Discrimination against the dying

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ABSTRACT

The purpose of this paper is to identify a kind of discrimination that has hitherto gone unrecognised. 'Terminalism' is discrimination against the dying, or treating the terminally ill worse than they would expect to be treated if they were not dying. I provide four examples from healthcare settings of this kind of discrimination: hospice eligibility requirements, allocation protocols for scarce medical resources, right to try laws and right to die laws. I conclude by offering some reflections on why discrimination against the dying has been hard to identify, how it differs from ageism and ableism, and its significance for end-of-life care.

INTRODUCTION

In 2014, an 89-year-old man named James Dempsey experienced complications from surgery and admitted himself to an Atlanta area nursing home. Dempsey's health began to deteriorate while in the facility and he started to have difficulty breathing. The patient requested help from his nursing staff several times, but the nurses ignored him. They did not check his vital signs, initiate cardiopulmonary resuscitation (CPR) or call 911. When they finally did attend to the dying patient, they had trouble operating Dempsey's oxygen machine and began laughing at the situation. The nurses eventually notified the paramedics and did eventually initiate CPR—but not until just before the paramedics arrived. It was too late. Because of a hidden camera that documented the nurses' reactions, they were sentenced to prison for neglect that led to James Dempsey's death.

The nurses in this case were outliers. Healthcare providers do not typically disregard dying patients in this way. Nevertheless, the nurses' actions are representative of a more troubling trend. Dying patients commonly face discrimination on account of their dying, not predominantly by an individual animus or prejudice of the sort displayed by the nurses in Dempsey's case but rather by law and policy, which is more worrying because it has a greater social impact.

I call discrimination against the dying 'terminalism' and I argue that bioethicists, healthcare providers and policy-makers have failed to confront it. We have heightened our awareness of and often our opposition to discrimination of all sorts in healthcare settings and society more generally, yet somehow we neglect one important group, dying patients, who face it routinely. Our neglect of the discriminatory treatment of dying patients is not as blameworthy as the discriminatory treatment that James Dempsey received from his nurses but it is blameworthy all the same. In section one, I say more about the nature of terminalism. In section two, I

provide four examples from healthcare settings of terminalism: hospice eligibility requirements, allocation protocols for scarce medical resources, right to try laws and right to die laws. I conclude in the final section by offering some reflections on why discrimination against the dying has been hard to identify, how it differs from ageism and ableism and its significance for end-of-life care.

IDENTIFYING TERMINALISM

Terminalism is discrimination against the dying. In senses both trivial and profound, all of us are dying because we are mortal creatures. 'He not busy being born is busy dying,' sings Bob Dylan. But for purposes of identifying a marginalised or vulnerable group susceptible to discrimination, this sense of 'dying' is obviously too broad. When we speak about the social group of dying persons, we do not mean to speak about everyone. But nor do we mean to speak principally about persons who are expected to die imminently. People whose death is imminent, such as a patient like James Dempsey who was waiting for emergency life-saving measures, count as dying in a technical sense but tend not to be the relevant individuals who are discriminated against by law and policy. The group of imminently dying persons is not socially salient, that is, membership in the group does not structure social interactions in a wide range of social contexts. Partly this is because membership in the group is, by definition, extremely short-lived, so it cannot play a role in a wide range of social contexts for any one person. In addition, members of the group of imminently dying individuals have a very narrow and immediate set of concerns, making the only relevant questions about treating them the questions that are related to their imminent death. Concerns about discrimination against the dying are, therefore, not focused on patients with cardiac arrests, gunshot wounds or other emergency situations.

Membership in a socially salient group is necessary in order for an individual to be a target of discrimination (Lippert-Rasmussen, pp30–36).² In a generic sense of discrimination, we discriminate against, for example, the left-handed when we design scissors or desks for right-handed persons. Yet the left-handed persons are not a socially salient group because being left-handed is not relevant to a wide range of social interactions in society. Therefore, the generic discrimination that the left-handed experience is not the morally relevant kind of discrimination such as that faced by being disabled or female. While the imminently dying are like the left-handed in not being socially salient, the class of persons who are dying in the sense relevant to discriminatory acts are those who suffer from a terminal illness. Belonging to the group of



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terminally ill patients does structure social interactions in a wide range of social contexts. The terminally ill often and to varying degrees do make significant social choices: they can work, play, create, converse, marry, divorce, move across the country, arrange their wills and in general decide how to spend their time. The fact that terminally ill individuals are dying will structure how their social choices are made and how they are treated by others and by laws or policies. Therefore, the terminally ill are a socially salient group and thus at least candidates for discriminatory acts. It is obviously the relevance of a terminal illness that explains my choice of the word 'terminalism' to identify discrimination against the dying, which I treat as identical to discrimination against the terminally ill.

The dying, then, are those whose death is expected relatively soon and whose illness is causing their death to be expected relatively soon. Typically, the expectation that an individual's death will be soon is formalised in a healthcare setting by receiving a prognosis of expected life left. In the USA, for example, it is standard (though not universal) to understand 'terminal illness' to include having a prognosis of 6 months or less to live.³ Other countries might adjust the length of this prognosis somewhat in identifying patients who are dying.⁴ Length-of-life prognoses are, of course, often wrong. The class of people who will in fact die in the next 6 months from an underlying illness only partially overlaps with the class of people who are expected to do so. Nevertheless, the latter group is the relevant one for defining the class of dying people. What I am proposing is not intended to be a novel definition of 'dying'; this definition is more or less assumed across a variety of medical and policy contexts in the West that are relevant to the terminally ill. But if we are going to identify the nature of terminalism, we need to say precisely who counts as dying.

We also need to say what counts as discrimination. As a first approximation, to discriminate against a class of persons is to treat them worse than they would expect to be treated if they were not in that class on account of their being members of that class. There is a large literature on the nature of discrimination and related concepts such as harm, unfairness and wrongness. This paper does not intend to address these topics in detail. My purpose is merely to sketch an unrecognised form of discrimination in broad terms and in a way that is as non-controversial as possible. Familiar analogues of racism and sexism are instructive. To discriminate against a certain race is to treat persons of a certain race worse than they would be treated if they were of a different race. Black people are discriminated against, for example, in the housing market when they are turned down for a mortgage that would have been extended to white people who had the same financial credentials. Similarly, the dying are discriminated against when, for example, they are denied effective treatment that they would have been offered had they not been dying. Section two below discusses examples of terminalism in more detail.

In a loose sense, 'terminalism' might not only refer to the discrimination against the dying but also prejudice or other negative beliefs about and attitudes against them. Again, as familiar analogues of racism and sexism reveal, prejudices amount to conscious or implicit biases that persons hold against a targeted group, such as that they deserve less respect than those outside of the group. James Dempsey's nurses likely held a prejudice against him on account of his dying. However, the biases and attitudes of people, troubling though they may be, are not themselves instances of unfairness or substantial harm stemming to the targeted group compared with the way these attitudes are manifest in disadvantageous treatment. What most bothers us

about Dempsey's nurses were their actions not their attitudes (even if it is true that their attitudes led to their actions). If nurses or other healthcare providers had a low view of dying patients but treated them without discrimination, we might reprimand them but we would not sentence them to jail. Moreover, while underlying bias or prejudice might be the impetus that motivates an act of discrimination, it need not be, as we will see in some of the examples below. Hence, we should think of terminalism in terms of discrimination rather than prejudice. I will use the phrase 'terminalist prejudice' to identify negative attitudes and beliefs, construed broadly, that are held against dying persons. Terminalist prejudices are, strictly speaking, not themselves instances of discrimination.

EXAMPLES OF TERMINALISM

I want to further elucidate this first approximation of terminalism by looking at some examples. Because the dying are defined as patients (ie, suffering from a terminal illness), it is natural that the examples of discrimination against them are to be found in medical contexts. In this, the dying resemble the elderly and the disabled: their social context is frequently dominated by health-care settings and so instances of discrimination are likely to be found there. Because the focus of this paper is on the morality and not the legality of discrimination against the dying, I set to one side whether the terminally ill make up a protected class under federal law. I discuss four examples of terminalism from medical contexts in this section.

The first example of terminalism is the eligibility requirements for receiving hospice care in the USA. Hospice emerged in the latter half of the 20th century as a way to provide specialised care for the dying. Access to hospice care increased dramatically in 1982 when Congress passed the Medicare Hospice Benefit. In order to use this benefit, however, dying patients were required to refuse treatment aimed at curing their underlying disease. This created a quandary for dying patients: either refuse the benefits of treatment specifically aimed at the dying (ie, hospice) or refuse treatments that were supposed to be life-prolonging. This eligibility restriction is terminalist: dying patients at least sometimes have a barrier to standard, effective medical care that we do not impose on the non-dying. The terminally ill are harmed by this eligibility requirement because there is evidence that curative treatments can offer substantial benefits, such as palliative ones, beyond their (primary) life-prolonging intent. ⁵ ⁶ Moreover, there is some evidence that some patients forego hospice because of their preferences to receive what is designated as life-sustaining treatment when it would be beneficial for them to be receiving hospice care, ⁷ again putting them in a worse position because of the discriminatory eligibility policy.

But it is not merely the federal restriction on receiving hospice care that discriminates against the dying. Because of the incentive structure for Medicare reimbursements, hospices also impose various restrictions on receiving hospice care, imposing additional disadvantages on terminally ill patients. For example, according to a recent study, 78% of hospices have policies that will turn away some patients who are receiving high-cost palliative treatments. This too is terminalist. There is a strong social consensus that people should not be denied necessary medical care simply based on the cost, and yet this happens regularly for the dying (at least if they also need hospice care).

It is important to see that my view is not that any suboptimal care for dying persons counts as discrimination.⁸ This would obviously take the concept of terminalism too far, for the non-dying also experience suboptimal care. Nor is it the case,

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importantly, that denying ineffective medical treatments to the terminally ill counts as discrimination, just as denying driver's licenses to blind persons does not discriminate: these kinds of treatments do not make the targeted individuals worse off. For example, it is not terminalist to withhold or withdraw dialysis for terminally ill patients with end-stage renal disease when the treatment is not anticipated to benefit the patient in any meaningful way. At the same time, we have seen that there are clear instances in the structure of our hospice eligibility practices and policies that do meaningfully discriminate against the terminally ill.

The terminalism of hospice eligibility is instructive about the nature of discrimination. Philosophers working on discrimination commonly distinguish direct discrimination from indirect discrimination. Direct discrimination occurs when an act or treatment intends to make persons of a group worse off (or when someone carrying out the act has some other objectionable mental state, such as indifference).9 For example, the 20th century US practice of redlining was direct discrimination against black people. Direct discrimination is typically motivated by prejudice or bias against the targeted group. The discrimination involved in hospice eligibility requirements is probably not direct discrimination: no one is trying to disadvantage the terminally ill and there is no obvious terminalist prejudice motivating the limitations on eligibility. The barriers to hospice care are instead based (ostensibly) on cost-saving measures. (Whether terminalist hospice policies actually do save costs overall has been challenged. 10) However, discrimination theorists, reflecting some legal rulings, regularly allow that discrimination can also be indirect. Indirect discrimination occurs when a socially salient group receives disadvantageous treatment without any bias, prejudice or intention to disadvantage. As we have seen, the eligibility requirements for hospice result in such disadvantageous treatment. Even while, all other things being equal, we should worry more about the ethics of direct discrimination than indirect discrimination, we should not ignore discriminatory practices merely on the basis that the disadvantageous results are

The second example of terminalism are certain prescriptions for the allocation of scarce medical resources. We witnessed this most recently with respect to the COVID-19 pandemic: ventilators were restricted from dying patients if such patients were deemed unlikely to survive much longer even with the benefit of a ventilator. In the earliest days of the pandemic, hospital systems developed protocols for assessing patients' likelihood of benefit from receiving certain scarce treatments. Representative protocols explicitly discounted people who were near death on the grounds that such patients were unlikely to live much longer 11 12 and bioethicists broadly endorsed distributing ventilators on the basis of saving the most lives and the most life-years. 13 14 These policies and policy proposals are terminalist: if the patients had not been dying, they would have been eligible for effective scarce medical treatments just as those who were not near death.

The terminalism reflected in allocation protocols during the COVID-19 pandemic was not new. In fact, the literature on scarce medical resources routinely proposes terminalist practices. Typically, the terminalism is captured in accounts that rely on such principles as saving the youngest first, maximising life-years or considering prognosis. ¹⁵ For example, the rules governing distribution of organs in the US are overseen by United Network for Organ Sharing, which, in determining one's place on the waiting list for an organ transplant, prohibits consideration of age, but allows consideration of medical need or utility. Organ transplants that are unlikely to keep a patient alive much longer

than the patient might otherwise expect to live are more likely to go to patients who are not dying.

The concept of discrimination is inherently normative in the following sense: we saw in section one it has to do with making one group disadvantaged or worse off than they otherwise would be. This does not mean, however, that discrimination is inherently morally wrong. There is a debate among theorists of discrimination about whether discrimination is inherently wrong (and if it is, what makes it wrong). Many theorists prefer a moralised account, where the wrongness of discrimination is a conceptual matter. In my account of terminalism in section 1, however, I have carefully defined terminalism so as to prevent it from being moralised. In this way, I leave open the possibility of justified terminalism. While 'discrimination' has the connotation of a kind of moral wrong, connotations are unreliable guides for moral truths. In my view, calling something discrimination does not yet say it should be condemned. Analogously, affirmative action programmes discriminate against individuals who are part of groups that traditionally have social or cultural power, but many theorists propose that this kind of discrimination is justified. Identifying something as discriminatory does not, without further analysis, tell us that we ought to stop it.

My view is that discrimination against the dying is only a prima facie wrong. We should not discriminate against the dying without an adequately good reason. While I will not argue these points here, I believe that the terminalism in allocating scarce medical resources is justified whereas the terminalism in hospice eligibility requirements is not. We need to evaluate the terminalist practices, as with other discriminatory practices I would argue, on a case-by-case basis. Some acts of discrimination might be all things considered justified.

Suppose I am right that the terminalism in allocating scarce medical resources is justified. It does not follow that there is nothing to gain by identifying this practice as discrimination. If an act is discrimination, it is better to identify it as such rather than not on the basis that true act-descriptions are desirable. Moreover, identifying justified acts of discrimination might also have moral significance. In the first place, in cases where other moral considerations override our obligations to avoid discrimination, we would do well still to remember and call attention to the (prima facie) wrongness of this discrimination, for this helps us to keep in mind why other acts of discrimination should be avoided. In the second place, justified discriminatory acts might still require a rich moral psychology. Appropriate moral attitudes to certain justified acts might include regret, grief, humility, repentance, etc. Diverting a trolley to cause fewer deaths is one such act, and so is the terminalist practice of withholding a ventilator from a dying patient in a pandemic.

Many theorists who endorse discrimination against the dying in allocating scarce medical resources show little to no awareness that the practice is discriminatory or that there is something regrettable about the practice, even if it is all things considered justified. For example, MaryKatherine Gaurke et al argue that it is wrong to discriminate against the elderly and the disabled in the allocation of scarce resources in a pandemic situation; however, they explicitly and confidently assert that terminally ill patients (which they define as having an expected life of 1 year or less) can be safely excluded from receiving such resources, for 'it seems fair to exclude those very few who might survive to hospital discharge only to die of an underlying malignancy within a few more months' (Gaurke et al, p24).¹⁷ Not only is this not identified as discrimination in a paper that is otherwise focused on avoiding discrimination (on the basis of 'valuing each person equally'), there is no moral sensitivity to the plight of

the dying or the seriousness of the endorsed terminalism. They offer no acknowledgement of the prima facie wrong and no remorse that the dying are denied effective treatment that they would otherwise receive. Even if the terminalist practice is all things considered justified, it nevertheless may be an occasion for moral sorrow.

The final two examples of terminalism are right to try laws and right to die laws. Starting in 2014, US states began to pass 'right to try' laws that allowed terminally ill patients to request access to medications that are not approved by the Food and Drug Administration (FDA). Federal legislation was passed in 2018. These laws are terminalist: the dying are discriminated against because the drugs that are being made accessible to them are neither safe nor effective—which is the exact reason the nondying are prohibited from accessing them. The laws shield drug companies and healthcare providers from legal liability and they often leave patients and their families on the hook for paying for the experimental treatment. The potential harm of these laws explains why, even though they have been popular among legislators, medical professionals are nearly unanimous in their opposition to them. 18 It is easy to see the discrimination if we change the eligibility criteria to another socially salient group: if we said that the right to try experimental drugs was available exclusively for racial minorities or trans people, the message would be that we do not care about protecting racial minorities or trans people from experimental and risky medical treatment.

One might object that right to try laws are not terminalist because terminally ill patients often desire to take greater risks with medical treatment given their terminal diagnoses. In other words, differential treatment of the terminally ill is appropriate to their condition. However, as opponents of right to try laws have consistently pointed out, terminally ill patients already have a process whereby they could seek experimental therapies that involve risk. This process, known as expanded access, was overseen by the FDA and an institutional review board (IRB) in order to protect patient safety. Patients' requests for experimental treatment were approved in greater than 99% of cases. 19 Expanded access is not terminalist because it aims to respond to the unique situation of the terminally ill without compromising on protecting patients. Right to try laws, on the other hand, jettison this protection, subjecting dying patients to unnecessary risk, pain and suffering. Again, acknowledging cases of terminalism does not commit one to treating dying and non-dying persons the same in every respect; terminalism is about what disadvantages and ill-treatment the dying are unduly subjected to in virtue of their status as dying.

Just as with right to try laws, right to die laws (euthanasia and assisted suicide) also exhibit terminalism when they restrict eligibility to the terminally ill. For example, in the US states where one can legally access aid-in-dying or physician-assisted suicide, one must have a prognosis of 6 months or less to live. Canada originally made euthanasia available only for citizens whose death was 'reasonably foreseeable' (before expanding its law beyond that limitation). Such restrictions are terminalist: assisted death laws that limit their services to the dying discriminate against them because death is offered to them to solve their problems. Such laws treat the dying worse than if they were not dying in so far as, on account of their dying, they might be better off dead. The existence of the laws and the reasons people take advantage of it are explicit that undergoing a terminal illness may be an experience incompatible with 'dignity' and a desirable quality of life. As with right to try laws, it is easy to see the discrimination of right to die laws if we change the eligibility criteria to another socially salient group: if assisted suicide or

euthanasia were legal exclusively for women or disabled people, the message would be that life as a woman or a disabled person is (very often) not worth living.

One might object that assisted death laws that limit eligibility to the dying actually discriminate against the non-dying by preventing them a real benefit, assisted death.²⁰ Here, we reach an impasse over the appropriateness of assisted death that cannot be adequately addressed in this paper. Nevertheless, even if one supports assisted death for everyone, one should be concerned about laws that target the dying beyond reasons of discriminating against the non-dying. We should consider how our social view and treatment of the dying is affected by policies that allow only the dying to access assisted death. For one thing, we have redefined terms in order to carry out what we take to be an important societal obligation of aiming to prevent suicides. In denying that the terminally ill are committing suicide by accessing assisted death, the professional organisation most committed to preventing suicide has given up its responsibility of addressing suicidal ideation among the terminally ill.²¹ This is terminalist: purely on the basis of group membership, one group gets suicide prevention and another gets suicide assistance. Moreover, the availability of the option of assisted death only for the terminally ill negatively influences the terminally ill who wish to live by causing them to doubt their choice. When assisted death is available only to the dying, a dying person may be prone to feel a need to justify his existence in a way that the non-dying, not having the option, need not do.²² This puts the dying at a disadvantage.

It is not only proponents of assisted death that are guilty of terminalism. In acquiescing to the eligibility for assisted death extended only to the terminally ill, some opponents of assisted death have inadvertently expressed terminalist views. For example, the American Psychiatric Association's 2016 statement on medical euthanasia says that 'a psychiatrist should not prescribe or administer any intervention to a non-terminally ill person for the purpose of causing death'. 23 This statement was intended to try to block the expansion of euthanasia and assisted suicide laws to the mentally ill, but on an explicit reading of the statement, it refused to condemn psychiatrists who provide terminally ill persons an intervention that causes their death, arguably giving tacit approval of the practice. And this is terminalist: it singles out a socially salient group and treats them worse on account of this group membership. Again, those who support assisted death will insist it's not worse treatment, but the APA's explicitly acknowledged position, regardless of whether we agree, is that participating in euthanasia for suffering patients is worse than refusing it.

The terminalism in right to try and right to die laws is instructive about the nature of discrimination. As we saw above, philosophers working on discrimination commonly distinguish direct from indirect discrimination, with the former being defined as involving an intent to disadvantage the discriminated group (or else have some other objectionable mental state, such as indifference, toward the group). The discrimination involved in right to try and right to die laws is arguably not direct—on the contrary, the objective is to provide a benefit to dying patients. However, these laws do involve 'direct' discrimination in a different sense: the group discriminated against is explicitly named. Let us call this explicit discrimination. Explicit discrimination can involve intent to harm, such as 'no blacks allowed', or unintentional harm, as the examples of right to try and right to die laws show: the intention of restricting eligibility to the terminally ill is not to disadvantage them even though that is what in fact happens. Even while, all other things being equal, we might think that

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intentional discrimination is worse than unintentional discrimination, there is something about explicit discrimination that is clarifying: it wears its target on its sleeve in a way that is relatively uncommon even in cases of intentional discrimination. For example, the best available evidence is that redlining was intentional discrimination, yet it was not explicit discrimination; banks did not display signs that said 'no blacks will be approved for a mortgage'. We might have cared a lot sooner about redlining if it were explicit. Naming the targeted group in the discriminatory policy at hand lends a salience to the issue that can sidestep questions about intent.

These four examples show that terminalism names a real contemporary issue. Nothing hangs on accepting any one instance of the four—if, for example, one had independent reasons for supporting aid in dying or right to try laws, terminalism could still be a problem worth confronting. The variety and scope of terminalism is up for debate, as it is with other forms of discrimination.

CONFRONTING TERMINALISM

The main purpose of this paper is to pick out a currently overlooked normative phenomenon in contemporary healthcare settings and suggest that we should at least notice it. With the examples above as a starting point, the practice of terminalism names a real phenomenon. And yet there is virtually no discussion of this phenomenon among bioethicists, healthcare providers or policy-makers. Several recent volumes devoted to care for the dying and ethics at the end of life do not so much as mention discrimination against the dying. ^{24–26} Of course, many people who care for the dying have pointed out that the terminally ill receive suboptimal care, ²⁷ but that is not the same as discrimination. Why has terminalism been so hard to identify? Part of the explanation is that we did not—until now—have a name for this discrimination. But what else, in general, prevented our ability to identify terminalism explicitly?

The first thing to say is that terminalism as it emerges today is a relatively recent phenomenon. While racism and sexism go deep in Western history, the same cannot be said of terminalism—even if it is true that there have always been some historical manifestations of discrimination against the dying. The medical and technological progress of the 20th century turned dying into a protracted process and thereby introduced opportunities for discrimination where they did not exist before.

The second reason that might explain why we have overlooked terminalism is that the person discriminated against is in a group that tends to have less agency on the whole than individuals in other groups who face discrimination. We saw in section two that instances of terminalism appear in medical contexts. This is because membership in this particular group, the dying, constricts the range of action available to members of this group much more than it does for other groups. Even more than the disabled or the elderly, the terminally ill are less likely to participate in a range of social contexts: they're less likely to seek employment, purchase a house, apply for admission to college or be pulled over by the police. Therefore, the opportunities for discrimination against the dying are more limited than the opportunities for discrimination against women, say, or racial minorities. And while this might be a good reason to worry more about discrimination against women and racial minorities than about discrimination against the dying, it does not mean that terminalism should be entirely ignored.

A third reason that we might be slow to identify terminalism is our own terminalist prejudices. Perhaps we just think that the disadvantages that fall on the dying are less important because, after all, the terminally ill are only around for a bit longer in any case. Many of us tend to think, explicitly or implicitly, that a worthwhile life involves both the kind of life that has a future and also enables a person to 'contribute' 'meaningfully' to society. One sees this kind of attitude reflected, for example, in Ezekiel Emanuel's views about the end of life: 'These people who live a vigorous life to 70, 80, 90 years of age—when I look at what those people 'do,' almost all of it is what I classify as play. It's not meaningful work. They're riding motorcycles; they're hiking. Which can all have value—don't get me wrong. But if it's the main thing in your life? Ummm, that's not probably a meaningful life' (Qtd. in²⁸). How much less meaningful is a life for those who cannot even play but only lie around on their death bed? Why should we worry if we disadvantage people whose lives are no longer meaningful?

These reasons begin to explain why we have not yet confronted terminalism head-on in our society. While I think terminalism has been hiding, I want to suggest it is hiding in plain sight—that we are aware of it at some level. Recognising the suboptimal care that terminally ill people receive may show an implicit awareness that the terminally ill, qua terminally ill, face disadvantageous conditions that result from the structure of social policies. The bioethicist Nancy Jecker has written about 'midlife bias' which she identifies as prioritising the values of midlife over and against values at other stages of life. ²⁹ Terminalism in a sense might fall out of such bias—and yet Jecker does not discuss discrimination of the dying directly. I do not wish to overstate the novelty of identifying terminalism. It should come as no surprise to the reader that the dying face discrimination. But it is almost never talked about directly in the terms I am using here.

Another way that we have approached awareness of terminalism is in our willingness to identify two distinct but related kinds of discrimination, namely ageism and ableism. In other words, terminalist concerns tend to collapse into concerns about discrimination against the old and the disabled. But it is worth clarifying how terminalism differs from ageism and ableism.

When bioethicists deliver their guidelines for distributing scarce medical resources, they are usually cognizant of the possibility of discrimination. Indeed, the COVID-19 pandemic saw some allocation protocols designed to avoid discrimination against the elderly, the disabled and those who suffer from healthcare disparities. Likewise, bioethicists defending various allocation proposals often spill a lot of ink insisting that their views do not amount to ageism and ableism. 14 15 17 30-32 Yet, they do not attempt to show that such proposals avoid discrimination against the dying. Similarly, critics of assisted death laws falsely assume that the relevant kind of discrimination in these laws is ableism and they twist themselves into knots trying to argue that the terminally ill are disabled.^{33 34} Some bioethicists go so far as to argue that we should cast discrimination against the dying as a kind of disability discrimination. 8 While disability rights groups, in my view, have legitimate concerns over assisted suicide laws, 35 this is only because the discriminatory character of these laws is adjacent to rather than a version of disability discrimination. While the terminally ill have some characteristics that overlap with the disabled, the disabled (qua disabled) are not exactly the target of assisted death laws in the USA.

Here is the point: the old and the disabled are not identical to the terminally ill, even if they frequently overlap. You can be dying even if you are 25 years old. You can technically be terminally ill even if you lack anything we might identify as a

disability. While ableism and ageism are close to the kind of discrimination I am concerned with in this article, they are distinct. So it is not enough to absolve oneself of discrimination by pointing out that their preferred policy (for scarce resource allocation, for example) exhibits no ageism or ableism. There is another relevant form of discrimination here that we have not sufficiently paid attention to.

Nevertheless, a dying patient's range of available activities, both physical and mental, usually begins to constrict (or one anticipates them doing so) and his dependency on others increases. The recognition of terminal illness occurs in health-care contexts and is based on measures of functionality, frailty, pain and others that can be categorised accurately as disability measures. Thus, I do not want to overstate the distinction. It is natural for disability rights activists to share concerns about policies that discriminate against the dying. And it is natural for concerns about terminalism to overlap significantly with concerns about ableism (and ageism).

In fact, it is possible even to view disability rights as a kind of model for the rights of the dying. Rights for the dying, in other words, can conceivably develop as a natural, logical extension of disability rights and even civil rights. These movements were successful in pointing out the dignity and respect that the disabled and racial minorities are owed, and changes in the law were made to prevent discrimination against these groups. Perhaps something similar is possible for terminalism. The scholar who has done the most to suggest disability rights as a model for rights for the dying is Harold Braswell.⁸ However, in later work Braswell expresses scepticism about the utility of antidiscrimination laws for dying people and suggests hospice reform as a matter of broader political efforts.³⁶ This scepticism may well be correct and it is beyond the scope of this paper to determine the political and social reforms necessary to secure the rights of the dying. That is why I am focusing on the morality of discrimination—naming the disadvantageous treatment that the terminally ill face as a prima facie wrong. Whether addressing and overcoming this discrimination is best done via legal changes (a la the civil rights movement) or policy changes along the lines that Braswell proposes or something else is left open. Nevertheless, I think our cultural moment has important sensitivities to discrimination of all kinds and so acknowledging terminalism can be a useful path forward to improve our care for the dying, perhaps working in tandem with other efforts to reform healthcare policy.

There seems to be no end to the kinds of discrimination we are keen to identify. Classism usually gets less attention than racism and sexism but is a common phenomenon. Ableism and ageism have emerged more recently as matters of concern. Peter Singer and others identify a distinct kind of discrimination in what they call speciesism, which is to discriminate against non-human species. Do we really need yet another -ism? The point of this paper is to show that we do, that discrimination against the dying occurs regularly in high-capitalist Western cultures. I think terminalism is relatively easy to see, that it has been hiding in plain sight, and the fact that we have not yet confronted it reveals in part our blind spots and prejudices. We don't want to think of ourselves as discriminating against yet another vulnerable group, yet we are plainly doing so.

The reason that terminalism matters is that dying persons matter. Our willingness to treat such patients badly assumes a kind of fatalism—where we imagine that a life with very little future means a less valuable life. Of course, there is nothing new in pointing out that the terminally ill deserve better. Certainly,

the plight of the dying and material attempts to improve it have a long history. Yet the fact that they are subject to discrimination, as I have argued in this paper, shows a special kind of mistreatment that they suffer. It is a matter of unfairness or harm or both that the dying withstand disadvantageous treatment merely on account of their group membership. Confronting terminalism forces us to ask an uncomfortable question: what do we owe the dying and how might we treat them as equals with those who have indefinitely long to live?

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REFERENCES

- Stevens A. Three nursing home workers plead guilty in death of neglected World War II vet. Atlanta Journal-Constitution; 2022. Available: https://www.ajc.com/news/crime/ex-nurse-pleads-guilty-in-death-of-neglected-world-war-ii-vet/UN6KBUIDEZDNNLT2 UAS4BUNN6M/
- 2 Lippert-Rasmussen K. Born free and equal? A philosophical inquiry into the nature of discrimination. Oxford: Oxford University Press, 2014.
- 3 Lynn J, Harrell FE, Cohn F, et al. Defining the 'terminally ill': insights from SUPPORT. Duquesne Law Rev 1996;35:311–36.
- 4 Hui D, Nooruddin Z, Didwaniya N, et al. Concepts and definitions for 'actively dying,' 'end of life,' 'terminally ill,' 'terminal care,' and 'transition of care': a systematic review. J Pain Symptom Manage 2014;47:77–89.
- 5 Odejide OO. A policy prescription for hospice care. JAMA 2016;315:257–8.
- 6 Aldridge Carlson MD, Barry CL, Cherlin EJ, et al. Hospices' enrollment policies may contribute to underuse of hospice care in the United States. Health Affairs 2012;31:2690–8.
- 7 Casarett D, Van Ness PH, O'Leary JR, et al. Are patient preferences for life-sustaining treatment really a barrier to hospice enrollment for older adults with serious illness. J Am Geriatr Soc 2006;54:472–8.
- 8 Braswell H. From disability rights to the rights of the dying (and back again). Laws 2017;6:31.
- 9 Altman A. Discrimination. The Stanford Encyclopedia of Philosophy; 2020. Available: https://plato.stanford.edu/entries/discrimination/ [Accessed 01 Oct 2021].
- 10 Spettell CM, Rawlins WS, Krakauer R, et al. A comprehensive case management program to improve palliative care. J Palliat Med 2009;12:827–32.
- 11 University of Pittsburgh. Department of critical care medicine, "allocation of scarce critical care resources during a public health emergency. 2020. Available: https://ccm.pitt.edu/sites/default/files/Model%20hospital%20policy%20for%20allocation%20of%20critical%20care_2020-03-23%20web.pdf
- 12 Daugherty Biddison EL, Faden R, Gwon HS, et al. Too many patients: a framework to guide statewise alocation of scarce mechanical ventilation during disasters. CHEST 2019:155:848–54.
- 13 Altman MC. A consequentialist argument for considering age in triage decisions during the coronavirus pandemic. *Bioethics* 2021;35:356–65.
- 14 Emanuel EJ, Persad G, Upshur R, et al. Fair allocation of scarce medical resources in the time of COVID-19. N Engl J Med 2020;382:2049–55.
- 15 Persad G, Wertheimer A, Emanuel EJ. Principles for allocation of scarce medical interventions. *Lancet* 2009;373:423–31.
- 16 Biddison LD, Berkowitz KA, Courtney B, et al. Ethical considerations: care of the critically ill and injured during pandemics and disasters: CHEST consensus statement. Chest 2014;146:e1455–555.
- 17 Gaurke M, Prusak B, Jeong KY, et al. Life-years & rationing in the COVID-19 pandemic: a critical analysis. Hastings Cent Rep 2021;51:18–29.
- 8 Dresser R. Right to try' laws: the gap between experts and advocates. Hastings Cent Rep 2015;45:9–10.
- 19 Holbein MEB, Berglund JP, Weatherwax K, et al. Access to investigational drugs: FDA expanded access programs or 'right-to-try' legislation Clin Transl Sci 2015;8:526–32.
- 20 Downie J, Schuklenk U. Social determinants of health and slippery slopes in assisted dying debates: lessons from Canada. J Med Ethics 2021;47:662–9.
- 21 American Association of Suicidology. Statement of the American association of suicidology: 'suicido' is not the same as 'physician aid in dying. 2017. Available:

Feature article

- https://suicidology.org/wp-content/uploads/2019/07/AAS-PAD-Statement-Approved-10.30.17-ed-10-30-17.pdf
- 22 Velleman JD. A right of self-termination *Ethics* 1999;109:606–28.
- 23 American Psychiatric Association. Position statement on medical Euthanasia. 2016. Available: https://psychiatry.org/File%20Library/About-APA/Organization-Documents-Policies/Policies/Position-2016-Medical-Euthanasia.pdf
- 24 Younger SJ, Arnold RM, eds. The Oxford handbook of ethics at the end of life. Oxford: Oxford University Press, 2016.
- 25 Davis JK, ed. Ethics at the end of life: new issues and arguments. New York, NY: Routledge, 2017.
- 26 Committee on Approaching Death: Addressing Key End of Life Issues, Institute of Medicine. Dying in America: improving quality and honoring individual preferences near the end of life. Washington (DC): National Academies Press (US), 2015. Available: http://www.ncbi.nlm.nih.gov/books/NBK285681/
- 27 Gawande A. Being mortal: medicine and what matters in the end. New York, NY: Metropolitan Books, 2014.
- 28 Hall SS. A doctor and medical ethicist argues life after 75 is not worth living. MIT Technology Review; Available: https://www.technologyreview.com/2019/08/21/

- 238642/a-doctor-and-medical-ethicist-argues-life-after-75-is-not-worth-living/[Accessed 05 Oct 2022].
- 29 Jecker N. Ending midlife bias: new values for old age. New York, NY: Oxford University Press, 2020.
- D John TM, Millum J, Wasserman D. How to allocate scarce health resources without discriminating against people with disabilities. Econ Philos 2017;33:161–86.
- 81 Persad G, Joffe S. Allocating scarce life-saving resources: the proper role of age. J Med Ethics 2021;47:836–8.
- 32 Bagenstos ŚR. Who gets the ventilator? Disability discrimination in COVID-19 medical-rationing protocols. *Yale Law J* 2020:130:1–25.
- 33 Reed P. Expressivism at the beginning and end of life. *J Med Ethics* 2020;46:538–44.
- 34 Gill CJ. Suicide intervention for people with disabilities: a lesson in inequality. *Issues Law Med* 1992;8:37–53.
- 35 National Council on Disability. The danger of assisted suicide laws. 2019. Available: https://ncd.gov/sites/default/files/NCD_Assisted_Suicide_Report_508.pdf [Accessed 23 Mar 2022].
- 36 Braswell H. The crisis of U.S. hospice care: family and freedom at the end of life. Baltimore, MD: Johns Hopkins University Press, 2019.