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Best interests versus resource allocation: could COVID-19 cloud decision-making for the cognitively impaired?

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ABSTRACT
The COVID-19 pandemic is putting the NHS under unprecedented pressure, requiring clinicians to make uncomfortable decisions they would not ordinarily face. These decisions revolve primarily around resource allocation in intensive care units (ICUs) and whether a patient should undergo invasive ventilation. Certain vulnerable populations have featured in the media as falling victim to an increasingly utilitarian response to the pandemic—primarily those of advanced years or with serious existing health conditions. Another vulnerable population potentially at risk is those who lack the capacity to make their own care decisions. Owing to the pandemic, there are increased practical and normative challenges to following the requirements of the Mental Capacity Act 2005. Both capacity assessments and best interests decisions may prove more difficult in the current situation. This may create a more paternalistic situation in decisions about the care of the cognitively impaired, which is at risk of taking on a utilitarian focus. We look to these issues and consider whether there is a risk of patients who lack capacity to make their own care decisions being short-changed.

INTRODUCTION
The COVID-19 pandemic is putting the NHS under unprecedented pressure, requiring clinicians to make uncomfortable decisions they would not ordinarily face. These decisions revolve primarily around resource allocation in intensive care units (ICUs) and whether a patient should undergo invasive ventilation. Certain vulnerable populations have already featured in the media as falling victim to an increasingly utilitarian response to the pandemic. Those of advanced years or with serious existing health conditions are being deprived of care, and in some cases have had DNACPR notices applied pre-emptively and without consultation. A further vulnerable population potentially at risk of such treatment during the pandemic is those who lack the capacity to make their own care decisions.

Cognitively impaired patients have their rights protected by the Mental Capacity Act 2005 (MCA 2005). However, owing to the pandemic, there are increased practical and normative challenges to following the requirements of the Act. Capacity assessments to determine the need for best interests decisions, as well as the best interests decisions themselves, are likely to prove more difficult in current circumstances due to a variety of obstacles. This may create a more paternalistic situation in decisions about the care of the cognitively impaired, which is at risk of taking on a more utilitarian focus. We look to these issues and consider whether there is a risk of patients who lack capacity to make their own care decisions being short-changed. Further, we suggest that a lasting impact on the care of cognitively impaired patients is a realistic expectation. As a result of these concerns, we assert the need for clinicians to remain aware of the requirements of the MCA 2005 and continue to promote the rights of patients who lack decision-making capacity even during the unprecedented pressures of the pandemic.
of patients in regaining laryngeal function following intubation and ventilation. Doctors may not, for these reasons, be able to take ‘all practicable steps’ as they usually would. It is also likely that their own ability to communicate with patients will be impaired, and the importance of both verbal and non-verbal communication has long been emphasised. Although the use of personal protective equipment (PPE) is necessary to reduce cross-infection, wearing masks and eyewear may further disorientate a confused patient in an unfamiliar environment. The use of PPE may also be challenging for patients who, for example, are hard-of-hearing and reliant on their ability to lip-read. There is, then, reason to be concerned that incapacitous patients may be identified as lacking capacity following suboptimal capacity assessments, and best interests decisions may be made inappropriately on their behalf. This would undermine such patients’ autonomy.

BEST INTERESTS PRACTICALITIES
Under the MCA 2005, patients who lack capacity to make decisions about their own care must have the decision made in their best interests, and the decision-maker would usually be the doctor providing treatment and care. The decision-making process requires that doctor to consult with those who know the patient well, which usually means close relatives. Any decision made must not be based on the fact that the patient lacks decision-making capacity. If a patient is deemed to lack capacity and the requirements of the MCA 2005 become applicable, a new set of obstacles present themselves. Amidst the pressure of the pandemic, the process of making a best interests decision is complicated.

One issue is staff redeployments. Clinicians from various fields are being moved to ICUs and required to work outside of their usual remit. ICUs may currently be leaving specialist care decisions to those from relevant specialties with the necessary expertise, but it is possible that during the peak of the pandemic the finite number of such specialists will be insufficient to do so. There are also concerns that this shortage may be worsened by late presentations not related to COVID-19. Seeking not to over-read. There is, then, reason to be concerned that capacitous patients may be identified as lacking capacity following suboptimal capacity assessments, and best interests decisions may be made inappropriately on their behalf. This would undermine such patients’ autonomy.

Assuming there is no legally appointed proxy decision-maker.

BEST INTERESTS VERSUS RESOURCE ALLOCATION
Resource allocation is the issue receiving the most attention in the bioethics space at present. This focus is necessary, but where it infringes on ethical values it is just as necessary to question the ethical robustness of approaches. Side-lining the best interests of cognitively impaired patients is not appropriate, and care should be taken to avoid this.

Efforts to better allocate scarce resources have already led to unpalatable decisions. A GP surgery in Wales recently wrote to a number of its patients with significant illnesses asking them to complete DNACPR forms, explaining to them that this would allow scarce ambulance resources to "be targeted to the young and fit who have a greater chance". Residents of several care homes in both Wales and East Sussex have also had DNACPR notices applied to their care plans as a blanket policy without having been consulted. Both of these decisions have been criticised as inappropriate, and they clearly show that the relative value of the more vulnerable members of society is being brought into question.

As tactless as they may have been, the main factors driving many of these moves were justified, namely comorbidities. This is reflected in the National Institute for Health and Care Excellence’s (NICE) COVID-19 guidance on critical care for adults which clarifies that comorbidities and underlying health conditions ought to be considered in all cases. While the GP surgery and care home examples were not directly best interests decisions, it is probable that at least some of the patients and residents would have lacked capacity to consent to a DNACPR notice. It is also worth noting that NICE recently faced heavy criticism, and were threatened with judicial review for advocating the use of
the Clinical Frailty Scale (CFS) to determine the suitability of all adults for hospital treatment in their initial COVID-19 guideline for critical care.11 Through this scoring system, a person unable to carry out high-order, independent activities of daily living would be scored ‘5’, thereby classifying them as ‘mildly frail’. The NICE guideline suggested that it may not be appropriate to provide patients with a score of 5 or more with hospital treatment. This classification was thought to unfairly discriminate against individuals with stable cognitive impairment, such as those with learning disabilities or autism. The CFS has since been declared as unsuitable for assessing frailty in patients with learning disabilities or under the age of 65. Instead, an individualised approach to assessing escalation of treatment has been deemed necessary, in consultation with family and/or paid carers.14 However, the utilisation of the CFS in the initial guideline demonstrates that the pressure to develop rapid national guidance has resulted in considerations of its application being overlooked, particularly in relation to vulnerable populations.

A recent case in the EWCOP, University Hospitals Bristol NHS Foundation Trust v ED,9 sought declarations that it would be lawful for ED’s treatment not to be escalated if her condition deteriorated. ED’s doctors opposed escalation in the form of CPR or ICU admission on the basis that they do not consider it in the patient’s best interests, with Mr Justice Moor noting in his judgement that one “says that this is not about rationing ICU beds. It is a best interests decision that he and Dr DF are agreed upon”. However, it ought to be questioned what role resource allocation may have played in this decision.

ED had previously been admitted to the ICU on several occasions and had three tracheostomies. On these occasions, no declaration from the EWCOP was sought. It was during a pandemic that is putting pressure on ICUs that the patient’s doctors felt it would be in ED’s best interests not to receive such care. That is not to say that the decision of the doctors was not made in the best interests of the patient, but it is possible that it was at least slightly influenced by pandemic considerations. Extrapolated, this could be interpreted in three ways:

1. The pandemic is prompting doctors to think more about rationing, which may result in the devaluing of the lives of patients who lack decision-making capacity and decisions not being made in their best interests (if one believes the doctors in this case were incorrect);
2. The pandemic is prompting doctors to think more about advance care planning (ACP), but merely as a practical consideration with no view to the pressures of the pandemic affecting the care a patient will or will not receive;15 or
3. The pandemic is prompting doctors to think more about rationing, which may result in patients who lack decision-making capacity having decisions made which happen to be more so in their best interests (if one believes the doctors in this case were correct).

It is possible, and indeed most likely, that all three are happening as a result of the pandemic. However, the second interpretation is the only one that is ethically reconcilable. Interpretations (1) and (3) are allowing the pandemic to affect the care of patients who lack decision-making capacity. Even if it is affected for the better—meaning interpretation (3) resulting in decisions being made in the best (better?) interests of the patient—it is still an instance of a preoccupation with resource allocation affecting care, which is concerning. Interpretation (2), however, is neutral in this regard and is therefore ethically reconcilable. An ACP would allow a patient who has decision-making capacity to take a more active part in decisions about their care when first admitted to hospital, and prepares for the likely event they lose that capacity.15 Assuming there is no attempt to persuade a patient in a particular direction, this would both enhance the autonomy of the patient before their situation deteriorates and relieve some pressure on clinical staff at a critical time for the NHS.

Yet there is evidence of how the pandemic has already compromised best interests decisions in social care. In order to increase bed capacity in acute NHS hospitals, the Coronavirus Act 2020 established that there is no longer a legal duty to provide NHS Continuing Healthcare (CHC) assessments to determine the care and residential needs of patients who are medically fit for discharge from hospital. Without these assessments, patients may be discharged into an environment over which they have little choice. While hospitals will have a duty to ensure they are discharged into a safe environment which meets their care needs (for example, home with a care package or a community hospital), patients have temporarily lost access to the mechanism through which they can explore their care or residence options free of charge. This emergency legislation has been justified in the context of the pandemic, serving the greater purpose of freeing up acute hospital beds. However, the impact of this on patients who lack the capacity to make decisions on their discharge is particularly concerning. As Ruck-Kene notes, there is considerable overlap between patients with impaired decision-making capacity and continuing healthcare needs, and their discharge options have been significantly narrowed by this legislative change.16 Rather than a multidisciplinary exploration of the values and preferences of the patient, in which the views of consultees are taken into account, a decision will be made by the patient’s medical team to ensure the patient’s safety and facilitate a quick discharge. Though these patients will have access to CHC assessments following the emergency period, there will inevitably be a backlog creating further delays in determining what care and residential support is in the patient’s best interests.

The demands of the pandemic have affected the ability of the NHS to provide care in general. As we hit the peak, it is unlikely that all patients will be able to receive life-saving care and yet more difficult decisions will have to be made. For instance, decisions about the discontinuation of the treatment of patients already receiving intensive care will have to be made. In such situations, Wilkinson reinforces the equivalence thesis in noting no difference between withholding and withdrawing treatment ceteris paribus.17 When this point is reached, cognitively impaired patients ought not to receive special treatment, but also not lesser treatment on the basis of their impairment. Doctors making decisions about the continuation of intensive care for cognitively impaired patients during the pandemic should be especially conscious of any resource allocation influence.

**LASTING IMPACT?**

Decisions being made in the NHS during the pandemic are being made very much in the context of the pandemic. The situation is, arguably, necessitating a utilitarian outlook to respond to the questions of resource allocation. One would hope, therefore, that things would return to ‘normal’ afterwards. Is this a realistic expectation, though?

10The original guidelines have since been updated.
11This interpretation might only be considered more broadly as it is unlikely to apply to the case discussed. In the case, the patient is cognitively impaired to the extent that she is unlikely to be able to meaningfully participate in ACP.
If a decision is made which is not in the best interests of a patient during the pandemic, and this is not a single occurrence, it begins to devalue the lives of patients who cannot make their own care decisions. Not providing care on a utilitarian basis, factoring in the patient’s cognitive impairment, is against the principles of the MCA 2005. Indeed, it begins to erode the rights of these patients under the United Nations Convention on the Rights of Persons with Disabilities.\(^1\)

What seems more realistic, then, is that this will have a lasting impact. That is not to say that there will be a prevailing assumption that patients who lack decision-making capacity ought not to receive intensive care. Such a situation has not arisen amidst the pandemic and is unlikely to. Rather, the basis that a cognitively impaired patient ought not to have their care affected because of that impairment may be undermined. There could be a mirroring of decisions made during the pandemic outside of emergency situations in the future, with doctors questioning more the value of invasive procedures to preserve the life of such patients.

**CONCLUSION**

There is no doubt that the COVID-19 pandemic is necessitating difficult decisions, and expecting any part of the NHS to operate as it usually does is unrealistic. Nonetheless, there are certain values which should not be easily side-lined, including the protection of the right of patients lacking decision-making capacity to have decisions about their care made in their best interests. Early responses to the pandemic have demonstrated a devaluing of the more vulnerable in society. Coupled with the practical difficulties facing the best interests process, we suggest that there is a very real risk of decisions being made which are not in the best interests of cognitively impaired patients—especially if such patients become infected with the virus and require invasive respiratory support.

This is not an assault on doctors. Doctors are under immense pressure handling the pandemic and have spoken out about how uncomfortable they are with some of the decisions they are being forced to make, especially given the lack of national guidance that patients who lack decision-making capacity ought not to have their care affected because of that impairment may be undermined. There could be a mirroring of decisions made during the pandemic outside of emergency situations in the future, with doctors questioning more the value of invasive procedures to preserve the life of such patients.

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