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FROM THE INSIDE

Moral distress in the intensive care unit during the pandemic: the burden of dying alone

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I am asked, almost daily, how it felt to look after adult COVID-19 patients in intensive care when I have been looking solely after critically ill children for the last 15 years. Intensive care is a unique profession. Intensivists are accustomed to the possibility of death on a daily basis. We look death in the eye, we play chess with him, and we know that with great investment (and some luck) on the children's intensive care unit, roughly 9 out of 10 times, we win [1]. That is our comfort zone.

Every death affects us, but we are proficient at facilitating a good death for those that we cannot save. That is our bread and butter. Loved ones around, analgesia, sedation, memory boxes, prayers, christenings, readings, singing, the lot. A good death is paramount for patients and their families, but do not underestimate its importance to healthcare staff too.

Overnight, in a heartbeat, our children's intensive care unit is an adult ICU staffed with healthcare providers trained to work exclusively with children. To protect those living at home from COVID-19, many of us moved into hospital accommodation. We have all had to operate outside our comfort zones; working all day in PPE is sweaty, uncomfortable business. Human interaction is different. We cannot read faces any more. We cannot see the smiles, the winks, the frowns each of us wears. It is remarkable, in retrospect, on how much we rely on these subtleties to communicate with each other on the unit. Non-verbal communication can signal most things, worry, elation, relief, the works. The job is much harder without it.

After the slow trickle of patients on the unit, the spate arrives, COVID-19 admissions galore. The comfort of our 9/10 survival rate in children is gone. This is a different animal, one we have not come across before, highly contagious and at this point in time, still poorly understood. Days away from my family morph into weeks. I lie in a sterile hospital room with no windows, increasingly feeling like that doctor from Glenn Colquhoun's haunting poem [2].

TODAY I DO NOT WANT TO BE A DOCTOR
Today, I do not want to be a doctor
Nobody is getting any better.
Those who were well are sick again
and those who were sick are sicker.
The dying think they will live.
The healthy think they are dying.
Someone has taken too many pills.
Someone has not taken enough.
A woman is losing her husband.
A husband is losing his wife.
The lame want to walk.
The blind want to drive.
The deaf are making too much noise.
The depressed are not making enough.
The asthmatics are smoking.
The alcoholics are drinking.
The diabetics are eating chocolate.
The mad are beginning to make sense.
Everyone's cholesterol is high.
Disease will not listen to me
Even when I shake my fist.

As the deaths mount, you realise the solace of a good death cannot be taken for granted. We can 'deal' with the high mortality rate, internalise it, brush it under the carpet. We use coping strategies that we have developed over our years of work on the paediatric intensive care unit. However, what kept us awake at night during the

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pandemic was moral distress; the thought that somehow we were complicit in allowing these patients to die alone. Alone, without their loved ones being able to say goodbye due to social distancing rules, visiting restrictions and PPE shortages for non-clinical personnel. Morphine and midazolam are poor substitutes for a human, familial touch.

Moral distress goes hand in hand with insomnia. We worked 14 hour shifts in a wearable sauna, went to bed and were still unable to sleep. Instead, we lay awake staring at the flickering fluorescent white lights at our hospital accommodation thinking about patients that did not get to say goodbye to their wives, husbands, children, or loved ones. There had to be a better way.

We thought of the idea of starting compassion ward rounds on the ICU. The concept was that a doctor and a family liaison nurse would undertake a videoconference call with a family member daily. This would allow them the opportunity to access, see and speak to the patient. During the end of life, families would get the chance to say goodbye remotely. So, we reached out to twitter. One of the platforms' better uses is linking up healthcare professionals to create a common pool of knowledge. Medical twitter did not disappoint.

Doctors, nurses, health professionals from far and wide weighed in within minutes of this call to arms like a legion of compassionate revolutionaries that had just been woken up. Soon we had a template for our battle plan, a patient-directed questionnaire that had already been developed to address the issue of patients dying alone [3]. This could (in part) alleviate COVID-19-related moral distress. We tweaked it to account for subtle cultural nuances and make it more legally robust. It was then presented to the hospital legal ethics committees; given the timeframe, gravity of the situation and people dying alone, the questionnaire was approved within a week (see Appendix Table).

The questionnaires were used across the hospital for adults with COVID-19 symptoms and allowed us to use their phones or hospital tablets to call their loved ones. It also enabled us to tailor end-of-life care, if necessary, based on their belief system, religion, musical and literary preferences. It was not perfect but it was better than dying alone. Within a week, word spread across the region and various charities donated 250 tablets to the hospital for this purpose alone. To reduce the potential for discrimination against ethnic minorities, we translated the questionnaires in a number of languages. The compassionate revolution was up and running!

A week later Mrs. Modi[1], arrived to our intensive care unit. The consensus was that her chances of survival were bleak; the critical care abacus rarely lies. She was 68-years-old and had already been at hospital for a week, having gradually deteriorated to the point where she needed critical care. She had limited use of English and primarily spoke Gujarati. She had not spoken to her family for 10 days. Imagine the fear these patients experience: fighting for their lives, on ventilatory support, on inotropes, unable to understand the spoken language, unable to communicate with us. It must be terrifying.

Mrs. Modi was one of the first patients to pilot compassion ward rounds. The first time she heard her daughter's voice over a video call, in her own dialect, there were tears of joy, not just from the patient, but everyone else on the unit. From that point on, she was galvanized.

Feeling her family's presence appeared to be the jolt that Mrs. Modi needed. A week on, she was wheeled out of critical care to the general ward. On her way out, she summoned the strength to whisper something to me in her own language with tears in her eyes. I can never be sure of what she said, but I suspect it was an expression of gratitude.

We cannot deny the impact that compassion has on our moral distress; it may even have had an impact in giving this patient her fight to survive back. Compassion rounds had done their job. That night, I had no trouble sleeping. The next day, I wanted to be a doctor again.

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Compliance with ethical standards

Conflicts of interest

The author declare no conflicts of interest in this paper.

Appendix

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[1] Patient details, identifiers and demographics have been changed to protect anonymity.

Hello my name is………

I prefer to be called………

My date of birth is ………

Thank you for caring for me and being a major part of my healing and care

People who are most concerned about me right now are:

………

………

Their phone numbers are:

………

………

It would really mean a lot to me and my loved ones to keep them informed about my progress by:

☐ Sending a photo of me (even if I am very unwell and look very poorly)
☐ Live video/audio so I can hear their voice and/or they can hear mine if the facilities are available
☐ Sending a text message to the numbers above to give them an update
☐ I consent to my own phone being used for this purpose if I am too weak to use it myself. I accept that the use of apps may not be fully secure (please write your access code if you wish us to do this).

Even if I appear unconscious it will lift my spirits (and yours) if you say my name and:

☐ Tell me something funny
☐ Play a particular song (please state which if you have a favourite))
☐ Sing a song
☐ Tell me a story
☐ Recite a poem (please state which if you have a favourite)
☐ Tell me about you
☐ Read a Bible reading
☐ Recite the Quran
☐ Read another sacred text (please state which)
☐ Sing a hymn or say a prayer
☐ Other (Please state)

Thanks for doing everyting you're doing for me and my loved ones.
Please take care of yourself too

***NB: Form to be filled by patient or by next of kin if patient is unable to**

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