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Holistic Lessons from a Pandemic

My experience of COVID-19 care was as a student volunteer on a gastroenterology ward and designated 'COVID ward'. The COVID-19 positive patients on this ward were elderly patients receiving ward-based, supportive therapy, as they were not candidates for non-invasive ventilation or intensive care. The lack of definitive treatment for COVID-19 served as a reminder of our reliance on other health determinants – frailty, psychological factors and social support to name but a few – in overcoming severe physical illness.[1] Two patients with COVID-19 stand out, both following the same course of illness. The first, an 86 year old lady, was deteriorating clinically, with reducing oxygen saturations and increasing levels of delirium. Consequently, it was decided that palliative treatment with oxygen therapy alone was most appropriate, and her daughter was allowed to visit as she was deemed to be nearing the end of her life. Within days of this decision, the patient began to improve and subsequently improved to the point where she was discharged at her pre-hospital baseline. The second patient, a gentleman in his 80s, followed an almost identical course.

These cases were notable as they indicated that, although the decisions to withdraw care were made appropriately and in accordance with current practice, doctors' assessments cannot always be correct, and patients do not always follow the expected course. This is particularly true in the context of COVID-19 – where the clinical course itself was and still is relatively unknown. This encouraged me to consider the process by which treatment decisions are made, how the pandemic may have affected this, and what lessons might emerge.

Treatment decisions were difficult in COVID-19 patients for a number of reasons. Firstly, the virus tends to affect older patients and those with co-morbidities more severely – groups that have poorer outcomes from treatments such as non-invasive ventilation (NIV) or intensive care.[2] The virus also has multiple effects including, but not limited to, pneumonia of ranging severity, acute respiratory distress syndrome, hyperviscosity syndrome, and cardiovascular effects, making it difficult to predict the course of illness.[3] Moreover, at the time of decision-making, many of these effects were relatively unknown and based on anecdotal evidence, and the long-term effects of severe COVID-19 illness were yet to be encountered.[4] In addition, decisions regarding treatment had to be made under more pressurised circumstances than usual – with clinicians having to consider resource allocation amongst fears that health services would be overwhelmed.[5] Furthermore, there was heightened health anxiety amongst the public, and the need to minimise the risk of transmitting the infection to staff and other patients.[6]

In response to the evolving pandemic, the National Institute for Clinical Excellence (NICE) published rapid guidance on treatment escalation decisions for patients with COVID-19.[7] This guidance emphasises utilising objective frailty measurements, specifically the Clinical Frailty Scale (CFS), to make predictions of a patient's likely outcomes from treatment and to base treatment decisions on these.[7] The patient is then triaged taking into consideration the likelihood of a positive outcome from a given treatment – falling broadly into three categories: supportive therapy alone; non-invasive ventilation; or full escalation to intensive care.[6] An outcome-based approach is important, especially when considering the allocation

of scarce resources and in avoiding the implementation of futile treatment; and is typical of decision-making in other scenarios such as transplant organ allocation.[8]

However, the CFS categorises patient frailty based on clinician judgement alone, as opposed to other scales which incorporate self-reported quality of life measures. This means it does not include the treatment preferences of the patient.[9] Consequently, when used as the main guide for determining treatment of a severely ill patient, there is potential for deciding upon treatments or outcomes that are unwanted by the patient. In addition, NICE concedes that the CFS should not be used in younger patients or those with disability and that "individualised assessment is recommended in all cases where the CFS is not appropriate".[7]

It is important to remember that the pandemic has also created, and continues to create, difficult treatment decisions for clinicians in the context of non-COVID patients, for example in the cancellation of cancer treatments and elective surgeries.[10] This was partly due to a strain on health system resources, but routine care was cancelled mainly due to the risk of virus transmission to both patients and staff in healthcare settings.[11] The widespread suspension of elective treatment may have forced clinicians to adopt a more individualised approach to treatment decisions e.g. in oncology as their usual 'automatic' options were not possible.[12] For example, one patient in Massachusetts with metastatic melanoma achieved a beneficial outcome from radiotherapy rather than surgery – the result of a review of the literature purely due to the risk of surgery in the context of COVID-19.[12] The pandemic may teach us that catch-all guidelines, whilst undoubtedly important in summarising the evidence for certain treatment decisions, should be adapted in the context of individual patients.

But what does an individualised assessment look like? NICE recommends discussing 'do not attempt cardiopulmonary resuscitation' (DNACPR) orders with all adult patients admitted with COVID-19.[7] Whilst clinically important, this addresses only an extreme of physical care and fails to include important psychosocial and physical factors.[13] For example, the psychological impact of long stays in intensive care, potential for long rehabilitation periods post-intensive care and a range of physical and mental health problems known as 'Post-Intensive Care Syndrome' may not be discussed with patients and families.[14] Curtis et al. argues that discussions concerning treatment in severe COVID illness should not focus on DNACPR orders, but a discussion of treatment goals, with the aim of providing 'goal-aligned therapy'.[15] This involves discussing desired potential outcomes, whether this be quality of life, independence in daily activities or other such factors, and then applying these goals when deciding on a treatment course.[13,15] COVID-19, through restricting our resources, teaches us that the availability of treatment options is not of itself a valid reason to use them, and that the most complex or intensive treatment may not always hold the best outcome for the patient. However, it is impossible to assess such situations without knowledge of patients' desires. In-depth, human, discussions about the goals of therapy may provide the solution.[15]

Having said this, it is inappropriate and most likely impossible to carry out such sensitive conversations upon admission to hospital with severe illness.[16] This is due to a variety of factors dependent on the situation, such as time constraints; lack of capacity; and heightened levels of anxiety.[16] Increased emphasis on routine advance care planning in

primary care, or setting of treatment goals in the whole population, would ensure that such information would be available before it is required.[16,17] Whilst COVID-19 is more severe in the elderly, it has also caused a number of people to become severely ill who would not have previously thought to plan for end of life and treatment decisions.[18] Knowledge of patient preferences in advance would ease the burden on intensive care doctors, who do not know the patients as well as primary care physicians, and may also assist in the allocation of resources when confronted with two patients of equal prognosis.[19]

One barrier to better implementation of advance care planning is the stigma that surrounds end of life discussions. Interestingly, anecdotal evidence shows that the universal threat of COVID-19 has made approaching such discussions easier for patients and practitioners.[10] There is a need to move away from advance care planning as an 'end of life discussion' and towards a system of goal-aligned care – which can apply to anyone and not just the very elderly or those with life-limiting conditions.[16] For example, in a study by Tinetti et al., patients who were asked identify their health priorities and were given treatment aligned with those were found to have a lower treatment burden and lower unwanted healthcare than those who received usual treatment.[20] In addition, 66% of these patients had? discussions with healthcare providers about their treatment goals during routine appointments, in comparison with 0% of the usual care group.[20] This is an example of an intervention that was successful in supporting human conversations around goals of treatment.[21] If such a system were widely implemented, we might have much more information on individual patients' preferences in advance of such dire situations as the COVID-19 pandemic. A universally implemented system might also help to replicate the effect that the pandemic had in removing stigma from conversations around treatment goals.

In conclusion, while these debates are not new, the pandemic has highlighted deficiencies in the implementation and prioritisation of individual treatment preferences. There is a need to destigmatise these holistic measures and incorporate them into routine care. In addition, we need to prioritise research into methods of enabling and destigmatising discussions concerning treatment goals, and recording the outcomes of such discussions, as this will enable us to improve the alignment of our practice with patient goals. The pandemic has been a source of great tragedy across the world, but we must use the discussions it has created to scrutinise our practice and become more compassionate in our care.

Word Count: 1499

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