But I accepted these disadvantages! Can you be discriminated against by holding a right?

Alma K Barner

To show that discrimination against the terminally ill is a real and worrisome phenomenon Reed presents four examples[1] . Here, I focus on the final two: right-to-try and right-to-die laws. I argue that they are not instances of discrimination, because they grant rights. Reed appears to have overlooked that rights differ from obligations in ways that leave his argumentation unsuccessful.

According to the most prominent theory of rights, rights function to protect the personal interests of their holders.[2] For that reason, strengthening rights implies weakening discrimination. Granting women the right to vote by itself meant that they were being less discriminated against. Rights also fail to meet standardly accepted definitions of discrimination. As Reed explains, for discrimination to occur, it is necessary that a significant disadvantage is imposed on a socially salient group. Policies can impose disadvantages by being obligations. While rights sometimes enable disadvantages, they never impose them. More precisely, rights may entitle their holders to subject themselves to disadvantages. The right to try entitles the terminally ill to subject themselves to harms caused by investigational drugs. The right to die entitles the terminally ill to voluntarily subject themselves to the deprivation of life. Contrast this with a policy that requires the terminally ill to take investigational drugs. Such a policy would be discriminatory.

Whether rights can nevertheless discriminate against their holders is an interesting question that has, to my knowledge, not yet been discussed in the philosophical and legal literature.

First, consider direct discrimination. Like obligations, rights can plausibly discriminate directly against their holders, whenever the reason behind granting the right is morally tainted.[3] Reed seems to suggest that right-to-die laws discriminate, because they insinuate that the lives of terminally ill patients are less worth living or lack dignity. If that was the rationale behind the law, it would be discrimination. Yet the intent of the law is to protect the personal interests of terminally ill patients. Right-to-die laws aim to protect the interests of those who express an ongoing desire to die, but are physically incapable of ending their lives. Similarly, one might worry that the motive behind right-to-try laws is to exploit the vulnerable and desperate. However, this is not the case. The rationale behind right-to-try laws is to protect patient's personal interests against the overly restrictive eligibility criteria that were issued by the Food and Drug Administration(FDA) for accessing investigational drugs.[4] Therefore, neither of these laws are instances of direct discrimination. Note that whether the law appears to portray a morally problematic image of the terminally ill to those who misunderstand its intent does not factor into whether the law is discriminatory or not.

> Let's move on to indirect discrimination. Indirect discrimination focuses solely on harmful consequences of policies. Yet in the context of rights, for the reason I mentioned above, harmful consequences are not enough to establish that discrimination occurs. Moreover, whether to protect rightholders against their own harmful choices is a matter of how strongly we value paternalism over more libertarian values. This is unrelated to the topic of discrimination. Reed's concern with right-to-try laws are the disadvantages the terminally ill face whenever exercising their right. Indeed, right-to-try laws are morally problematic. They are plausibly a misguided effort to help the terminally ill, as terminally ill patients tend to have cognitive biases in favor of investigational drugs. These drugs often turn out too risky for patient use and generally have a low success rate. To abolish the right to improve the welfare of the terminally ill and to protect them against their choices would be an act of paternalism. It is likely that such an interference in their liberty is justified. Alternatively, and more in support of libertarianism, one could preserve their right to try but introduce more extensive guidance during the decision-making process.

In the case of right-to-die laws, Reed is, rightfully so, concerned that terminally ill patients sometimes feel pressured by others into exercising their right. However, note that this is a contingent side effect of the law; it does not make the law itself discriminatory. In response, it is sometimes suggested that protective measures be introduced to ensure that the terminally ill can freely exercise their right.[5] Additionally, even to show that discrimination occurs on an individual level, whether the pressure the terminally ill experience is in fact based on discriminatory prejudices is an issue that would still need to be established.

Finally, it is worth clarifying that right-to-die and right-to-try laws can discriminate, but against the non-terminally ill. These rights are only granted to a specific social group. As such, differential treatment is a necessary condition for discrimination. In the case of right-to-die laws Reed bemoans that right-to-die laws in the USA are artificially restricted to the terminally ill. This seems to be the basis for his claim that they discriminate against the terminally ill. Because of this restriction, it can be argued that right-to-die laws are inherently unequal without rational justification, and therefore, discriminate. But if they do, they discriminate against those excluded from the right, that is, those who would wish for assisted suicide but are not terminally ill, such as severely disabled individuals, for example. In the same vein, one can argue that right-to-try laws discriminate against the non-terminally ill who wish to try out investigative drugs, such as Long Covid patients, for example.

In his paper, Reed presents four examples of discrimination. I discussed his final two. While his first, the Medicare Hospice Benefit Act, is plausibly a case of indirect discrimination, note that such a law would likely be illegal in many Western capitalist countries outside the USA. This leaves us with one general example, a case of justified discrimination. To conclude, while discrimination against the terminally ill certainly exists, Reed has (luckily) failed to present much evidence to support his initial claims that the terminally ill commonly or routinely face discrimination by law and policy and that this is a troubling trend.

Correspondence to Dr Alma K Barner, Philosophy Department, Universität Salzburg Kultur- und Gesellschaftswissenschaftlichen Fakultät, Salzburg 5020, Austria; alma.barner@email.de

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ORCID iD
Alma K Barner http://orcid.org/0000-0003-4158-2775

REFERENCES

1 Reed P. Discrimination against the dying. *J Med Ethics* 2024;50:108–14.
2 Wenar L. Rights. The stanford encyclopedia of philosophy. 2023. Available: https://plato.stanford.edu/archives/spr2023/entries/rights/ [Accessed 24 Oct 2023].
3 Discrimination A. Discrimination. The stanford encyclopedia of philosophy. 2020. Available: https://plato.stanford.edu/archives/win2020/entries/discrimination/ [Accessed 24 Oct 2023].
4 Dresser R. "Right to try" laws: the gap between experts and advocates. *Hastings Cent Rep* 2015;45:9–10.
5 Wiesing U. The judgment of the german federal constitutional court regarding assisted suicide: a template for pluralistic states? *J Med Ethics* 2022;48:542–6.