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Equality or utility? Ethics and law of rationing ventilators

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It is predicted that there will be a severe shortage of ventilators in coming weeks for the respiratory support of patients severely affected by coronavirus disease 2019 (COVID-19). The National Institute for Health and Care Excellence (NICE) has recently issued guidelines that set out decision-making procedures for allocation of intensive care and ventilation.[1] These essentially state that factors that affect the probability of survival, such as frailty in older patients, are relevant, but it eschews consideration of factors, such as age, length of life, quality of life, and disability. Following criticism, NICE explicitly clarified that frailty scores should not be used to inform decisions in patients younger than 65 yr, or with a stable learning disability.[2]

In ethics, there are two broad approaches to this problem: egalitarianism and utilitarianism. According to egalitarianism, every person should be treated equally according to need: equal treatment for equal need. Philosopher John Harris argues that each rational person wants at least three things from healthcare: (i) the maximum possible life expectancy for him or her, (ii) the best quality of life for him or her, and (iii) the best opportunity or chance for him or her of getting both (i) and (ii).[3] Treating people as equals involves giving equal weight to each person's own claim. As Harris recognised, a principle of equality cannot only be selectively invoked by those with disability (on pain of itself being discriminatory), but also applies to those who happen to have poor prognoses or diseases that are expensive diseases to treat.[4]

The UK National Health Service (NHS) is founded on egalitarian principles. The first principle of the NHS constitution states, 'The service is designed to improve, prevent, diagnose and treat both physical and mental health problems with equal regard.'[5] Equality of access requires that we ignore the probability of a patient benefiting from treatment. However, this is inconsistent with accepted practice. For example, every day, older women in Britain are denied access to *in vitro* fertilisation (IVF) because they have a lower chance of a successful outcome.[22] IVF is rationed very clearly on the basis of age, with treatment not provided to those over the age of 39 because it is highly unlikely to be successful. This is considered a proportionate means of ensuring the maximum benefit is derived from limited IVF resources.

Egalitarianism requires only consideration of need. It rejects consideration of probability, length, or quality of life. As John Taurek[6] famously argued, faced with the decision to rescue five people or one, we should toss a coin because that gives everyone an equal chance of what matters most to him or her: their life. When not everyone can be saved, egalitarianism requires lotteries or other procedures to fairly allocate resources.

In contrast, according to utilitarianism, the right course of action is that action which maximises utility, or the good

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Table 1 Approaches to distributive justice. NICE, National Institute for Health and Care Excellence.

	Egalitarianism	Utilitarianism	NICE guidance
Probability of survival	−	+	+
Length of life	−	+	−
Quality of life	−	+	−

produced. English philosopher Jeremy Bentham is the father of utilitarianism and is famous for his phrase, 'the greatest good for the greatest number'.

Utilitarianism requires consideration of the probability of success, length, and quality of life. Utilitarianism is actually at the heart of the NHS and the allocation of medical resources. The quality-adjusted life year (QALY) used by Clinical Commissioning Groups (CCGs) is a measure of the utility of medical treatments. It is a year of life adjusted by its quality. The cost per QALY of £20 000 to £30 000 limit is a utilitarian, not egalitarian, limit. (It is worth noting that every country has a limit on how much it spends on a treatment.)

The current practice guidelines issued by NICE are neither utilitarian nor egalitarian. They differentiate between people on the basis of probability of survival (as predicted, supposedly, by frailty), but not length or quality of life (Table 1). This will maximise the numbers of lives saved, but not give everyone an equal chance, nor will it maximise the good of the outcome in terms of years of life saved, adjusted for their quality.

Other relevant considerations

Clinical decisions are focused primarily on the interests of the relevant patient. Determinations about appropriate treatment options focus on whether the burdens of the treatment are likely to be outweighed by the potential benefits. For some patients, the burden of ventilation will not be outweighed by the potential benefits becuase of the patient's prognosis. These patients should not be provided ventilation because it would not be in their interests. The focus of this article though is patients who are likely to experience an overall benefit from ventilation. If COVID-19 does result in a shortage of ventilators, difficult decisions will need to be made about which patients should receive this benefit. This becomes a question of distributive justice, in which concerns beyond the immediate patient must be considered.

If Peter's chance of survival with treatment is 30% and Paul's is 40%, then equality of opportunity requires tossing a coin (or some kind of lottery). Indeed, even if Zak's chance is 1%, equality still requires he gets an equal chance of the best outcome for him (provided it is in his interests). Decisions to prioritise those who are most likely to benefit are based on a utilitarian approach that seeks to maximise benefits.

Operating within a constrained system

A doctor's duties are ostensibly egalitarian, in the sense that they are required to treat each patient in accordance with their clinical need. A doctor has a 'duty to provide a treatment that he [sic] considers to be in the interests of the patient and that the patient is prepared to accept'.[7] The patient's views and values must inform the identification of treatment options. A patient 'is entitled to decide which, if any, of the *available* forms of treatment to undergo' (emphasis added).[27,28] The doctor is not under an obligation to provide medical treatment just because a patient demands it.[8] A doctor's duty must be understood in the context in which a doctor provides treatment and the treatments that are available. Doctors frequently make judgments about the just allocation of limited resources.

These often masquerade as judgements of futility.[9] It is also important to recognise that considerations of probability of outcome are inegalitarian.[10]

Whilst doctors may focus on the clinical need of their patients, they work in a system that relies on utilitarian principles. Decisions in the NHS must be made to ensure limited medical resources are allocated ethically, efficiently, and effectively.[11] The courts have repeatedly acknowledged that healthcare is a limited resource and that difficult decisions must be made to ensure these resources are used effectively. The case of R v Cambridge Health Authority, ex parte B is illustrative of this. The case involved a 10-yr-old child with cancer, for whom previous treatments had been unsuccessful and whose parents were seeking two phases of treatments that each had around a 10% chance of success and would cost £75 000. The Health Authority had determined it would not fund the treatment. Sir Thomas Bingham recognised '[d]ifficult and agonising judgments have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients'.[12]

It has been recognised that there is a wide discretion for the state to determine how resources should be appropriately allocated and that Article 8 of the European Convention on Human Rights 'does not give a patient a right to any particular type of medical treatment from the State, given the fair balance that has to be struck between the competing interests of the indivdual and society as a whole'. [13]

In the NHS, CCGs determine the broad categories of health services that will be purchased and NHS Trusts provide those services in accordance with the agreed standards.[14] In purchasing appropriate services, there is not an absolute duty to provide particular services, and the CCG is 'entitled to have regard to the resources available to it'.[15] Just because a treatment would offer a patient a clinical benefit, this does not mean it must be provided, 'the need to demonstrate clinical effectiveness and value for money is only the first stage in assessing priority'.[16]

Discrimination

The Critical Care National Clinical Reference Group, who authored the NICE guidance, recently released a statement that provides background to the NICE guidance. It suggests, 'It is not appropriate to ask clinical staff to make rationing decisions (i.e. make value judgements as to whether one person has a more established case for treatment based on ethical considerations alone) as this introduces considerable potential for introduction of unconscious bias and inconsistency in decision-making'.[17] The document goes on to discuss that it is unlawful to make decisions on the basis of age alone.[17] The statement clearly arose out of concern about suggestions made in the media that people over a particular age should not

receive intensive care treatment during the COVID-19 crisis.[18] This followed suggestions in Italy that patients over the age of 80 yr might not be admitted to intensive care.[29]

As the Critical Care National Clinical Reference Group's statement suggests, it would be unlawful to make decisions solely on the basis of age or disability. The Equality Act 2010 provides it is unlawful to discriminate, either directly or indirectly, on the basis of protected characteristics. Two characteristics relevant to this discussion are age and disability.[19] Direct discrimination on the basis of age or disability occurs if a person is treated less favourably because of their age or disability.[20] Disability is defined as a physical or mental impairment which has a substantial and long term adverse effect on the person's ability to carry out day-to-day activies.[19] The Act applies to the provision of health services in the NHS.[21] Enactment of a policy to give preferential access to intensive care on the basis of age or lack of disability appears to be *prima facie* discrimination. For example, if a policy were implemented that people over the age of 80 with COVID-19 should not be admitted to the ICU, people over the age of 80 will be disadvantaged on the basis of their age.

This gives rise to the question of whether a policy of not providing intensive care treatment based on age or because of something arising in consequence of a disability during a pandemic is a 'proportionate means of achieving a legitimate aim'.[20] It has been recognised in relation to age-based discrimination in employment that governments should be 'accorded a margin of discretion when it comes to assessing proportionate means'.[23] Further, direct age based discrimination may be justified on the basis of 'social policy objectives'.[24] Any measures must be appropriate to achieve the legitimate aim and necessary to do so, and that the gravity of the effects of the discrimination must be weighed against the importance of the legitimate aims.[24] If there are insufficient intensive care resources, difficult decisions will need to be made, often in a short amount of time, about who should receive the available resources. Age and reduced capacities arising from disability are two factors that may indicate a reduced probability of benefitting from intensive care treatment, because of a reduced probability of survival and life expectancy. In light of the reduced probability of benefits relative to the rest of the population, it may be argued that discriminating is a proportionate means of achieving a legitimate aim. The legitimate aim is maximising the benefit that can be obtained from limited intensive care resources. It may be argued the measure is proportionate because it provides an effective criterion for making fast decisions using objective criteria.

It is, however, unlikely that this argument would be accepted because age-based or disability related thresholds are not proportionate. This is because they are not necessary to achieve the aim, and the consequences for those not provided treatment are grave. The aim of ensuring the benefits derived from treatments are maximised may be achieved by assessing the likely effectiveness and outcomes for each individual. Whilst age or disability may be indicative at a population level of a reduced benefit, at an individual level they are imprecise and there are a range of other potentially relevant factors.

More targeted and proportionate approach

Whilst it may be unlawful discrimination to exclude people over a particular age or with a particular disability from accessing treatment, this does not necessarily preclude a utilitarian approach. A utilitarian approach seeks to ensure the greatest good to the greatest number. The NICE guidance states that frailty and co-morbidity should be relevant considerations to assess the likelihood of survival, suggesting probability of survival should be considered in determining whether treatment should be provided. This would not be directly discriminatory because, although age or disability may impact an assessment of the probability of survival, it is the probability of survival that is determinative. As identified above, this concern with probability of survival stems from a utilitarian concern that treatments be used in a way that will maximise the number of people who will survive.

If this approach is accepted, then it is not clear why further measures would not be used to maximise utility. This could include considering the *length of life* available to the person. This would not be directly discriminatory because if the person's age were changed but their life expectancy did not, then the decision would not be different.

> If Bob was 80 and had a life expectancy of 8 yr and John was 40 and had a life expectancy of 48 yr, it may be argued that John should be given priority. This would provide 40 years of additional life rather than 5 years. This is only using age as a proxy for what is actually at issue - life expectancy. If John was only expected to live one year, it would make sense to prioritise Bob. Age is not necessarily indicative of life expectancy.

It may be argued that quality of life could also be considered. It could similarly be argued that this would not constitute direct discrimination because a person with a disability would be treated the same way as a person without one if they had the same quality of life. The difficulty for this position is that assessments of quality of life generally appear to be intrinsically linked to disability. For example, QALY assessments identify reduced quality of life through disability. If an assessment of quality of life was nothing more than an assessment of the level of a person's disability, then making decisions on this basis would constitute direct discrimination. However, if the assessment could be conducted on some other basis (e.g. the person's subjective assessment of their quality of life) or with other relevant factors, it may not necessarily constitute direct discrimination. Ultimately, this would depend on whether it was considered a proportionate, and a measure that overtly devalued the lives of people with disabilities is unlikely to be considered proportionate.

Indirect discrimination

Although criteria based on length of life and quality of life do not necessarily constitute direct discrimination, it may be argued that making decisions on this basis constitutes indirect discrimination in relation to age and disability. Indirect discrimination occurs when a criterion or practice would place a person at a comparative disadvantage to someone who did not share the protected characteristic.[25] Decisions made on the basis of life expectancy and quality of life are indirectly discriminatory because older people and people with some disabilities will be placed at a disadvantage if those with a greater life expectancy or greater quality of life are preferred. If this argument is accepted though, it must also be recognised that making assessments on the basis of frailty to determine the probability of survival may equally constitute indirect

discrimination. Older people and people with particular disabilities will be assessed as more frail and are less likely to survive COVID-19. Whilst criteria for length of life and quality of life are likely to be *prima facie* indirect discrimination, so too is the NICE guidance's probability of survival.

This leaves the question of whether this is a proportionate response to a legitimate aim. All three considerations appear to have the same aim, ensuring limited resources are used effectively and efficiently by ensuring the maximum possible benefit is derived. This is plainly a legitimate aim: the NHS is required to allocate resources ethically, efficiently, and effectively.[11] So, are the three considerations proportionate to achieving this aim? In relation to each consideration, the answer may be that it depends on the extent to which they are imposed. For example, in relation to probability of survival, it may be proportionate to prefer a person with a 90% chance of survival over a person with a 5% chance of survival, but it may not be proportionate to prefer a person with a 40% chance of survival over a person with a 30% chance. In relation to length of life, it may be proportionate to prefer a person who is likely to live 40 yr over a person who is likely to live 6 months, but it may not be to prefer a person who is likely to live 10 yr over a person who is likely to live 8 yr. In relation to quality of life, it may be proportionate to prefer an otherwise healthy person over a minimally conscious or unconscious person, but it may not be proportionate to prefer a person who is blind over one who is not.

Taking a purely utilitarian approach may constitute indirect discrimination. But this may be the case whether the relevant consideration is probability of survival, length of life, or quality of life. If NICE is willing to accept one of these as a relevant consideration (probability), it is not clear why all of them would not be considered. What is important is that they are considered in a proportionate manner.

Precautionary utilitarianism

To achieve this proportionality, we suggest that what may be described as 'precautionary utilitarianism' should be adopted. This approach would give some weight to ensuring equality of opportunity, recognising that people should not be discriminated against arbitrarily. But it would still recognise that decisions should be made to go some way towards the greatest good for the greatest number. A consequence of this may be that some groups are placed at a disadvantage in accessing treatments. But this is only because they would derive significantly less benefit from the treatments. If the difference in the benefit they would derive would be marginal, it may not be acceptable to differentiate between people on this basis. This means more minor differences in probability, length, or quality of life should be ignored, but more significant differences should be relevant. Strictly, such an approach would be consequentialist but not utilitarian, because it does not fully maximize the good. We use the word "utilitarian" as it is more familiar in popular discourse.

The proposed precautionary utilitarian approach appears to be consistent with lay attitudes to determining how limited medical resources should be expended. In a survey of lay attitudes, Arora and colleagues[26] found that participants generally preferred to direct treatment to patients with a higher chance of survival, higher life expectancy, and less severe disability. However, they also found that as the relevant differences between the patients decreased, participants were more supportive of an egalitarian approach.[26]

Conclusions

The NICE guidance purports to adopt an egalitarian approach to the provision of ventilation during a potential shortage arising from COVID-19. Despite this, it introduces the utilitarian consideration that treatment should be provided to those with the greatest probability of survival. The guidance provides no justification for this theoretical inconsistency and instead suggests that the introduction of further utilitarian considerations would be unlawful discrimination.

The NICE guidance and the Critical Care National Clinical Reference Group appear to oversimplify the questions of discrimination in order to draw a false distinction between the type of rationing they condemn and the rationing they encourage. The Critical Care National Clinical Reference Group equates rationing on the basis of a single issue (which would be unlawful discrimination) with all rationing. A more nuanced approach to rationing that is aimed at maximising the benefits derived from limited resources would not be discriminatory, provided the focus was on a clinical assessment of the person and the likely benefits they would derive from the treatment. The only criterion that may be unlawful is quality of life. This is because of the way quality-of-life assessments are generally conducted in practice, with disability centrally linked to an assessment of a reduced quality of life. Despite this, the suggestion that any utilitarian approach would lead to unlawful discrimination is unsustainable.

The current NICE guidance provides an unstable compromise between egalitarianism and utilitarianism. Instead, a precautionary utilitarian approach should be adopted. This would recognise the importance of striving towards the greatest good for the greatest number, but it would also recognise that, in circumstances in which there is little net gain in discriminating based on a relevant factor, people should be treated equally. We should consider, to some degree, not only the probability of achieving a beneficial outcome, but also the value of that outcome. It is ethically justifiable to give lower priority to patients who will have a significantly lower chance of survival, and also those who will have a significantly reduced length or quality of life. This strikes a balance between equality and utility.[10]

The Critical Care National Clinical Reference Group claims, 'It [NICE guidance] explicitly states that Critical Care clinicians are the primary decision makers with respect to the provision of Critical Care treatments'. This is right. But their claim that clinicians should not ration limited treatments is wrong. When they make decisions on the basis of probability of beneficial outcome by appeals to frailty or co-morbidities, they are rationing. Such rationing decisions are best made by clinicians in possession of all the relevant facts. But they need to be guided in those decisions by ethical principles. Those principles should balance equality and utility. Those principles should be proportionate and consider probability, length, and quality of life when these are severely diminished.

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Drafting of legal section: JC
Drafting of ethics section: JS
Editing of article: DW
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Declaration of interest

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