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Personal Narrative

# The "wreckage" left by the COVID-19 passage: Thoughts of a palliative care nurse

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**Abstract**
Today, according to Johns Hopkins University, the overall number of global COVID-19 cases has exceeded 244 million with more than four million deaths. Humankind is currently facing an unprecedented global crisis. The impact of this crisis on the healthcare system is potentially far greater than we imagine. This narrative presents a series of stories lived by a palliative care nurse in COVID's time to show how the pandemic itself is a form of inequity and health disparities on the human experience. In my previous narrative, written in April 2020 and published in the Patient Experience Journal Vol. 7, Issue 2, I wrote, "I think how many lives we will lose while we try to maintain life." Now, we are realizing how many more lives we are going to lose, beside those from COVID-19. Now, we are receiving COVID-19's spoils and wreckage. Now and in the future, it will be the time for us, as health professionals, to encounter these dramatic stories, the stories of the "children of COVID-19," the people who were deeply affected and may have died because of the pandemic but without being infected by the virus.

**Keywords**
COVID-19, impact, collateral damage, patient, continuum of care

## Introduction

Today Ana is without a father.

Ana is 12 years old, loves unicorns, sports and chocolate cake, is very expressive about her ideals and with an impressive plan for the future. A future without her father.

Ana's father, Anthony, my patient in the palliative care unit, died at the age of 37, not with COVID, but with brain cancer, found in COVID's time, and that made all the difference. He never started the treatments that were planned at the time of diagnosis. He was never called for the radiotherapy appointment.

I realize with Ana and Anthony and so many others, *"that the idea conveyed by the media, that we are all in the same situation, is not at all true; we are, in fact, facing the same storm, but we aren´t all in the same boat."*[1]

We are all asking many pressing questions about COVID-19: How long it will last? How many people will be affected? How do we protect ourselves and our communities? But questions about COVID-19 go well beyond the pandemic itself.[2] Ana and Anthony could have had a different future. We'll never know.

Pandemics have occurred throughout history. The international community has made progress and improvements toward preparing for and mitigating the impacts of pandemics, but there is significant gaps and challenges that contribute to the devastation of the current global pandemic.[3]

Because of those perceived "cracks," as the pandemic progresses, COVID-19 is teaching history new lessons. It reveals the holes in the healthcare delivery system worldwide and puts a spotlight on inequities that can have lasting side effects on patients and providers,[4] *"…the indirect health effects of COVID-19 show the pandemic has created additional barriers for patients accessing essential care through restrictions on movement, lack of service provision, stigma, impoverishment from loss of livelihoods, and avoidance of care due to concerns over contracting the virus."*[5]

During 2020, mortality in Portugal, my country, was 10.6% higher than the 2015-2019 average, but the number of deaths by COVID-19 represents 41.8% of the total deaths.[6] In January 2021, almost 40% more people died, but COVID-19 was the cause of only one in four deaths. And this happens all over the world. Even at the height of its surge, COVID-19 never became the leading cause of death in the U.S.[7]

As we entered the year-one mark of the coronavirus pandemic, more reports emerge of the indirect health effects of the pandemic. What will our care and concern (or carelessness and unconcern), particularly during the COVID-19 pandemic, say about us as a society in the future?

Now is the time to learn from the "cracks" perceived during the pandemic and start a deep and urgent conversation at a local, national and international level in order to avoid an "ethical and moral catastrophe" that we will all be ashamed of.

## General narrative: A synopsis of the stories highlighting relevant moments

Teresa died at the age of 41. She left behind a husband with three very young children. Teresa had an aggressive stomach tumor and waited six months for a test that was able to show what caused the gastric disorder that she had been complaining about for more than one year. After she was referred to our palliative care team for intense, uncontrolled pain and until her death, only 15 days had passed.

The COVID-19 pandemic, which spread with a unexpected higher velocity, has broken the backbone of the conventional healthcare system in most countries.[8] We now realize that COVID-19 will have a ripple effect on global healthcare systems, pushed to and beyond their limits, and forces the world to reckon with our collective level of pandemic unpreparedness.[3]

Quantifying the morbidity and mortality burden from pandemics poses a significant challenge,[4] because the indirect health impacts of pandemics increase morbidity and mortality even further, like Teresa's and Anthony´s deaths. In low and middle-income countries alone, there are an estimated 100 million casualties as an indirect effect of the virus and the lockdown measures (early estimate).[9]

In response to the COVID-19 pandemic, cancer screening and routine diagnostic work was deferred and only urgent symptomatic cases prioritised for diagnostic intervention. In addition, health professionals being redirected will increase the risk of many deaths from health problems not related to COVID-19.[10,11]

In Portugal, it is predicted that during the pandemic more than 12 million consultations and surgeries remain undone.

Julia, 49 years old with twin daughters age 10, has an aggressive breast cancer. Mastectomized in October 2020, she waited three months for a second cycle of chemotherapy to be rescheduled after being infected with COVID-19. She is very concerned about the fact that the disease may have progressed during this period.

The COVID-19 pandemic dramatically altered the delivery of outpatient care in 2020. Beginning in March 2020, healthcare practices began deferring elective visits, modifying their practices to safely accommodate in-person visits and increasing the use of telemedicine.[12]

Studies from England show that substantial increases in the number of avoidable cancer deaths are to be expected as a result of diagnostic delays due to the COVID-19 pandemic in the UK.[13] All around the world, many medical treatments such as chemotherapy have not been given and were postponed.[14]

Joana, 22 years old, had a poorly controlled bipolar disorder since 2018. In 2020, presential psychiatric consultations were successively rescheduled. She always said on the phone that everything was fine and could wait for the next date. She committed suicide in July 2020.

A survey done by Young Minds revealed that up to 80% of young people with a history of mental health issues reported a worsening of their condition as a result of the pandemic and lockdown measures.[15] Many of the lockdown measures, with the intention of saving our lives, are paradoxically related to a weakened immune system, stemming from a loss of purpose in life, social isolation and related mental health issues leading to outcomes such as increased suicide rates.[16,17] Furthemore, WHO (2020) already recognizes the lasting impact of COVID-19 on mental health and well-being of health professionals,[18] and the mental health effects in the general population as a whole will be a global catastrophe.[19]

Manuel was 57 years old in March 2020 and had very frequent coughing episodes with bloody sputum. He was warned by his wife and children to go to a healthcare service right away. He never went, for fear of contagion by the coronavirus. In November 2020, after ten months of evolution of the first alarming symptom, he was taken to an emergency room where advanced and disseminated lung cancer was found. There was no criteria for curative treatment. He passed away in a week, without seeing his wife and children again, with no visits and no goodbyes.

We already know that some of the precursors of indirect health impacts are depletion of resources to provide routine care and decreased access to routine care.[3] Additionally, we have fear, a very important fact to consider, because even today many patients are still delaying or deferring important care for fear of exposure to COVID-19.

Moreover, healthcare systems around the world are seeing decreases in urgent and emergency care for acute illnesses. In many countries, emergency admissions for cardiac chest pain and transient ischemic attacks are decreased by about 50% as people are avoiding hospital visits. In the United States, for example, the number of severe heart attacks being treated in hospitals dropped by nearly 40%. These examples show that eventually there will be higher death rates from other causes.[15]

On the other extreme, we have the irrational fear of being infected that leads to seeking unnecessary care, further burdening the healthcare system.[20]

While COVID-19 continues to wreak havoc on our population, the public health response to it has caused widespread ripple effects that will reverberate throughout healthcare for years to come. This collateral effect that the pandemic causes on our patients' and families' lives will be catastrophic.[3] Since these effects are stronger for vulnerable groups, this will widen the existing inequalities.[21]

Joaquim, 63 years old, was the victim of a hemorrhagic stroke one afternoon in May 2020, promptly rescued and admitted to a specialized stroke unit. The recovery was impressive with small physical sequelae that still prevent his independence from ADLs but that would be overcome by the rehabilitation and recovery treatment that he would undergo. He was discharged from the specialist unit to another hospital, and from there to a convalescence unit, and then onward to a care home where he waited for rehabilitation. That necessary rehabilitation never came. At this moment, Joaquim is in a long-term care facility, dependent on others for all activities, with ankylosis and severe spasticity and complex communication problems. He feeds by feeding tube due to increasing dysphagia. The expectation to recovery is now small or non-existent.

Hospitals, during the worst days of the pandemic, were not able to offer all the possible services, though they were serving emergencies.[8] Everything that was not urgent or COVID-related were put on hold.

Luís was 72 years old, single, without a close family caregiver. In January 2020, he went to his family doctor for important constitutional complaints: weight loss of 6 kg in six months, anorexia, asthenia and hypersudorese nocturne. The doctor performed complementary diagnostic tests that pointed to a malignant lung injury. He was referred for evaluation by pneumology specialist, who saw the patient for the first time in August with evident deterioration of the general condition, severe pain and total dependence. Admitted in hospital and asked for palliative care support, he died two days later.

One of the most critical implications of COVID-19 is its effect on global public health programs. It is sobering to consider the many pressing health issues that needed greater attention in 2020 still need to be addressed while going through an unprecedented shock to the health system.[2]

With regard to the numbers, the only thing that seems for certain in every country is that mortality has skyrocketed over these days due to COVID-19, but it is difficult to understand what effect the pandemic is having in other pathologies. To this, it is necessary to add that several experts consider that the number of deaths by COVID-19 can be underestimated, for example, many deaths happen in nursing homes or care homes without people being tested which shows that not all infected people are entered in the global counts. And, to complicate the scenario, in cases where a patient infected with COVID-19 already has other pathologies (such as respiratory disease, cancer or heart problems), it becomes much more difficult to determine whether the cause of death was this new coronavirus or one of the pathologies the patient already suffered from. The question in this case, which is difficult to answer, is whether the patient died of COVID-19 or with COVID-19.

So, as to whether the pandemic is increasing or decreasing the number of deaths for other reasons, there is no consensus between experts, not only because those who could be dying from other diseases are dying from COVID-19, but also because the current situation of lockdown is likely to reduce mortality from other causes such as car accidents or accidents at work. But we can also see an increase in domestic accidents that are often underestimated or deaths related to the worsening of mental problems.

Both phenomena have a name: "advanced mortality" and "indirect mortality." The first is the case of someone with an important underlying disease and a short life expectancy that, when infected, is clinically decompensated. The death is anticipated and occurs sooner than expected. But the opposite also happens, defined as indirect mortality, something that occurs in situations of epidemics or catastrophe when the health and social structure is changed abruptly. People postpone the time to go to the hospital to avoid saturating them or because they are afraid of contagion. A vulnerable group, such as the elderly who live alone, are often left without a family or social network that would normally detect and alert someone when something happens to the person. Destructuring all support systems has increased mortality at all levels.

This should have an important impact on the mortality rate not only now but in the months and years after the pandemic. According to experts, it is possible the excess of mortality that we witness these days will be followed with a decrease in mortality that of previous years on those same dates when the mortality by COVID-19 is reduced or, in the best scenario, disappears. Due to inequity and health disparaties, the deaths in the time of COVID-19 were recorded in the most fragile population, which possibly would be, at least partially, the deaths that we would expect to occur in the weeks, months and years to follow.

## Reflections/recommendations based on experience

Anthony waited for a therapeutic decision consultation; Terese waited for an exam; Julia waited for chemotherapy; Joana waited for presential psychiatric consultations; Manuel waited for the end of COVID-19 to "safely" go to the doctor; Joaquim waited for rehabilitation treatments; and Luís waited for a specialist consultation. They all waited and waited and died waiting for something that existed before the pandemic, that was guaranteed, that was safe.

The rapid and ongoing spread of COVID-19 across the world has taken everyone by surprise with many healthcare systems struggling to cope with the effects on our wider health and wellbeing and has impact on every healthcare service directly or indirectly. Nevertheless, we cannot yet grasp the full scale of the problem, the "collateral damage," caused on every single patient and family that needed and relied on profissional care. Now, due to COVID-19, there is no equity in access to essential care. We know for sure that there is important personal damage, loss and grief.

But beside the spoils that COVID-19 is leaving in its passing, now it is time to accept COVID-19 as a part of medical practice and extend standard care to all patients with due precautions. COVID-19 was not the first severe pandemic, nor will it be the last. So, the reflection and decisions we make today will shape the world for years to come. We need to strengthen our patient-centred approach, because every patient needs to feel they are important to us. Let us not ignore non-COVID patients and offer them the best possible care, the care they all deserve.

It is time to write history itself and protect all our patients from the impact of catastrophes, because if we don't, they surely will, once again, promote disparities on the Human Experience.

## References


1. Simões AL. Thoughts of a palliative care nurse in times of pandemic. *Patient Experience Journal*. 2020; 7(2) , Article 9: 27-30. doi: 10.35680/2372-0247.1464
2. GBC Health Mission. *Beyond COVID-19: Ripple Effects of a Pandemic;* 2020. URL:https://gbchealth.org/beyond-COVID-19-ripple-effects-of-a-pandemic/. Accessed February 21, 2021.
3. Madhav N, Oppenheim B, Gallivan M, Mulembakani P, Rubin E, Wolfe N. Pandemics: Risks, Impacts, and Mitigation. In D. Jamison H. Gelband S. Horton et al (ed). *Disease Control Priorities: Improving Health and Reducing Poverty* (3ªed.) International Bank for Reconstruction and Development / The World Bank. Library of Congress. 2018. Washington, USA. ISBN (electronic): 978-1-4648-0528-8.
4. Price A. The lasting impact of the COVID-19 pandemic on our healthcare delivery system. *Berkeley Conversations*. 2020. URL: https://news.berkeley.edu/2020/05/04/the-lasting-impart-of-the-COVID-19-pandemic-on-our-healthcare-delivery-system/. Acessed March 14, 2021.
5. Regan L, Chi Y-Ling (2020). The Indirect Health Effects of COVID-19: The Challenges of Living through a Pandemic. *Center for Global Development.* URL: https://www.cgdev.org/blog/indirect-health-effects-COVID-19-challenges-living-through-pandemic. Acessed March 1, 2021.
6. INE – Instituto Nacional de Estatística. A mortalidade em Portugal no contexto da pandemia COVID-19. Destaque. INE: Portugal. 2021. URL: https://www.ine.pt/xportal/xmain?xpid=INE&xpgid=ine_destaques&DESTAQUESdest_boui=473843801&DESTAQUESmodo=2 Accessed March 10, 2021.
7. Bhat VS. Collateral effect of COVID-19 on public health in low-resource countries.*Tropical Doctor*. 2020;50(4): 390–391. doi: 10.1177/0049475520941276.
8. Nathoo A. Komodo Health Industry Voices—Mapping the ripple effects of a pandemic: We have to measure more than just COVID-19. *Fierce HealthCare*. 2020. URL: https://www.fiercehealthcare.com/tech/industry-voices-mapping-ripple-effects-a-pandemic-we-have-to-measure-more-than-just-COVID. Accessed February 21, 2021.
9. Zetzsche DA, Consiglio R. *One Million or One Hundred Million Casualties? – The Impact of the COVID-19 Crisis on the Least Developed and Developing Countries*. University of Luxembourg: Law Working Paper Series; 2020. URL:http://dx.doi.org/10.2139/ssrn.3597657 Accessed January 19, 2021.
10. Heath S. How Will Coronavirus Impede Patient Access to Care? Patient Engagement Hit; 2020. URL: https://patientengagementhit.com/news/how-will-coronavirus-impede-patient-access-to-care Accessed January 19, 2021.
11. Gorvett Z. *Why most COVID-19 deaths won't be from the virus*. BBC. London; 2020. URL: https://www.bbc.com/future/article/20200528-why-most-COVID-19-deaths-wont-be-from-the-virus Accessed February 15, 2021
12. Mehrotra A, Chernew M, Linetsky D, Hatch H, Cutler D, Schneider H. The Impact of COVID-19 on Outpatient Visits in 2020: Visits Remained Stable, Despite a Late Surge in Cases. *Commonwealth Fund*. 2021. doi:10.26099/bvhf-e411. URL: https://www.commonwealthfund.org/publications/2021/feb/impact-COVID-19-outpatient-visits-2020-visits-stable-despite-late-surge. Acessed March 4, 2021.

13. Maringe C, Spicer J, Moris M, Purushotham A, Nolte E, Sullivan R, et al. The impact of the COVID-19 pandemic on cancer deaths due to delays in diagnosis in England, UK: a national, population-based, modelling study. *The Lancet*. 2020; 21(8):1023-1034. doi 10.1016/S1470-2045(20)30388-0.
14. Sud A, Jones ME, Broggio J, Loveday C, Torr B, Garrett A, et al. (2020). Collateral damage: the impact on cancer outcomes of the COVID-19 pandemic. *Ann Oncol*. 2020; 31(8):1065-1074. doi: 10.1016/j.annonc.2020.05.009.
15. Sarner M. Maintaining mental health in the time of coronavirus. *New Sci*. 2020;246: 40–46. doi:10.1016/S0262-4079(20)30819-8
16. Torales J, O'Higgins M, Castaldelli-Maia JM, Ventriglio A. The outbreak of COVID-19 coronavirus and its impact on global mental health. *Int. J. Soc. Psychiatry*. 2020;66: 317–320. doi:10.1177/0020764020915212
17. Zhou X, Snoswell CL, Harding LE, Bambling M, Edirippulige S, Bai X, et al. The role of telehealth in reducing the mental health burden from COVID-19. *Telemed. E-Health*.2020;26:377–379. doi:10.1089/tmj.2020.0068
18. WHO - World Health Organization. *Mental Health and Psychosocial Considerations During the COVID-19 Outbreak*. WHO; 2020. URL: https://apps.who.int/iris/bitstream/handle/10665/331490/WHO-2019-nCoVMentalHealth-2020.1-eng.pdf Accessed February 2, 2021.
19. Izaguirre-Torres D, Siche R. COVID-19 disease will cause a global catastrophe in terms of mental health: a hypothesis. *Med. Hypotheses*. 2020;143:109846–109846. doi:10.1016/j.mehy.2020.109846.
20. Falcone RE, Detty A. Agustine J. The Next Pandemic: Hospital Management. Emergency Medical Reports. *Relias Media* 2015;36 (26): 1–16. URL: https://www.reliasmedia.com/articles/136827-the-next-pandemic-hospital-management. Acessed March 1, 2021.
21. Holmes EA, O'Connor RC, Perry VH, Tracey I, Wessely S, Arseneault L, et al. Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. *Lancet Psychiatry*. 2020;7:547–560. doi:10.1016/S2215-0366(20)30168-1.