

DISABILITY DISCRIMINATION IN EMERGENCIES: THE RETURN OF TAUREK?

DISCRIMINAÇÃO POR DEFICIÊNCIA EM EMERGÊNCIAS: O RETORNO DE TAUREK?

BEN DAVIES¹

(University of Sheffield, England)

ABSTRACT

John Taurek famously advocates an unpopular view in ethics: when deciding whom to rescue, *the numbers don't count*. We should instead give everyone the same chance of surviving by choosing at random. Surprisingly little engagement has taken place between the detailed and rich literature on whether the numbers count in rescue cases, and the practical question of whether certain facts about patients are eligible for consideration in real-world prioritisation, e.g., in emergency triage during a pandemic. I suggest that a position close to Taurek's maps on to real-world arguments by groups representing disabled individuals. Whereas Taurek is focused on equalising *survival chances*, some disability rights activists and scholars appear to argue in favour of equalising *selection chances*. I construct an argument in favour of this position by appealing to the idea of "opacity respect". I then consider the implications of this approach for broader principles of affirmative action in healthcare.

Keywords: Healthcare Ethics; Prioritization; Respect; Disability.

RESUMO

John Taurek defende, de forma notória, uma visão impopular na ética: ao decidir quem resgatar, *os números não contam*. Ao invés disso, devemos dar a todos a mesma chance de sobreviver escolhendo de forma aleatória. De forma surpreendente, tem havido pouco debate entre a literatura rica e detalhada sobre se os números contam em casos de resgate e a questão prática de saber se certos fatos sobre os pacientes são elegíveis para consideração na priorização do mundo real, por exemplo, na triagem de emergência durante uma pandemia. Sugiro que uma posição próxima da de Taurek mapeia os argumentos do mundo real por parte de grupos que representam indivíduos com deficiência. Enquanto Taurek se concentra na equalização das *chances de sobrevivência*, alguns ativistas e acadêmicos dos direitos das pessoas com deficiência parecem argumentar a favor da equalização das *chances de seleção*. Construo um argumento a favor desta posição apelando à ideia de "respeito opaco". Considero, então, as implicações desta abordagem para princípios mais amplos de ação afirmativa nos cuidados de saúde.

Palavras-chave: Ética da Assistência à Saúde; Priorização; Respeito; Deficiência.

Introduction: Numbers and probabilities

John Taurek's 1977 paper, 'Should the numbers count?' presents a claim that is as unpopular as it is well-known in contemporary analytic philosophy. That claim is that when we are confronted with a situation where we must choose which lives to save, the numbers involved should not 'count'. For instance, the captain of a ship is called to an emergency, and faces a choice between sailing to the north of an island to rescue a large group of people, or to the south where a much smaller group has gathered. The captain knows that whichever group she chooses to sail to first, the rising waters make it likely that the others will drown. Contrary to most people's intuitive response, Taurek argues that the fact that one option will save many more lives than the other should not be a decisive factor in the captain's decision. What the captain should do instead, he argues, is flip a coin; the reason for this is that it gives each individual an equal chance to survive (see Peterson 2008; Miller Tate forthcoming for similar ideas related to pandemic ethics; see Lang and Lawlor 2016 for a challenge to this being Taurek's view). Opting automatically for the greatest number gives some individuals—those in the smaller group—a much lower survival chance than others.

I suggest that this paper and the resulting exchange since it was published has some implications for a real-world debate, around the use of survival chances in emergency ICU admissions, and the claim that this discriminates against individuals with disabilities. I will explore some of the claims that were made by disability rights groups and representatives about the problems with approved triage methods used during the Covid pandemic, and to consider what ethical principles might best reflect those concerns. I will take several influential statements of disability rights in the pandemic, all drawn from the United States. I do not take these to represent the views of all disabled people, or of all people concerned with the rights of disabled people. But they represent an important idea that requires some consideration.

A brief note on Taurek before I proceed. While Taurek's best-known example is the ship's captain, he introduces his paper by considering a case with more direct applicability to triage: he asks his reader to imagine that they have a drug in their personal possession, and that one can either give the dose to one person who needs all of it, or five people who need 1/5 of it. Interestingly, Taurek does allow for the idea that there is a difference between public and private ownership: he suggests that if the ship being captained was publicly owned, there might be a broad agreement that it should be used to automatically save the biggest number. However, I do

not think this blunts the affinity between Taurek and the case of disability rights that I will discuss. For Taurek says that if the reason there are few people at the south of the island is that this is known to be a sparsely-populated area, then the southerners would have no reason to enter into an agreement to maximise lives saved; for they would then know ahead of time that in an emergency, the boat would not come for them. Similarly, some of the complaints made during Covid in the name of disability rights concern *predictable* differences in resource intensity, predicted post-treatment well-being, and long- and short-term survival chances (though others concerned bias in assessing these criteria). If disabled patients know that a focus on maximising lives saved would be used to justify excluding them from using publicly-owned resources for treatment, they would have no reason to sign up to this agreement.

This is thus a very different case from one in which a group of us who have no way of knowing which of us will do better or worse in an emergency all agree that we should save the greatest number. In *that* case, our agreement maximises each of our survival chances, and so is entirely rational to agree to. It would not be rational for individuals with disabilities to agree to a policy which *minimised* their personal survival chances. And I agree with Taurek that, as such, it is not reasonable to insist that they must sign up to such an agreement.

Disability rights and efficiency

Some Covid triage policies explicitly mentioned disability as an excluding factor from ICU admission. For instance, Mello et al (2020) note that some approaches based “triage decisions on quality-of-life judgments or exclude patients with specific conditions that constitute disabilities”, such as the US state of Alabama’s (since abandoned) guidance that called on hospitals to withhold ventilators from those with “severe or profound mental retardation”, “moderate to severe dementia”, and “severe traumatic brain injury”. Mello et al list a range of official complaints from disability rights organisations in the USA focusing on particular state triage protocols (see also Chen and McNamara 2020; McQuillen and Terry 2020; Felt et al 2021; Panocchia et al 2021), while Scully (2020) details some forms of bias against disabled people that may contribute to such issues, such as “the assumption that disability *necessarily* goes hand-in-hand with compromised health”.

But objections regarding disability rights do not exclusively focus on explicit references to disability in triage protocols. Others focused on the much more common accusation of *indirect* discrimination through

considering measures related to efficiency. For instance, in the Brazilian context Araujo et al (2023) advocate the use of Sequential Organ Failure Assessment scores to triage patient according to likelihood of recovery, with ties being resolved by consideration of where a patient is in their life-cycle (i.e., a rough consideration of age; see Davies 2022 for discussion). However, they are critical of a related proposal which would employ the ECOG Performance Status scale, which measures levels of dependence and ability to perform self-care tasks, and which is thus directly discriminatory against disabled patients.

Similarly, Mello et al (2020) distinguish between considering “whether someone has a disability”, and “the patient’s prospects of benefitting from treatment”. Mello et al do rule out some versions of this latter judgement, such as quality of life judgements, and *long-term* survival prospects, such as maximising the number of life-years saved. But they insist that complaints “veer...off the mark” by “suggesting that it’s unfair...to consider patients’ near-term prognosis” in triage, e.g., in assigning lower priority to patients who likely to die within a year of treatment even if admitted to ICU (see also Stramondo 2020). Mello et al object to such approaches, insisting that “consideration of near-term prognosis is accepted in medical ethics and clinical practice”, and that entirely ignoring prognosis would in fact be worse for patients with disabilities; for instance, since it would make no distinction between ventilating “a patient with advanced metastatic pancreatic cancer who is expected to die within weeks” and “a patient who is visually impaired but has no conditions affecting near-term prognosis”.²

Contrast this with some political statements during the pandemic. In a letter to then-Senate Majority Leader Mitch McConnell and Minority Leader Chuck Schumer near the start of the Covid-19 pandemic, Maria Town (2020)—President of the American Association of People with Disabilities (AAPD)—urged Congress to prohibit “the rationing of scarce medical resources on the basis of anticipated or demonstrated resource-intensity needs, the *relative survival probabilities* of patients deemed *likely to benefit* from medical treatment, and assessments of pre- or post-treatment quality of life” [my emphasis], but allowed that providers had no obligation to provide “quantitatively futile” care.³ Senator Elizabeth Warren and colleagues wrote to then-Secretary of State for Health Alex Azar, urging him among other things not to permit exclusions from treatment for patients with a “lower (but *non-negligible*) probability of survival” [my emphasis]. Finally, Hellman and Nicholson (2021) note that the Americans with Disabilities Act (ADA) says that disabled people should have “an equal opportunity to obtain the same results as others”.

Although Hellman and Nicholson do not endorse this, one might read the ADA as advocating something like Taurek's view: that disabled patients should have an equal chance of *survival* as other patients. The Town and Warren letters are more ambiguous; they do not directly say that disabled patients should have equal survival chances, simply that they should not be discriminated against for having lower survival chances. But they both accept a lower bound on this claim: Warren's letter allows (implicitly) for excluding patients with a 'negligible' survival chance, while Town explicitly allows for exclusion where treatment would be quantitatively futile.

Taurek's argument has come in for plenty of criticism (Kamm 1993; Scanlon 1998: 229-241; Otsuka 2000). Of particular note here is Katharina Berndt Rasmussen's insightful paper (2012), 'Should the probabilities count?'. Rasmussen notes that if we take Taurek literally, we end up with a very odd result. In Taurek's original example, we are to imagine that the group the captain chooses will *definitely* be saved. But as Rasmussen points out, most choices aren't like this. When life-saving attempts are undertaken, those attempts have different probabilities of succeeding. For instance, in Taurek's original example, one raft might be in choppier waters, or more likely to break apart before the ship arrives. Given Taurek's focus on equalising *survival* chances, this produces the result that, rather than toss a coin, we should adopt a selection procedure that is heavily weighted towards rescue attempts that are less likely to succeed. The reason is this: in a case where not all can be rescued, a victim's chances of survival are their chances of being *selected* for a rescue attempt multiplied by the chances of that attempt succeeding. Imagine that of our two earlier raft groups, a rescue of raft A is estimated to have only a 10% chance of success; an attempt to rescue raft B has a 50% chance of success. If we take Taurek's approach and toss a coin, we get the result that the person on A has a 5% survival chance, and those on B have a 25% chance, a significant inequality. Thus, says Rasmussen, to achieve Taurek's goal we would need to heavily weight our selection procedure (e.g., through a weighted lottery) towards the attempt which is less likely to be successful. This seems odd. In fact, the result is even stranger than Rasmussen recognises: in many cases, equalising survival chances will require us to introduce the option to save nobody, since the chance of being selected may not be able to be split up without remainder in a way that produces equal survival chances.

Rasmussen's argument, I think, gives us reason to reject the idea that I have suggested *could* be read in the ADA, that disabled patients must have an equal chance of survival. Where a patient's disability gives them a lower chance of survival compared with patients without that disability,

insisting on equal survival chances would perversely tell us to bias selection procedures towards patients who are least likely to survive.

One might think, then, that what we should insist on is closer to the idea contained in the Town and Warren letters. While they are less explicit, I think we can read in them the claim that what should be equalised is not *survival* chances, but chances of being selected. The fact that a patient has a lower chance of survival (long-term or short-term), is judged to have lower post-treatment well-being, or uses resources more intensely, is not relevant in whether they should be admitted to treatment.

However, as noted, the Warren and Town letters do allow for *some* consideration of short-term survival chances, namely where treatment is futile, or survival chances are negligible. As Rasmussen points out in the context of her discussion of Taurek, this generates an uneasy position. As she notes, while the idea of equalising selection chances rather than survival chances might look attractive, it cannot be taken literally. For imagine now that the captain judges that it would be *impossible* to rescue the group on the south of the island. An insistence on equal survival chances here would be bizarre—clearly, the northern group should be rescued. As Rasmussen says, then, the position we get is not that survival chances should not matter; it is that they matter, but only sometimes. This seems to be the position of the Warren and Town letters: survival chances do not matter (we should not discriminate between a patient with a 60% chance of surviving ICU, and one with a 45% chance) for the most part; but they do matter when the odds are low enough to be negligible. One might imagine (though this is not endorsed by either letter) similar positions with respect to other factors such as long-term survival chances, well-being, or resource intensity.

Such positions, then, are only partly about equality. In setting boundaries (Factor *f* matters, but only once we reach a particular threshold), they also have something in common with *sufficientarian* approaches to justice. As such, they inherit a key problem for sufficientarian views, which is how to fix the threshold non-arbitrarily. I will come to this question shortly. But before that, in the next section, I will try to motivate further the idea that a fact about individuals might be relevant, but only up to a particular threshold. Such a view can seem puzzling; if something like short-term survival probability is relevant in some contexts, why is it not relevant in all contexts? I think we can see a way to justifying this by drawing on the idea of ‘opacity respect’.

Opacity respect and its use in society

Ian Carter (2011) has argued for the idea of 'opacity respect' as grounding a stance he calls "evaluative abstinence", i.e., a "refusal to evaluate persons' varying capacities". Carter proposes opacity respect as a solution to the problem of how we can justify a belief in moral equality among persons given that many potential grounds of such equality are held unequally by persons. It is an explanation of Rawls's own approach to this problem, which appeals to the idea of 'range properties'. Rawls proposes that the basis of moral equality between individuals is the binary property of being a moral person. This property itself depends on further properties which are not binary—in Rawls's view, the possession of certain cognitive capacities—but where one only needs to possess them to a certain degree to qualify as a person. Once one has *sufficient levels* of these capacities, possessing them to a greater degree does not make one *more of a person*. Carter suggests that we can justify such a view by appealing to the idea that it would be disrespectfully undignified to have one's capacities assessed in a detailed way. So long as we know that people possess the relevant property to a sufficient degree, we should adopt a stance of evaluative abstinence beyond this.

Carter's opacity respect is concerned with a distinction between a person's "internal" and "external" characteristics; opacity respect involves ignoring the former. The interpretation of opacity respect that could be used to resist prioritisation on the basis of cost-effectiveness is somewhat different to this, and thus can only be said to be inspired by Carter's discussion, rather than adopting the conception he outlines. The relevant capacities which are ignored in Carter's argument are those which ground our agency; the most obvious candidate in the present argument would be something like the capacity to "convert" health resources into health benefits. The aim in appealing to it would not be to establish moral equality, but rather to note that it is already practically adopted in many areas, including in non-emergency healthcare. Thus, we might see having a 'non-negligible' chance of survival as a range property: while A's survival chances might be *better* than B's, her chances do not have the property of being 'non-negligible' to any greater degree. Similarly (though again I stress that these ideas are not endorsed in the Warren or Town letters), one might think that differences in projected quality of life are not typically relevant, except when the patient will have a sufficiently bad quality of life, or that resource intensity (e.g., that a disabled patient might need to occupy a hospital bed for longer) is not relevant, unless it is sufficiently great. For instance, Kirsten Meyer has suggested that while we should generally ignore the amount by which a patient will benefit from a treatment when conducting triage—for instance, we should not automatically prioritise a

patient who will gain an additional 20 years of life over one who will gain an additional 10—we are justified in excluding a patient whose benefit will be sufficiently low: Meyer offers the example of giving someone only “a few more weeks”, since claims to treatment require that the benefit be “significant” (2006: 141).

There are many reasons for which a patient (group) might have lower chances of survival, or derive less benefit from a treatment. For instance, the fact that a person lives in poverty means that they are less likely to have a long life, and more likely to suffer ill health. The fact that a person lives in a state where they experience severe bigotry on the basis of their race, sexuality, gender, or some other characteristic may also affect their health and chance of living for a long time.

In general, though, these characteristics are not considered when a patient comes into a healthcare setting. Similarly, imagine that we knew that patients from a particular racial group, or patients who were very poor, had much worse survival chances than others for ICU treatment during Covid. I suggest that even so we should not use these facts as proxies to maximise the number of lives saved; we should not exclude poor patients from treatment, for instance, simply because they had worse survival chances.

Opacity respect in emergencies

Should we consider cost-effectiveness in emergencies? By cost-effectiveness, recall, I mean one or more of: prioritising patients who are more likely to survive treatment; prioritising those who will live longer; prioritising those who doctors judge will have a better quality of life; or prioritising those for whom standard care will not come with additional complications, and hence costs. In all these cases, I ignore the issue of individuals for whom doctors judge treatment will not be in their best interests. Such cases may also involve discrimination – so much has been claimed by disability activists. But my interest here is in cases where all patients are acknowledged to be capable of benefitting from treatment, but some patients are excluded on the grounds that they are *less* cost-effective than others.

One potential justification is one that was frequently offered during the Covid pandemic, namely that we should try to do the most good; for instance, that we should try to save the most lives. Individuals whose care requires more resources, who will occupy beds for longer, or who are more likely to die despite treatment are seen, on this view, as impediments to this goal. For instance, someone who occupies a bed for twice as long as

the average patient will, in some circumstances, take the place not of one alternative patient, but two. Had this individual been refused access to intensive care, two lives could have been saved. Similarly, someone who has a low probability of surviving treatment will, if treated, make it more likely that no good at all comes from treatment.

Such a maximising approach to cost-effectiveness may be ruled out by an appeal opacity respect. Where treatment is in a patient's best interests, an approach grounded in opacity respect suggests that they should be given an equal chance of receiving it, ignoring various ways in which they may be less efficient to treat, even if this results in some costs, including in the total number of lives lost. One way to reject this, of course, is to reject the idea of opacity respect entirely, and insist that we should always do what is most cost-effective since this will maximise total benefit. If refusing to accommodate individuals with disabilities or who do not speak the dominant language is more cost-effective than accommodating them, then we should not do so. If some non-health related characteristic clearly makes a patient less likely to survive long enough to benefit from treatment, then another patient should be treated ahead of them.

An alternative response is to claim that opacity respect does apply in non-emergency cases, but not during emergencies. However, we need to be careful here. An emergency is, by definition, different from the ordinary run of life. But in thinking about whether to abandon opacity respect, we need to see precisely what difference justifies such abandonment. It cannot be that lives are at stake; ordinary health care deals in life and death every day (Reid 2020). Thus, the justification would have to be similar to that given against the opacity respect of accommodation in ordinary circumstances: that in this case, the cost is simply too great.

That is possible: if a policy of entirely ignoring cost-effectiveness would lead to medical institutions being overwhelmed, or numbers of deaths an order of magnitude greater than what could otherwise be expected, it might be seen as too great a cost. But what is surely not sufficient for this argument is simply that *more* deaths will occur, and that death is a serious cost for each person who dies, and for their families. For it is also a serious cost for disabled people who will die without treatment. The severity of the cost *for each individual* during emergencies, then, cuts both ways. A policy of ignoring cost-effectiveness will lead to a higher incidence of this severe cost; but it will also give individuals with disabilities a chance to avoid the very same severe cost. Consider again Mello et al's argument that a triage policy which failed to discriminate on the basis of short-term survival chance would in fact be worse for patients with disabilities, since it would offer no resources to reject the admission of a patient who is known, due to

metastatic cancer, to have only weeks to live with or without ventilation. One question is how likely such cases are to occur if a radical opposition to disability discrimination *does* allow judgements of benefit *to the patient* to rule out ventilation or ICU admission. If a patient with metastatic cancer has only weeks to live with or without ventilation, it is much less likely to be worth it for them to be ventilated. So while we cannot rule out cases where it is marginally worth it for the patient, but other patients with disabilities stand to benefit much more, such cases are unlikely to be frequent enough to stand as a significant society-wide cost of the kind that would justify refusals of accommodation in other contexts.

Each patient who might benefit from ICU is in a state where they are in significant need. Some seem to take this fact as giving a particularly strong justification to cost-effectiveness; where we cannot ensure that all are able to be brought above a sufficiency threshold, we should aim to bring as many as possible. Along these lines, Savulescu et al (2020) suggest that “there are no egalitarians in a pandemic”; they would probably suggest that there are no sufficientarians in a pandemic either. Similarly Aquino et al (2021) note that “Periods of disaster and public health crisis tend to upend traditional priorities, shifting towards the utilitarian goal of saving the largest number of lives”; Panocchia et al (2020) describe a shift from “person-centred” to “community-centred medicine”; and Scully (2020) suggests that “During major health emergencies such as pandemics...Although it would be an oversimplification to say that healthcare switches completely from a focus on individual patient interests to utilitarianism, there is a shift towards the public health logic of maximizing the good for the greatest number of people”.

The alternative view I have sketched here suggests something different. The severity of need involved, one might argue, makes it particularly important to apply opacity respect, and to ignore differences individual capacities to convert resources into ‘health benefit’ beyond a particular threshold. What opacity respect requires is that we ignore *variations* within certain factors in deciding how to prioritise patients, and particularly in deciding whether to exclude some patients from emergency treatment.

But as mentioned at the end of Section 2, this invites the question of how we are set the threshold. As Rasmussen’s argument shows us, the answer cannot be that the threshold is set at equal chances, either of survival or selection. But we face a worry that any other option would be arbitrary. For instance, considering benefit size, we might ask why Meyer selects ‘a few weeks’ rather than one week or a few months. Similarly, considering short-term survival prospects, once we move beyond equal

chances any particular number seems arbitrary: why define a 'non-negligible' chance as 10% rather than 5% or 15%?

I think that the question of benefit size is easier to resolve than the question of probability. For we can appeal, as John Harris has done, to the question of whether the *patient* would regard the outcome as worth having. And this will be in part dependent on what treatment looks like: would the costs involved in ICU admission, for instance, be worth a few more weeks of life? For some, the answer is clearly no. But it will depend in part on what those few weeks offer! If the patient would be sufficiently aware to spend a little more time with their family, or to experience a major life event such as an upcoming marriage, then that short time might be worth it.

Note that relying on the patient's perspective does not require that doctors ignore questions of futility. For I was careful to say that the relevant question is whether the patient *would* regard the outcome as worth having. This is not the same question as whether the patient requests or demands treatment; patients may demand treatment even when, if they knew what it would be like and what their post-treatment outcomes would be, they would not regard it as worth having. Caution is needed here: removing ourselves one step from the patient's actual perspective raises the risk of bias in assessing quality of life, something to which disabled patients are particularly vulnerable. But the basic idea is important, that we respect the patient's values even while recognising that their actual requests are not always the best way to do so.

A threshold for probability is harder. In part, we may be helped by the practicalities of the case under consideration: very precise estimations of probability are not possible in ICU admission, and so the question of why a 10% chance should be selected rather than, say 9% or 11% is not pragmatically relevant. It may be that in practice, many cases can either be classified uncontroversially as 'futile'/'negligible' or not, and that it is only in a subset of cases which cannot be so clearly classified that the question emerges. In such case, the heuristic to only exclude patients whose chances of survival are negligible (rather than simply 'low') may be helpful. But the underlying arbitrariness is still troubling, to me at least.

Conclusion

I have suggested that a prominent concern raised in the context of disabled patients' rights during Covid can be philosophically informed by considering debates around Taurek's view that the numbers should not count. Problems with Taurek's focus on equalising survival chances have implications for this issue, and push us towards considering a more sufficientarian approach, relying in part on Carter's proposal of opacity

respect. I do not pretend to have given a fully satisfying account; but I hope to have shown why the idea of ignoring short-term survival chances (above a particular threshold) is more plausible than many seem to believe.

Notes

¹ Lecturer, Department of Philosophy, University of Sheffield. PhD Philosophy (2015) King's College London. This article was the result of a research visit to the Universidade Federal de Santa Catarina (UFSC), and several presentation opportunities as UFSC and other universities in Brazil. I am grateful to all participants and hosts for those talks, but especially to Darlei Dall'Agnol for organising my visit. This article benefited from funding from the Wellcome Trust (grant 221220/Z/20/Z) and through the 'Bioethics, Distributive Justice, and Pandemics' project from CNPq (grant 409953/2022-9). Contact: ben.davies@sheffield.ac.uk. Orcid: <https://orcid.org/0000-0003-4612-7894>.

² See Bognar (2020) for a defence of using Cost-Effectiveness Analysis calculations at the macro-level. Triage policies which explicitly prioritise between patients are a potential exception to Bognar's claim that "doctors are not expected to make cost-effectiveness calculations at the bedside; while it is true that doctors are not expected to make "calculations" of the sort involved in CEA, efficient use of resources and maximisation of benefit, which is the primary motivation behind, cost-effectiveness, do explicitly figure in such decisions).

³ Town's letter was previously archived on the AAPD website (see bibliography) but has since been removed. For other references to the letter see Liddiard (no date); and Adams (2022).

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Received/Recebido: 31/10/2023
Approved/Aprovado: 06/02/2024