2020

Solitude and fear during the great coronavirus war

Chiara Catania
1Division of Thoracic Oncology, IEO, European Institute of Oncology, IRCCS, Italy, Via Ripamonti 435 Milan Italy

Ester Del Signore
2Division of Thoracic Oncology, IEO, European Institute of Oncology, IRCCS, Italy, Via Ripamonti 435 Milan Italy

Letizia Gianoncelli
3Division of Thoracic Oncology, IEO, European Institute of Oncology, IRCCS, Italy, Via Ripamonti 435 Milan Italy

Follow this and additional works at: https://pxjournal.org/journal

Part of the Health Services Research Commons

Recommended Citation

This Personal Narrative is brought to you for free and open access by Patient Experience Journal. It has been accepted for inclusion in Patient Experience Journal by an authorized editor of Patient Experience Journal.
Solitude and fear during the great coronavirus war

Cover Page Footnote
Acknowledgements: This work was partially supported by the Italian Ministry of Health with Ricerca Corrente and 5x1000 funds. Authors’ contributions: All Authors contributed equally This article is associated with the Patient, Family & Community Engagement lens of The Beryl Institute Experience Framework. (http://bit.ly/ExperienceFramework). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_PtFamComm

This personal narrative is available in Patient Experience Journal: https://pxjournal.org/journal/vol7/iss3/3
Personal Narrative

Solitude and fear during the great coronavirus war

Chiara Catania, MD, European Institute of Oncology, chiara.catania@ieo.it
Ester Del Signore, European Institute of Oncology, ester.delsignore@ieo.it
Letizia Gianoncelli, European Institute of Oncology, letizia.gianoncelli@ieo.it

Abstract

When you get ill, the first thing that comes to your mind is, “Will I make it? Will I survive?”. COVID19 has a major impact on mental health. A sadness that inundates us like a river in flood and which we cannot hold back. But the thing that torments is the solitude. Those who struggle towards recovery do it alone, and those who do not make it die alone.

An emblematic experience of a sense of loneliness, depression and death during illness is deeply described. We tell how the love of family and friends can help to recover from the abyss. Fighting this battle and winning it alone is painful. A lonely death is even more painful. We must stick together virtually and think about each other. The work done with enormous strength and tenacity by doctors and nurses is a great hope for a better time. It does raise the hope that a future generation will be able to truly take care of mankind. When all this ends, we must not go back to normal. We must be reborn, better.

Keywords

Perception of loneliness, death, helplessness, coronavirus, patient experience, COVID-19

Numbers. Numbers of dead and sick people. Numbers increasing every day due to coronavirus. Many deaths, many sick people who are suffering, too many to bear. A sadness that inundates us like a river in flood and which we cannot hold back. It is difficult to think of anything else. It is an all-pervading thought. But the thing that torments me most is SOLITUDE.

People who fall ill or are hospitalised because of a coronavirus infection are compulsorily segregated. It is no longer possible to see them, to give them strength, to hold their hands, to smile at them, to instil them with hope. Those who struggle towards recovery do it alone and those who do not make it die alone.

Even if we doctors and all nurses use words of comfort to try to mitigate patients' fear, this will never have the effect of the presence of a friend, a relative or a loved one.

When you get ill, the first thing that comes to your mind is, “Will I make it? Will I survive?”. Among family, friends and patients there are those who hope, there are those who despair, there are those who pray, there are those who wait; always in solitude and always with a great sense of helplessness.

My uncle, 65 years old, fell ill while he was in a centre for the treatment of obesity. During his stay in this facility he contracted coronavirus. On March 26, he began to develop symptoms: fever (37.8 °C), weakness and muscle pain. The centre already had people infected by coronavirus. On appearance of symptoms, my uncle was immediately isolated. He went from group exercises, outdoor walks, eating with his fellow residents to total isolation. I contacted the local doctors and asked if it was coronavirus.

“Yes,” they said.

The suspicion of COVID-19 was confirmed by a positive CT scan of the chest on March 26 and by the nasopharyngeal swab. He was immediately started on hydroxychloroquine, low molecular weight heparin and azithromycin with partial benefit. He had persistent dyspnoea with minimal effort, low blood oxygenation, dysgeusia, weakness, loss of appetite and muscle pain. His blood oxygen saturation breathing air was 88% and rose only to 90% with continuous positive airway pressure. Blood tests performed in the following days showed a progressive increase in C-reactive protein, lactate dehydrogenase and fibrinogen levels. The CT scan of March 31 showed aggravated bilateral interstitial disease and the blood tests were worsening. On April 2, he developed hyperpyrexia (40 °C) unresponsive to paracetamol and concomitant desaturation. He was then started on steroids and antivirals and given increased oxygen support. My uncle was deteriorating.

We rushed to buy another drug, another hope, but no certainty: tocilizumab. The tocilizumab was first administered on Sunday, April 5. In the days that followed, my uncle’s general condition improved markedly. His
fever, muscle pain, tiredness and lack of appetite disappeared. His saturation improved. A control chest CT scan on April 6 showed a marked improvement in the pulmonary interstitial disease and blood tests documented normalisation of C-reactive protein and fibrinogen levels.

While I was taking the tocilizumab to the centre, my uncle asked me: “Are you really coming here? To me? For me?” Not only inside the centre but also outside, there was a world that was working for him. This encouraged him. Then he asked me if, once I got to the centre, I could come and say hello to him, because it would mean a lot to him.

Immediately after, he phoned me again and said, “I wanted to tell you something. I’ve changed my mind! Only come if you are not at risk. Sorry! I was only thinking about my need to see someone from the family!”

He felt alone. After delivering the drug, my uncle started giving me the directions to get from the outside to a point of the centre that corresponded to his room so that I could see him at the window. I searched for it. There it was!!

"Uncle, here I am! Can you see me?"

My uncle stared at me for a long time, then started to cry. At the beginning he was unable to speak, choked with emotion. He was overjoyed. He had seen me from afar, but he had seen me, and therefore he felt close to me. That visual contact had been more important than any phone call, more important than any video call. That eye contact and that greeting at a distance gave him the strength to support his solitude for many other days. They made him feel better but it was never like the eye contact that is almost physical contact for us human beings. Think for a moment about your first love when you were young. Just seeing your loved or desired one, even from afar, was enough to set your heart racing and for you to feel filled with warmth and infinite happiness.

He said to me, "The doctors are good ... they are all masked ... I only recognize them from their voices."

We are living in a war. Today, in this war, we have a better chance of keeping in touch than in previous wars. But it is still a war and like all wars it creates fears, anguish, a sense of loneliness, fear of dying. You can’t see a conclusion, you can’t see a light at the end of the tunnel. And you are alone and also unwell. There is the fear of infecting your loved ones, and also the fear of being cured but of being not really cured and, therefore, of carrying a virus inside you that is potentially deadly for other people as well. You don’t want to infect other people, you don’t want other people to go through the same excruciating physical and mental suffering that you have experienced.

My uncle asked me, "Will they discharge me only when I am definitely cured? When can I be sure that I am not a danger to other people? I live alone and I am alone! I don’t want to go home if I’m not sure I’m completely cured." The fear of the after. The fear of being infectious and of being infected again. The uncertainty of the "new" life. All these aspects worm into the brain and it is difficult to get free of them.

Fighting this battle and winning it alone is painful. A lonely death is even more painful - both for the person who fought for that life and for those who had to witness the battle from a distance. Powerless. Atrocious suffering. My 76-year old mother, my uncle’s sister, asked me what she could do. How could she help him? Sleepless nights. Fear. She was alone as well. Afraid of the phone ringing in case it was bad news, but also wanting to hear someone to give her strength and courage. One morning I telephoned my mother.

She replied, "Hello!! Thank goodness you called me."

"Why? What has happened?" I said.

"No, nothing. I needed to hear someone, but I couldn't call anyone!"

Paralysed by fear, unable to react. The elderly are the most frail, not only in defending themselves against the disease but also in facing the entire war. Habits that change, grandparents and children who can no longer go to see them. The elderly need to be part of the flow of life, it makes them feel alive and valuable. Solitude amplifies the sense of emptiness and uselessness and, for those who are elderly and close to the end of their life and who already feel a sense of death, this solitude and emptiness can be intolerable. A death in advance.

It is a real tragedy for the human soul. We must stick together virtually and think about each other. The work done with enormous strength and tenacity by doctors, nurses, auxiliaries and also by the hospital cleaners who are in contact with both patients and healthcare professionals, by the hospital kitchen staff, and by the civil protection service, is wonderful and a great hope for a better time. It does not soothe the pain of lonely people, the pain of missing people, but it does raise the hope that a future generation will be able to truly take care of mankind.

When all this ends, we must not go back to normal. We must be reborn, better.
Acknowledgements

This work was partially supported by the Italian Ministry of Health with Ricerca Corrente and 5x1000 funds.

Authors’ contributions

All Authors contributed equally.