

Dementia, frailty and triage in a pandemic

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I am grateful to the commentators for their deep engagement with the issues raised in my paper.(Wilkinson 2020) They raise a number of important challenges and questions about the use of frailty in triage decision making in intensive care. In this short response, I will discuss some of the empirical and contingent concerns with frailty assessments, disagreements about which ethical factors should or should not be incorporated into triage, and important questions about the harms of intensive care. I will draw on the following hypothetical case (an expanded version of a case suggested by Vinay et al).

*Max is a 66 year old man who has a past medical history of high blood pressure and diet controlled diabetes. He was diagnosed with Alzheimer's disease aged 59, and now has severe dementia and has been living in a nursing home for 6 months. He does not recognise family members and does not understand where he is. He can answer questions, though is often confused, and can no longer sustain a conversation. He requires full assistance with all personal cares.*

*In January 2021, he develops a fever, cough, and breathing difficulties and is diagnosed with COVID-19.*

*Max does not have an advance care plan.*

*Should intensive care admission be an option for Max?*

The fundamental aim of triage, whether on the battlefield, in the emergency department, or in intensive care, is to rapidly and reliably assess patients like Max who are presenting with medical need and then to ethically allocate medical treatment.

#### 1. Reliability of frailty assessment

Some commentators raised questions about tools like the Clinical Frailty Scale (CFS), used in some UK intensive care guidance. For example, McGreevy and Rhodes suggest that the CFS is at best a “broad phenotypic brush”.(2021) Feder et al and Reynolds et al, raise questions about the variability of such assessments – either between assessors, or for an individual patient, over time, if their condition and dependency fluctuates. These concerns may apply to only some ways of assessing frailty, and might be addressed by further empirical evidence. They do not lead to necessary rejection of frailty as a criterion in triage.

Clearly, we should use the most reliable clinical tools available, and those who use them should receive adequate training in their use. In the original paper, I highlighted the relative paucity of evidence about the reliability of the CFS. A more recent paper, has reported a very high level of inter-rater reliability in elderly ICU patients.(Flaatten *et al.* 2021) The CFS has also been shown to be valid and reliable for predicting 30 day mortality amongst patients presenting to an emergency department.(Kaeppli *et al.* 2020)

Batra and Latham cite important evidence that frailty can be reversed, perhaps particularly in younger patients. They use this to raise concerns about frailty's use in triage. As they note, there are potentially valuable interventions to prevent and address frailty (particularly in early or mild forms). But it is potentially a mistake to extrapolate this to the question of triage. If a frail patient is critically ill and in need of intensive care – we do not have any ability to acutely reverse their frailty. If they survive intensive care – they of course should have access to available beneficial therapies and rehabilitation. However, given their pre-existing frailty they are less likely to survive, and likely to be more frail afterwards.

These concerns about the reliability or prognostic significance of clinical frailty are perhaps greatest for milder degrees of frailty. This might converge with the suggestion that I made in the original paper that for reasons of value pluralism and parity,(Wilkinson and Savulescu 2018) milder levels of frailty may not be deemed grounds (on their own) for exclusion from intensive care. However, this would not apply to a patient like Max, whose condition is sadly unambiguous, and non-reversible.

## 2. What justification for triage?

If there were a decision not to offer Max intensive care treatment, that could be on the basis that he has a reduced chance of survival (for example, compared with patients of a similar age but without dementia), that if he survived, it would be for a shorter period of

time, or on the basis of his quality of life. Several commentators rejected some of these reasons.(Atkins and Das 2021; Batra and Latham 2021; Hortal et al 2021; McGreevy and Rhodes 2021; Reynolds *et al.* 2021) As I argued previously, health systems should be clear about their ethical rationale for triage and allocation of treatment to allow open debate within the wider community,(Orfali 2021) but also to allow triage to be applied consistently. The Clinical Frailty Scale equates the degree of frailty with dementia. However, as Vinay et al note, patients with greater degrees of dementia may or may not have other features of the frailty syndrome (loss of biological reserve, failure of homeostasis, vulnerability to intercurrent illness). It may be difficult to know Max's chance of survival if he required mechanical ventilation. There are reports of high mortality among patients with dementia who have had COVID,{Hariyanto, 2021 #4029} and more than 80% 1 year mortality for patients with advanced dementia receiving mechanical ventilation for pneumonia or septicaemia.{Sharma, 2020 #4030} But it is often difficult to separate out other confounding factors (such as comorbidity and age), as well as the impact of treatment limitation decisions (and self-fulfilling prophecies).

But although it is controversial, it is important to address directly whether the fact that Max has severe progressive cognitive decline is ethically relevant to a triage decision in the setting of highly limited resources. Imagine that we need to choose whether to admit to intensive care a patient like Max with severe underlying dementia, or another 66 year old (call him Jacob) with similar severity of COVID, but no dementia. A number of commentators appear to reject giving priority to Jacob on the grounds that this would be discrimination. As I noted previously, a decision to prioritise patients with a higher chance of survival is also discrimination, since to 'discriminate' is simply to choose between patients. But whether it would be just or unjust might depend on the level of resource shortage and

also on which ethical values we prioritise. If we have the option, we should of course expand our intensive care capacity to provide beneficial treatment to as many people as possible.(McGreevy and Rhodes 2021) But such efforts have opportunity costs (including the impact on patients with non-COVID related illness), and they have limits. We need to decide what to do once we have reached those limits.

One reason for choosing to treat Jacob rather than Max is because the former would benefit more from successful treatment. As commentators point out, there are serious challenges in comparing the value or benefit of life-prolonging treatment between patients. Health professionals should be extremely cautious about making such judgements. But some comparisons are more clear-cut than others. It is not seriously questionable whether in general survival for 20 years is better than survival for 2 years. If our health system had to choose between two different treatments (one of which prolonged life for 2 years, the other for 20 years), we would not be equivocal or ambivalent about such a choice. Of course, there can be exceptions, individual cases where it would be better to survive for a shorter rather than a longer time. But such exceptions do not invalidate the general judgement, nor a policy about allocation of highly limited resources. Similarly, there is no genuine uncertainty about whether life with severe dementia is less of a benefit than life without dementia.<sup>1</sup> That is not to deny the value of life to those with severe dementia. If resources are available, if the benefits of the specific treatment outweigh the risks, (and if they would have wished it) they should receive life-sustaining treatment. However, if we are forced to choose between treating Max or Jacob, whether that is for allocation of an intensive care

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<sup>1</sup> To be clear: the claim is about benefit or value *to the individual*, not about the benefit or value to others. Reynolds et al argue that following the insights of the 'mere difference' view, disabilities do not necessarily have a negative prudential effect on a person as a whole. However, as they acknowledge, the view that cognitive disabilities (and perhaps particularly severe or profound cognitive disabilities) are 'mere differences', rather than 'bad differences' is much more controversial.(Reynolds *et al.* 2021)

bed, or a solid organ for transplantation or extra-corporeal membrane oxygenation, it would be, in the views of many, wrong to simply toss a coin to decide. Empirical evidence does not resolve the ethical question, but recently we gave 763 members of the UK general public a series of hypothetical scenarios to assess their views on the factors which should be included in ventilator triage in a pandemic. A considerable majority of respondents chose to allocate treatment to patients who would have a higher chance of survival, longer life expectancy or a lesser degree of frailty.{Wilkinson, 2020 #3954} We did not ask specifically about dementia, but in a scenario potentially similar to the choice between Max and Jacob, 74% of respondents chose to allocate treatment to a non-disabled patient rather than one with profound cognitive disability.

### 3. Harms and triage

A different (though related) reason to treat Jacob rather than Max is because of a lower risk that Jacob would be harmed by such treatment. Feder et al, in their thoughtful commentary, highlight the potential harms that are associated with critical care in the setting of an illness like COVID.(Feder et al 2021)

Those of us who work in intensive care are intimately aware with the risks of such treatment. By its nature, and notwithstanding our best efforts to provide analgesia and sedation, intensive care is intrusive and often deeply unpleasant. In the short term, Max, by virtue of his underlying illness, would be at higher risk of a range of specific complications including multi-organ failure, bleeding, thrombosis, pressure sores, nosocomial infection, and ICU delirium among others. Those complications would be part of the reason why he would be less likely than other patients to survive. They would contribute to the burden of treatment that Max would experience while in intensive care. If he were to survive, they would make recovery more difficult for him.

These harms are clearly relevant to discussions that might be had with Max's family about treatment options in the setting of his severe COVID and whether in fact it would be in his best interests to take him to intensive care. Feder and colleagues talk about the value of offering palliative care as a first-line option, not merely as a second-best alternative if intensive care is not available. As they point out, it is crucial for clinicians to talk openly, sensitively and honestly with families about the potential benefit and harms of different treatment options. Taking a palliative approach to Max's care would protect him from treatments that could cause considerable harm, ensure that he is comfortable, and increase the chance that, if (as we might suspect) this is his final illness, he experiences what he and his family might consider a "good death".

Good communication and advance care planning can avoid some rationing dilemmas, and might avoid difficult decisions for Max. However, there are considerable challenges. As Hortal et al point out, public misunderstanding and fears in the setting of a global pandemic and headlines about resource shortages may lead patients to request active treatment out of a fear of abandonment. That leads us back to the central question of the paper, a question that will remain relevant beyond this pandemic. What do we do when we have more patients choosing (and potentially benefiting) from intensive care than we have available capacity? How should we decide between them? Patient frailty is by no means the only factor that should be included in decision-making. But it is one important, useful and relevant consideration.

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