paid and often live in communities six months, a year? Moreover, because my husband's and my immune systems are so compromised now, we don't know what else we can catch. That's why I still refrain from seeing my mother, who is almost 87 years old and lives in an apartment building. I don't go to that building. When I go to see her once a week, she comes downstairs, we keep six feet apart and have our masks on. She gets very upset about that because she believes I need to spend more time with her, which is heartbreaking.

These days I only go to work and am extra cautious there. On those very rare occasions that we go to a store, we wear double masks, K95 and a surgical mask

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where social distancing is difficult, went from building to building. Some even had several jobs, and they were going around without being tested, spreading the disease. Once they were tested with positive results and dismissed from work, they wouldn't stay home because they needed money. The order was that if somebody didn't have symptoms for 48 or 72 hours, depending on the facility, they can return to work after 14 days of quarantine. The second test was not even required.

There are a lot things that I do not agree with and do not understand, which can be done differently. First, test everybody on a regular basis. Also, provide monetary reimbursement, which actually some facilities did. At some point, the facility I work for was paying extra \$3, then extra \$10, then double to people who tested negative and continued to work, so that they would stop going from place to place. But that didn't last long.

And of course, the government could've started working on the vaccine and medication much earlier; closed the country; contained the spread; not been so greedy and stopped saying that we didn't have a problem.

What's Next?

I was afraid to go back to work. I did the antibodies test and, they tell me, there's 90% probability that now I am immune. The problem is that nobody knows for how long the immune system is going to work – three, on top of it, and gloves and sanitise everything. Still, there's this horrible feeling of 'what's next?' Nobody knows that.

I just pray a vaccine is available soon, testing is more reliable, more people are tested, and the spread is somehow stopped. Unfortunately, the whole world is now infected, and with the borders opening we don't know how the infection control will be, the quarantine, the people's minds! There are still so many who say it's all nonsense. A relative has just told me – "I'm not afraid of dying." So what? I am!

I don't want anybody to suffer like we did. But to those who don't grasp what kind of suffering you go through, I just want to say, "Wanna try?" It's very painful to say that because I wouldn't wish this on anybody. But people – who don't believe, who don't care about themselves – need to have some responsibility to protect others. That's the biggest problem. Yes, there are many who will never get sick, even if they are infected. But they are spreading the infection and putting others at risk. Some go through this and survive, and some don't.

A family member of a patient who died said to me, "You have helped so many already, we need you back so you can help others." So I'm trying my best to help them to survive. I don't want to die. I want to live a little longer. Not 'a little,' much longer! And if my story helps anybody to realise what the world is going through, and that it has to be taken seriously, I would be more than happy.