Revisiting the equity debate in COVID-19: ICU is no panacea

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ABSTRACT
Throughout March and April 2020, debate raged about how best to allocate limited intensive care unit (ICU) resources in the face of a growing COVID-19 pandemic. The debate was dominated by utility-based arguments for saving the most lives or life-years. These arguments were tempered by equity-based concerns that triage based solely on prognosis would exacerbate existing health inequities, leaving disadvantaged patients worse off. Central to this debate was the assumption that ICU admission is a valuable but scarce resource in the pandemic context.

In this paper, we argue that the concern about achieving equity in ICU triage is problematic for two reasons. First, ICU can be futile and prolong or exacerbate suffering rather than ameliorate it. This may be especially true in patients with COVID-19 with emerging data showing that most who receive access to a ventilator will still die. There is no value in admitting patients with poor prognostic indicators to ICU to meet an equity target when intensive critical care is contrary to their best interests. Second, the focus on ICU admission shifts focus away from important aspects of COVID-19 care where there is greater opportunity for mitigating suffering and enhancing equitable care.

We propose that the focus on equity concerns during the pandemic should broaden to include providing all people who need it with access to the highest possible standard of end-of-life care. This requires attention to culturally safe care in the following interlinked areas: palliative care, communication and decision support and advanced care planning.

INTRODUCTION
As COVID-19 spread internationally, healthcare services in many countries became overwhelmed. One of the main manifestations of this was a shortage of intensive care beds, leading to urgent discussion about how to allocate these fairly. In the initial debates about allocation of scarce intensive care unit (ICU) resources, there was optimism about the ‘good’ of ICU access. However, rather than being a life-saving intervention, data began to emerge in mid-April showing that most critical patients with COVID-19 who receive access to a ventilator do not survive to discharge. The minority who survive leave the ICU with significant morbidity and a long and uncertain road to recovery. This reality was under-recognised in bioethics debates about ICU triage throughout March and April 2020. Central to these discussions were two assumptions: first, that ICU admission was a valuable but scarce resource in the pandemic context; and second, that both equity and utility considerations were important in determining which patients should have access to ICU. In this paper we explain how scarcity and value were conflated in the early ICU COVID-19 triage literature, leading to undue optimism about the ‘good’ of ICU access, which in turned fuelled equity-based arguments for ICU access. In the process, ethical issues regarding equitable access to end-of-life care more broadly were neglected.

Equity requires the prevention of avoidable or remediable differences among social, economic, demographic, or geographic groups. How best to apply an equity lens to questions of distribution will depend on the nature of the resource in question. Equitable distribution of ICU beds is significantly more complex than equitable distribution of other goods that might be scarce in a pandemic, such as masks or vaccines. ICU (especially that which involves intubation and ventilation i.e. mechanical ventilation) is a burdensome treatment option that can lead to significant suffering—both short and long term. The degree to which these burdens are justified depends on the probability of benefit, and this depends on the clinical status of the patient. People are rightly concerned about the equity implications of excluding patients from ICU on the grounds of pre-existing comorbidities that directly affect prognosis, especially when these align with and reflect social disadvantage. But this does not mean that aged, frail or comorbid patients should be admitted to ICU on the grounds of equity, when this may not be in their best interests.

ICU TRIAGE DEBATE
The COVID-19 pandemic generated extraordinary demand for critical care and required hard choices about who will receive presumed life-saving interventions such as ICU admission. The debate has focused on whether or not a utilitarian approach aimed at maximising the number of lives (or life-years) saved should be supplemented by equity considerations that attempt to protect the rights and interests of members of marginalised groups.

The utilitarian approach uses criteria for access to ICU that focus on capacity to benefit, understood as survival. Supplementary equity considerations have been invoked to relax the criteria in order to give a more diverse group of people a chance of entering ICU. Even if these pitfalls are avoided,
policies based on maximising lives saved entrench existing health inequalities because those most likely to benefit from treatment will be people of privilege who come into the pandemic with better health status than less advantaged people. Those from lower socioeconomic groups, and/or some ethnic minorities have high rates of underlying comorbidities, some of which are prognostically relevant in COVID-19 infection. Public health ethics requires that we acknowledge how apparently neutral triage tools reflect and reinforce these disparities, especially where the impact can be lethal.7

But the utility versus equity debate is more complex than it first appears. Both the utility and equity approach to ICU triage start from the assumption that ICU is a valuable good—the dispute is about how best to allocate it. Casing ICU admission as a scarce good subject to rationing has the (presumably unintended) effect of making access to critical care look highly appealing, triggering cognitive biases. Psychologists and marketers know that scarcity sells.8 People value a commodity more when it is difficult or impossible to obtain.7 When there is competition for scarce resources, people focus less on whether they really need or want the resource. The priority becomes securing access to the resource.

Clinicians are not immune to scarcity-related cognitive bias. Clinicians treating patients with COVID-19 are working under conditions of significant information overload but without the high quality clinical research (generated from large data sets and rigorous methodology) usually available for decision-making. The combination of overwhelming numbers of patients, high acuity and uncertainty regarding best practice is deeply anxiety provoking. In this context it is unsurprising that, at least in the early stages of the pandemic, they may not have the psychological bandwidth to challenge assumptions about the benefits of ICU admission for patients with severe disease. Zagury-Orly and Schwartzstein have recently argued that the health sector must accept that doctors’ reasoning and decision-making are susceptible to human anxieties and in the “...effort to ‘do good’ for our patients, we may fall prey to cognitive biases and therapeutic errors”.10

We suggest the global publicity and panic regarding ICU triage distorted assessments of best interests and decision-making about admittance to ICU and slanted ethical debate. This has the potential to compromise important decisions with regard to care for patients with COVID-19.

THE EMERGING REALITY OF ICU
In general, the majority of patients who are ventilated for COVID-19 in ICU will die. Although comparing data from different health systems is challenging due to variation in admission criteria for ICU, clear trends are emerging with regard to those critically unwell and requiring mechanical ventilation. Emerging data show case fatality rates of 50%–88% for ventilated patients with COVID-19. In China11 and Italy about half of those with COVID-19 who receive ventilator support have not survived.12 In one small study in Wuhan the ICU mortality rate among those who received invasive mechanical ventilation was 86% (19/22).13 Interestingly, the rate among those who received less intensive non-invasive ventilation (NIV) was still 79% (23/29).14 Analysis of 5700 patients in the New York City area showed that the mortality for those receiving mechanical ventilation was 88%.14 In the UK, only 20% of those who have received mechanical ventilation have been discharged alive.15 Hence, the very real possibility of medical futility with regard to ventilation in COVID-19 needs to be considered.

It is also important to consider the complications and side effects that occur in an ICU context. These patients are vulnerable to hospital acquired infections such as ventilator-associated pneumonias with high mortality rates in their own right,16 neuromyopathies,17 and skin damage. Significant long term morbidity (physical, mental and emotional challenges) can also be experienced by people who survive prolonged ventilation in ICU.12 18 Under normal (non-pandemic) circumstances, many ICU patients experience significant muscle atrophy and deconditioning, sleep disorders, severe fatigue,19 post-traumatic stress disorder,20 cognitive deficits,21 depression, anxiety, difficulty with daily activities and loss of employment.22 Although it is too soon to have data on the long term outcomes of ICU survivors in the specific context of COVID-19, the UK Chartered Society of Physiotherapy predicts a ‘tsunami of rehabilitation needs’ as patients with COVID-19 begin to be discharged.23 The indirect effects of carer-burden should also not be underestimated, as research shows that caring for patients who have survived critical illness results in high levels of depressive symptoms for the majority of caregivers.24

The emerging mortality data for patients with COVID-19 admitted to ICU—in conjunction with what is already known about the morbidity of ICU survivors—has significant implications for the utility-equity debates about allocating the scarce resource of ICU beds. First, they undermine the utility argument as there seems to be little evidence that ICU admission leads to better outcomes for patients, especially when the long term morbidity of extended ICU admission is included in the balance of burdens and benefits. For some patients, perhaps many, the burdens of ICU will not outweigh the limited potential benefits. Second, the poor survival rates challenge the equity-based claim for preferential access to treatment for members of disadvantaged groups. In particular, admitting frail or comorbid patients to ICU to fulfil equity goals is unlikely to achieve greater survival for these population groups, but will increase their risk of complications and may ultimately exacerbate or prolong their suffering.

The high proportions of people who die despite ICU admission make it particularly important to consider what might constitute better or worse experiences of dying with COVID-19, and how ICU admission affects the likelihood of a ‘good’ death. Critical care may compromise the ability of patients to communicate and engage with their families during the terminal phase of their lives—in the context of an intubated, ventilated patient this is unequivocal.

Given the high rates of medical futility with patients with COVID-19 in ICU, the very significant risks for further suffering in the short and long term and the compromise of important psychosocial needs—such as communicating with our families—in the terminal phase of life, our ethical scope must be wider than ICU triage. Ho and Tsai argue that, “In considering effective and efficient allocation of healthcare resources as well as physical and psychological harm that can be incurred in prolonging the dying process, there is a critical need to reframe end-of-life care planning in the ICU.”25 We propose that the focus on equity concerns during the pandemic should broaden to include providing all people who need it with access to the highest possible standard of end-of-life care. This requires attention to minimising barriers to accessing culturally safe care in the
following interlinked areas: palliative care, and communication and decision support and advanced care planning.

PALLIATIVE CARE
Scaling up palliative and hospice care is an essential component of the COVID-19 pandemic response. Avoiding non-beneficial or unwanted high-intensity care is critical when the capacity of the health system is stressed. Palliative care focuses on symptom management, quality of life and death, and holistic care of physical, psychological, social and spiritual health. Evidence from Italy has prompted recommendations that, “Governments must urgently recognise the essential contribution of hospice and palliative care to the COVID-19 pandemic, and ensure these services are integrated into the healthcare system response.” Rapid palliative care policy changes were implemented in response to COVID-19 in Italy, including more support in community settings, change in admission criteria and daily telephone support for families. To meet this increased demand, hospice and palliative care staff should be included in personal protective equipment (PPE) allocation and provided with appropriate infection preventon and control training when dealing with patients with COVID-19 or high risk areas.

Attention must also be directed to maintaining supply lines for essential medications for pain, distress and sedation. Patients may experience pain due to existing comorbidities, but may also develop pain as a result of excessive coughing or immobility from COVID-19. Such symptoms should be addressed using existing approaches to pain management. Supply lines for essential medications for distress and pain management, including fentanyl and midazolam are under threat in the USA and propofol—used in terminal sedation—may also be in short supply. The challenges are exacerbated when people who for various reasons eschew or are unable to secure hospital admission decline rapidly at home with COVID-19 (the time frame of recognition that someone is dying may be shorter than that through which hospice at home services usually support people). There is growing debate about the fair allocation of novel drugs—sometimes available as part of ongoing clinical trials—to treat COVID-19 with curative intent. But we must also pay attention to the fair allocation of drugs needed to ease suffering and dying.

COMMUNICATION AND END-OF-LIFE DECISION-MAKING SUPPORT
End-of-life planning can be especially challenging because patients, family members and healthcare providers often differ in what they consider most important near the end of life. Less than half of ICU physicians—40.6% in high income countries and 46.3% in low–middle income countries—feel comfortable holding end-of-life discussions with patients’ families. With ICUs bursting and health providers under extraordinary pressure, their capacity to effectively support end-of-life decisions and to ease dying will be reduced.

This suggests a need for specialist COVID-19 communication support teams, analogous to the idea of specialist ICU triage teams to ensure consistency of decision making about ICU admissions/discharges, and to reduce the moral and psychological distress of health providers during the pandemic. These support teams could provide up to date information templates for patients and families, support decision-making, the development of advance care plans (ACP) and act as a liaison between families (prevented from being in the hospital), the patient and the clinical team. Some people with disabilities may require additional communication support to ensure the patients’ needs are communicated to all health providers. This will be especially important if carers and visitors are not able to be present.

To provide effective and appropriate support in an equitable way, communication teams will need to include those

Box 1 Supporting communication and compassionate care during COVID-19

Despite the sometimes overwhelming pressure of the pandemic, health providers continue to invest in communication, compassionate care and end-of-life support. In some places, doctors have taken photos of their faces and taped these to the front of their PPE so that patients can ‘see’ their face. In Singapore, patients who test positive for SARS-CoV-2 are quarantined in health facilities until they receive two consecutive negative tests. Patients may be isolated in hospital for several weeks. To help ease this burden on patients, health providers have dubbed themselves the ‘second family’ and gone out of their way to provide care as well as treatment. Elsewhere, medical, nursing and multi-disciplinary teams are utilising internet based devices to enable ‘virtual’ visits and contact between patients and their loved ones. Some centres are providing staff with masks with a see-through window panel that shows the wearer’s mouth, to support effective communication with patient with hearing loss who rely on lip reading.

Current controversy

with the appropriate skills for caring for diverse populations including: interpreters, specialist social workers, disability advocates and cultural support liaison officers for ethnic and religious minorities. Patient groups that already have comparatively poor health outcomes require dedicated resources. These support resources are essential if we wish to truly mitigate equity concerns that arise during the pandemic context. See Box 1 for examples of specific communication and care strategies to support patients.

ADVANCE CARE PLANNING

ACPs aim to honour decisions made by autonomous patients if and when they lose capacity. However, talking to patients and their loved ones about clinical prognosis, ceilings of treatment and potential end-of-life care is challenging even in normal times. During COVID-19 the challenges are exacerbated by uncertainty and urgency, the absence of family support (due to visitor restrictions) and the wearing of PPE by clinicians and carers. Protective equipment can create a formidable barrier between the patient and the provider, often adding to the patient’s sense of isolation and fear. An Australian palliative care researcher with experience working in disaster zones, argues that the "PPE may disguise countenance, restrict normal human touch and create an unfamiliar gulf between you and your patient." The physical and psychological barriers of PPE coupled with the pressure of high clinical loads do not seem conducive to compassionate discussions about patients’ end-of-life preferences. Indeed, a study in Singapore during the 2004 SARS epidemic demonstrated the barrier posed by PPE to compassionate end-of-life care.

Clinicians may struggle to interpret existing ACPs in the context of COVID-19, given the unprecedented nature and scale of the pandemic and emerging clinical knowledge about the aetiology of the disease and (perhaps especially) about prognosis. This suggests the need for COVID-19-specific ACPs. Where possible, proactive planning should occur with high-risk patients, the frail, those in residential care and those with significant underlying morbidities. Ideally, ACP conversations should take place prior to illness, involve known health providers and carers, not be hampered by PPE or subject to time constraints imposed by acute care contexts. Of note here, a systematic review found that patients who received advance care planning or palliative care interventions consistently showed a pattern toward decreased ICU admissions and reduced ICU length of stay.

CONCLUSION

How best to address equity concerns in relation to ICU and end-of-life care for patients with COVID-19 is challenging and complex. Attempts to broaden clinical criteria to give patients with poorer prognoses access to ICU on equity grounds may ultimately lead to a worse death. The capacity for harm not just the capacity for benefit should be emphasised in any triage tools and related literature. Equity can be addressed more robustly if pandemic responses scale up investment in palliative care services, communication and decision-support services and advanced care planning to meet the needs of all patients with COVID-19. Ultimately, however, equity considerations will require us to move even further from a critical care framework as the social and economic impact of the pandemic will disproportionately impact those most vulnerable. Globally, we will need an approach that does not just stop an exponential rise in infections but an exponential rise in inequality.

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