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ARTICLE

# Refusals and Requests: In Defense of Consistency

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#### Abstract

Physicians place significant weight on the distinction between acts and omissions. Most believe that autonomous refusals for procedures, such as blood transfusions and resuscitation, ought to be respected, but they feel no similar obligation to accede to requests for treatment that will, in the physician's opinion, harm the patient (e.g., assisted death). Thus, there is an asymmetry. In this paper, we challenge the strength of this distinction by arguing that the ordering of values should be the same in both cases. The reason for respecting refusals is that, in such cases, autonomy outweighs well-being. We argue that the same should be true in request cases, which means that requests should not be denied only due to the treatment being too harmful in the physician's opinion. Our strategy is to consider and reject a number of arguments for the asymmetrical view, including an appeal to the doing—allowing distinction and positive and negative rights. The duty to respect refusals is still greater than the duty to grant requests on our view, but, by arguing that the ordering of values is the same in both cases, we show that there is less of a distinction in healthcare between requests and refusals than many currently believe.

Keywords: autonomy; beneficence; medical assistance in dying; patient-centered care; medical paternalism

### Introduction

Consider the following case:

*Refusal:* An adult patient is in need of a life-saving blood transfusion; without it, she will die. However, she is a devout Jehovah's Witness and firmly believes that it would be inconsistent with her values to accept a blood transfusion. She fully understands that if she refuses the transfusion, she will die.

Many philosophers and bioethicists, and indeed most physicians, believe that the physician ought to respect the patient's refusal in cases of this sort. The law in many places also supports this. Patients with decision-making capacity have the right to refuse any type of treatment they wish, and, when they do, the physician is ethically and legally obligated to comply. Considerations about the patient's well-being—such as by appealing to the principles of beneficence or nonmaleficence—are silent here. The patient's refusal is autonomous, and that is all that matters.

Now consider the following case:

*Request:* An adult patient requests a life-ending treatment. He firmly believes that continued living would be inconsistent with his values. He understands that taking the requested dosage of secobarbital will quickly bring about his death.<sup>2</sup>

In contrast to Refusal, most bioethicists believe that physicians have no grounds for acting on the request and even that it would be wrong for them to do so.<sup>3</sup>

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Consideration of our intuitive judgments about the two cases reveals an asymmetry. In Refusal, autonomy is the only relevant consideration; the fact that the patient had decision-making capacity was all we needed to know to judge that the physician's compliance with the refusal is appropriate. Any concerns about the patient's well-being—that is, that the patient is going to die because she does not get the transfusion—are completely defeated by autonomy. Of course, Request also involves an autonomous request; but judgment in that case often differs even if the patient gives valid consent. According to one commonly held view, in addition to satisfying an autonomy condition, requests of this sort must also satisfy a well-being condition. That is, the request must aim at increasing their well-being by, for instance, alleviating their suffering or treating a particular kind of medical condition. Absent such a condition, even an autonomous request followed by informed consent should be denied. So, given that no such condition is present in Request, the physician ought not to grant the patient's request in that case. Indeed, on one standard version of this view, the physician acts wrongly by granting it.<sup>5</sup>

In both cases, we are faced with a conflict between two values: autonomy and well-being. And in both cases, by hypothesis, the patient's decision satisfies autonomy. Yet, it is only in Request that well-being outweighs autonomy; in Refusal, autonomy defeats well-being. What can explain this difference? What reason do we have for accepting this asymmetry?

There are two general ways forward.

- Symmetry: We can accept that these two cases should be treated symmetrically and reject one of the intuitive judgments cited above.
  - (a) Reject "Refusal": This means either rejecting the claim that the physician should accept the patient's refusal in Refusal; or
  - (b) *Reject "Request"*: rejecting the claim that the physician should deny the patient's request in Request.
- (2) Asymmetry: The second option is to accept both of these intuitive judgments, which means denying that these two cases should be treated as symmetrical. In this case, the task is to offer a justification for why these two cases should be treated differently.<sup>6</sup>

Our approach in what follows is to begin with a defense of the intuitive judgment in Refusal, which we think is best captured by emphasizing the value of autonomy over other considerations, such as well-being. If this is correct, option 1a is a non-starter, and our remaining options are either to reject the intuitive judgment in Request (1b) or else to offer a justification for the asymmetry between the two cases (option 2). We consider the main reasons one might give for denying symmetry and find them all wanting. Thus, we are left only with the option of denying the intuitive judgment in Request—option 1b. In the end, we argue that this conclusion is not as troubling as it might initially seem.

To be clear, our argument in what follows concerns only the relative ordering of autonomy and well-being. As we will describe, there are many other reasons that might apply in cases like Refusal and Request, concerning matters like resources and physicians' rights. Our conclusion here is not that physicians are morally required to accede to requests like Request; this will depend on a broader range of factors, to which our present discussion cannot give sufficient treatment. Rather, our point is simply that the relative ordering of autonomy and well-being should be consistent across all like cases, so there is a strong pro tanto reason to comply. The justification for denying the request should not be "the intervention would be too harmful," since that should be left up to the patient.

Some other points are worth flagging about the distinction between refusals and requests. The first is that the details of the situation can vary, including the stakes involved. One can refuse minor procedures, such as extra tests, and requests are rarely of the life-ending sort described above. The disagreement can also concern risk, such as when a patient requests an intervention that might work but which is too risky in the physician's opinion. However, it is most illuminating, and easiest for comparison's sake, to focus on high-stakes cases.

The second point is that, although we argue that the ordering of autonomy and well-being should be the same in refusals and requests, other differences are possible. For example, it is likely that the threshold for valid refusal is lower than the threshold for valid consent. To give valid consent, the consent must be

suitably informed. To give valid refusal, in contrast, only capacity and voluntariness are required. Refusal does not have an information or understanding condition. This is true not just in healthcare, but in other cases: If someone offers you sex or a loan or to join the military, your refusal is valid even if you do not hear the details of the proposal.

The third point is that the distinction between refusals and requests can be murky. Consider a patient on a mechanical ventilator who says that she wants the ventilator removed, which will cause her death. This can be framed as a refusal, since she is refusing to let the care continue: "Doctor, I refuse to go on like this. If you don't remove this tube at once, I'll sue you for battery." We believe, however, that it is better to frame this as a request, since she is asking that the doctor disconnect the machine. Refusals in this sense are respected when the patient is left alone; requests, in contrast, require someone else to act. Consent has a transformative power: Were the doctor to remove the ventilator without the patient's consent, it would be wrong, but, with consent, the act is transformed into something morally permissible. Of course, at the bedside, few clinical ethics consults will turn on whether the patient is making a request or a refusal, and, since we are arguing that the ordering of values in refusals and requests is the same, it is less important for us to settle the hard cases than it is for other views.

One more ethically relevant difference is worth flagging here. We accept the intuitive judgment that it is worse to override a refusal than it is to fail to accede to a request. Giving the Jehovah's Witness blood products against her objections is a greater wrong than declining the request for an assisted death would be. This is because, so long as the patient has decision-making capacity and is making a voluntary choice in Refusal, there is essentially nothing else that could justify overriding her. The situation is different in Request, where there are multiple factors that could justify the physician in declining to assist the patient in dying, including, perhaps, the physician's own right to autonomy. So we are not claiming that Refusal and Request should be assessed identically. Rather, our claim is that the reordering of well-being and autonomy is unjustified in Request.

### Symmetry: Refusal and autonomy

Let us begin by considering the judgment in Refusal. Although we do not believe that being informed is a necessary condition for valid refusal, to make the cases more alike, we are stipulating that the patient's refusal is sufficiently well-informed about what her refusal entails; she is not subject to any coercion; she does not have any of the conditions that we might think would negatively affect her decision-making capacity (e.g., profound mental illness, severe sleep deprivation, shock, impairment from medication); and her decision flows from her deeply held values. In other words, the decision is autonomous, according to whatever account of autonomy we care to stipulate.8

Another important element of the case is that accepting the blood transfusion is necessary for the patient's life to continue. In other words, the transfusion is necessary to promote her well-being, at least medically speaking. This point invokes concerns about beneficence or nonmaleficence—that is, the idea that a core goal of medical treatment should be to improve the patient's well-being. Surely this feature of the case is what makes it at all controversial or ethically interesting in the first place: If it were not a blood transfusion, but rather a routine and not especially important blood pressure check, then most would not find the patient's refusal to evoke significant disagreement or concern. The fact that her refusal will result in her death, however, elicits concern about allowing an otherwise healthy patient to refuse lifesaving care when the care involves little risk.9

So, Refusal involves a tension between two values, autonomy and well-being. Most will agree that, provided that the patient's refusal is truly autonomous in the way previously detailed, the physician has no basis for resisting her refusal and forcing her to accept a blood transfusion. In other words, between these two values, autonomy trumps well-being. Why should we endorse this judgment of priority?

The basic idea here is that it would be overly paternalistic to override or reject a patient's autonomous choice in favor of promoting her well-being. We tend to think that we ought to defer to patients' autonomous choices in the absence of serious countervailing considerations. There may be many such considerations, such as risk or harm to others and public costs; but the patient's own well-being is not a

consideration that is capable of overriding her exercise of autonomy. If the patient lacked decision-making capacity and therefore could not act autonomously, then well-being considerations should play a bigger role in governing the physician's decisions. In most cases, if a substitute decision-maker is not available, a physician should proceed with a blood transfusion for a patient who is unconscious, incapable of understanding the information relevant to her condition and treatment options, or too young to give meaningful consent or refusal. Moreover, physicians must attempt to provide the patient with adequate information about how refusing a treatment will impact their well-being. These points illustrate the fact that physicians are right to aim at promoting well-being; none of the foregoing points count against the relevance of well-being or beneficence. The point, however, is that when autonomy is satisfied, this suffices to override these other conditions. 11

Despite its broad appeal, the view that autonomy trumps well-being does not enjoy universal acceptance. For one thing, some might worry that this judgment does not apply in all cases. To give an example from a different context, some believe that physicians (or others with the relevant authority) should force-feed prisoners who participate in hunger strikes. <sup>12</sup> If this is true, then it casts doubt on the idea that autonomy will always trump well-being. It is worth noting, however, that the majority of bioethicists and philosophers writing on this issue seem to share a broad agreement that force-feeding is morally wrong, since it violates the autonomous choices of the prisoners. <sup>13</sup>

Furthermore, most philosophers who deny that physicians ought to respect the patient's refusal in cases like this believe such a refusal fails to satisfy autonomy. One view is that the patient's judgment is based on irrational beliefs. On another view, the particular features of the doctrine of certain religious communities seem unduly coercive and restrictive, which calls into question a believer's ability to make an autonomous decision that conflicts with that doctrine. On these views, the patient's choice is not autonomous, so it does not make sense to discuss autonomy's priority over well-being. One could accept our argument here—that autonomy trumps well-being—while denying that cases of this sort involve a priority of autonomy, since autonomy is missing altogether. Although autonomy is clearly missing in some cases of this sort, we see no reason for thinking this is true as a conceptual matter. We therefore believe it is fruitful to consider what our judgment should be in cases in which autonomy is present, at least by stipulation.

When autonomy and well-being are both present in a given case of refusal, autonomy trumps well-being. We ought, therefore, to embrace the intuitive judgment behind Refusal. If this is true, then our remaining options are as follows: We can either treat Refusal and Request the same, which requires rejecting the intuitive judgment we saw in Request, or else accept the intuitive judgment in Request and offer an explanation for why these two cases should be treated asymmetrically. We turn now to this latter option. We will canvass what strikes us as the most plausible explanations for this asymmetry and show that none of them succeeds. If this is correct, then we are left with only one remaining option: reject the intuitive judgment in Request.

# Asymmetry: What could justify treating Refusal and Request differently?

At this point, one might grant that physicians ought to accede in Refusal and yet deny that this compels us to give autonomy the same weight in Request. And this is because there are morally significant differences between Refusal and Request that justify treating them differently—or so goes the argument. But what are these differences, and why should they justify treating these cases differently?

One possible salient difference in Request appeals to the distinction between doing and allowing, or killing and letting die. Whereas in Refusal, the physician merely allows the patient to die by granting her refusal, in Request, the physician actively kills the patient by acceding to his request. According to this view, active killing (doing) is worse than passively allowing one to die, all else being equal. <sup>15</sup> If this is true, then granting the patient's request might be morally wrong, whereas granting the patient's refusal is not.

The distinction between doing and allowing is most useful in cases where we must weigh the comparative strength of our duty to avoid harming against our duty to render aid. For example, this distinction is helpful in showing why, all else being equal, we have a greater moral reason to avoid killing

an innocent person than to avoid rescuing an innocent person. But although the distinction seems to apply in cases of this sort, it is hard to see why it should make a difference in cases like Request. After all, when a patient autonomously requests that some action be done to her, it no longer seems right to treat it as a harm or at least a wrongful harm. That is, her consent—in this case, via his autonomous request—makes what would have otherwise been a harm in the absence of such a request a (pro tanto) permissible act. <sup>16</sup>

To see this, consider an analogy. If we ask whether it is worse for A to punch B in the face, or for A to allow B to be punched in the face, we might conclude, with help from the doing—allowing distinction, that the former is worse than the latter, all else being equal. But if B has consented to being punched in the face —for example, if A and B have agreed to a sanctioned boxing match, or if B has autonomously requested a punch—then our reasons for thinking it worse than merely allowing B to be punched in some related scenarios have disappeared. His autonomous request serves to negate the importance of the distinction between these two types of harm, in part because it does not seem right to call it a harm anymore at all. (And even those who believe it is still a harm should agree that it is not a wrongful harm.) No doubt it will still *hurt*; but it is not a *harm*, in the morally relevant sense.<sup>17</sup>

This point is similar to a related point James Rachels makes in his classic paper "Active and Passive Euthanasia." Rachels argues that we cannot appeal to the distinction between doing and allowing to argue that active and passive euthanasia ought to be treated differently. When all else is equal in a given case, if passive euthanasia is justified, so too is active euthanasia. The mere fact that one is passive and the other is active does not by itself make a moral difference.

To be clear, Rachels does not put this point in terms of autonomy's relative priority to well-being. Although he does consider some cases in which autonomy is a factor, he also considers other cases in which autonomy is irrelevant, such as with newborns. Thus, unlike our present discussion, his argument does not require that a patient has made an autonomous choice. Furthermore, Rachels occasionally invokes the value of well-being in an effort to undermine the doing—allowing distinction: In some cases, it is *better* to actively hasten death, as opposed to letting someone wither painfully.

In short, there are important differences between what Rachels aims to show and what is relevant to our present argument. And yet, despite these differences, we can nevertheless extend Rachels' basic point. Refusal and Request seem to share all the same morally relevant features, apart from falling on opposite sides of the doing—allowing distinction. Even if one thinks that the difference between doing and allowing is morally relevant, it is not clear how this distinction alone could justify reordering the priority of autonomy and well-being in these two cases, given that the feature that makes it wrong and a harm—that is, the lack of consent—does not apply. If autonomy trumps well-being in allowing cases, then, in order to preserve the asymmetry, we must identify some element of doing cases that explains why either well-being is more significant or autonomy is less significant. But it is not clear what part of this distinction could explain this. The mere fact that in Request the physician is *doing* the relevant action does not tell us anything about how these two values ought to be ordered and mutatis mutandis for allowing the outcome in Refusal. We therefore see no reason inherent to the distinction between doing and allowing to think that autonomy is of lesser significance compared to well-being in cases of doing than in cases of allowing. In a discussion of assisted dying, Jeff McMahan makes a similar point:

[W]hen it is permissible for a person to do a certain act, it should also be permissible for a third party to do that act for him, at his request, provided that in doing the act the third party would not be unfairly favoring the one person over another.<sup>19</sup>

One might instead appeal to a related distinction—namely, the distinction between negative and positive rights (and duties). In general, negative rights are rights against interference. In the present context, this means that patients have a weighty negative right against others' interference with their bodily autonomy. This is the type of right the patient exercises in Refusal: The patient has a negative right against the physician (and, indeed, anyone else) interfering with her bodily autonomy. As a corollary, the physician has a stringent duty not to force the patient to accept the blood transfusion. By contrast, positive duties generally concern the securing of important goods, interests, or protections. In the present

context, this means that patients also have a positive right to medical assistance from qualified professionals, which is the right the patient attempts to exercise in Request.<sup>20</sup> (Or, if a right to assistance is too strong, then such assistance is at least permissible.) But positive rights generally impose much less stringent duties on others than do negative rights. To be sure, physicians have a general duty to provide care based on the patient's positive right, but this right is more easily outweighed than in the case of negative rights.<sup>21</sup> This is in part because, as a general matter, positive rights make greater demands on others than do negative rights: Positive rights require of the duty-bearer that they act or render aid, whereas negative rights require only inaction and non-interference. In other words, positive duties tend to be less stringent than negative duties with similar outcomes because positive duties involve a greater imposition on duty-bearers.<sup>22</sup> And it is at least partly for this reason that we generally think that it is easier to justify infringing a positive right than a negative right.

This distinction as applied to Refusal and Request appears, at first glance, to avoid the problem that beset the doing—allowing distinction. After all, unlike the more basic doing—allowing distinction, the difference between positive and negative rights (and duties) *does* seem to pick out a morally relevant difference between the two cases—namely, the fact that Refusal involves a negative right, whereas Request involves only a positive right (or at least a permission). Given that all else is equal, it seems that the right in Request is weaker than the right in Refusal. And this, it might seem, is enough to show why we should treat the two cases differently.

We grant that this distinction helps to ground an important difference between the rights in the two cases, which in turn provides the resources for understanding the extent of the physician's duties in both cases. In particular, this distinction helps explain the intuitive judgment, which we grant, that physicians have greater moral reason in general to comply with patients' refusals than patients' requests, all else being equal. Physicians have negative duties to avoid interfering with the bodily integrity of their patients, and the threshold for justifying forcibly administering a medical procedure to a patient who steadfastly refuses it is incredibly high. By contrast, given that it involves only a positive duty, the threshold for declining to act on a patient's request for assistance is comparatively low. Moreover, positive duties in general—and this is certainly true in Request—require more than just an agent's positive action: They also require resources, certain particular kinds of access, skills, individual labor, and so on. Thus, there is a wider range of considerations relevant to determining whether one can or ought to fulfill a positive duty. That is, all else being equal, there are many more reasons that might count against fulfilling a positive duty than would be true of an otherwise similar negative duty.

The differences between the positive right in Request and the negative right in Refusal are important, particularly concerning the extent of the physician's obligations and our all-things-considered judgments about what he ought to do. But although these are important issues concerning the broader question of what the physician ought to do, neither of them bears on the question we initially sought to answer here—namely, what can explain the difference between the ordering of the values of autonomy and well-being in the two cases?

We grant that positive duties are generally less stringent than negative duties, which is reflected in what physicians can be morally required to do; we grant that positive duties tend to require considering a broader range of relevant factors. But it does not follow from either of these facts that we are justified in reversing the relative priority between autonomy and well-being between the two cases. For one thing, the special factors relevant to positive duties do not make any necessary reference to either autonomy or well-being. It is not as if concerns about the patient's good suddenly become much more important or salient in cases where the treatment is requested as opposed to refused, nor is it the case that the value of autonomy is weakened—either absolutely or relative to well-being—in cases where the patient invokes a positive right. There is simply no connection between the ordering of these two values and the type of right or duty in question.

Moreover, the fact that the physician's positive duties are less stringent than her negative duties concerns only the question of what we can demand of the physician in terms of positive action. Whether or not the physician can justifiably decline to comply with the patient's request does not, however, turn on the independent importance of the patient's good relative to her autonomous choice. Rather, it

concerns the duty's weight, which is to say, the extent of the demands it can justifiably place on the physician.

To see this point more clearly, consider a case in which the physician, having assessed the patient as fully capable and autonomous, is willing to grant the request. In this case, the distinction between positive and negative duties is not nearly as relevant: The physician voluntarily accedes to the request, so there is no longer any concern about the extent of this duty's imposition. Those who think the positive—negative duty distinction is what explains the reversal in ordering between autonomy and well-being do not have grounds for maintaining that ordering once the physician accedes to the request. Absent some further arguments, they must hold that autonomy trumps well-being in this case. But it is hard to see why the physician's acceding to the request produces this reordering effect. What about the physician's choice serves to change the relative values of these two values themselves?

We suspect that even if a physician voluntarily accedes to the request, many will still claim that it is wrong to do so. These objectors' concerns do not rest entirely with the extent of the demands placed on the physician, but rather with the idea that physicians could reason this way at all—that is, by prioritizing autonomy over well-being—in cases like Request. If it is indeed true that some will hold on to this judgment in this case, then the distinction between positive and negative rights and duties does not offer an explanation for the asymmetry.

To be sure, the weight of this duty is determined in part by the harm (or loss of good) that would thereby be done. Duties that protect agents from more serious harms are, appropriately, more serious duties. But one would need a further argument to explain why the physician would do harm to the patient in a case like Request. After all, the request is fully autonomous. And, as we have already suggested, complying with the request of a fully autonomous patient does not qualify as a harm, at least in the sense relevant here.

## Symmetry: Rejecting the intuition in "Request"

If the foregoing arguments are correct, then there is no clear basis for preserving the asymmetry between Refusal and Request. As such, the only remaining option is to reject the judgment in Request, which held that well-being trumps autonomy. The better view is to treat cases like Refusal and Request the same: When looking to the values of autonomy and well-being, the former wins out.

One might object that rejecting this intuition would give rise to several unpalatable conclusions, which might be so serious as to make one of the other claims comparatively easier to accept. For one thing, one might worry that allowing autonomy to trump well-being in cases like Request will give rise to dramatic shifts to physicians' professional roles: If this were the norm, physicians would turn into professional killers, or, to borrow a phrase from Leon Kass, "scalpels for hire." <sup>23</sup>

Since we have addressed this point at length elsewhere, we will offer some briefer responses here. Our first response is that Kass is mistaken that it is objectionable to use medicine to help people live in accordance with their values. Many types of treatment are already autonomy-centered, including vasectomy, tubal ligation, gender confirmation surgery, and nontherapeutic abortion. Most of the time, these procedures are not medically indicated or proposed by the physician, and they do not involve healing. Rather, people get them because they want them. Of course, some of these treatments are morally controversial, but few people have an issue with, for example, tubal ligation because it is request-based. Similarly, physicians are justified in providing nontherapeutic abortions because having an unwanted baby is a significant disruption to one's life. Promoting autonomy is an important goal of medicine.

Second, some might worry that our view is committed to a strong obligation of physicians to fulfill requests and that this might outweigh the right of physicians to decide which treatments to offer. We disagree on the extent that physicians have a right to conscientious objection, but nothing about our view here threatens conscientious objection. As we have said, although our view posits a pro tanto duty to promote autonomy, there are many reasons why the physician need not accede to requests, including, perhaps, matters of conscience.

Finally, there is a general worry that a request-based system will upend healthcare and, perhaps in the extreme, society. This worry holds that, if patients can request treatments, nothing will stop young people from getting assistance in dying while in the throes of a breakup, or people accessing opioids for pleasure, or someone using gene editing to make himself taller so he can be better at basketball. But as we stated above, an absolute right to care does not follow from a request, and there are many reasons why the requests just listed could be refused, including equality, concerns that the request is not autonomous, and the risk of harm to others.

Those who remain unpersuaded by our argument have two options. The first is to offer an explanation for the asymmetry in the value ordering of autonomy and well-being. Such an argument must explain why autonomy trumps well-being in cases of refusal, but the ordering is reversed in cases of request. As we have argued, we doubt that such an argument can be made. The other option is more radical. Some will be convinced that the asymmetry cannot be explained, but, rather than agree with us that autonomy trumps well-being, they will go the other way by claiming that well-being should consistently outweigh autonomy. This is the way medicine used to be done. The physician would determine what he thought was best for the patient and then he would do it. We find this approach indefensible, as do nearly all physicians and bioethicists. Therefore, one of the other options is necessary.

#### Conclusion

There is a sense in which our point here is modest. Our claim is that autonomy, when it exists, should consistently outweigh well-being in medicine. For most physicians, refusal is an ethical red line. The law supports this by defining non-consensual treatment assault. The ethical and legal justification for this position is that people have a right to decide what happens to their bodies, and providing care that is in line with the patient's values is a core value of medicine. Our point is that the value ordering does not change when the patient requests a treatment instead of the physician offering one. Autonomy should outweigh well-being in both cases. But, as we have argued, the strong duty to respect refusals does not transfer at equal strength to a duty to accede to requests, for there are many reasons—scarcity, the risk of harm to others, the physician's medical ability, and conscientious objection—that might justify declining the request.

At the same time, giving an increased role to requests will change the healthcare system. We believe that this is for the best, as recognizing a role for requests will increase patient autonomy in healthcare, which will continue the move toward patient-centered care. As physicians start to see their patients' values as increasingly relevant to their healthcare choices, we need to understand how physicians ought to reason about these cases. Our model offers guidance, though of course, only partial guidance.

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### Notes

- 1. In this paper, we use "well-being" since, as a value, it is explanatorily prior to the principles of beneficence and nonmaleficence, which are derived from it. In fact, principlism might be partially responsible for the prevalence of the asymmetry we oppose between refusals and requests, since it focuses on the duties of the healthcare provider instead of the patient. Nevertheless, our argument is the same if principles are used instead of values, so readers are invited to substitute according to their preferences.
- 2. We have chosen this example of a Request due to its relevance to the case we selected in Refusal. But it is worth highlighting that many other examples frequently discussed in the literature involve requests that do not involve termination of life, but rather drastic changes to one's body—for example, those who experience body integrity identity disorder (BIID). For recent discussion, see

- Gibson RB. Elective impairment minus elective disability: The social model of disability and body integrity identity disorder. *Journal of Bioethical Inquiry* 2020;**17**(1):145–55.
- 3. See Gert B, Bernat JL, Mogielnicki RP. Distinguishing between patients' refusals and requests. *Hastings Center Report* 1994;**24**(4):13–5. We have chosen the examples in Refusal and Request because of their salience, but we intend our argument to apply generally in healthcare. Other types of refusal should be respected, and they are, as respect for Do Not Resuscitate orders shows. Exactly what types of requests should be respected is, of course, a major question. We have argued elsewhere that autonomous requests for physician-assisted death are justified (see Davis J, Mathison E. The case for an autonomy-centered view of physician-assisted death. Journal of Bioethical Inquiry 2020; 17: 345–356). Our aim here is not to offer a complete account of the view, but, less ambitiously, to show that respecting requests is justified.
- 4. This approach is particularly common in the euthanasia literature. For example, L.W. Sumner says, "The arguments from well-being and autonomy provide the basic justificatory framework for assisted suicide and voluntary euthanasia." Sumner LW. Assisted Death. New York: Oxford University Press; 2011:91. Jurriaan De Haan writes, "while the patient's autonomous request for euthanasia is a contributing factor indeed, his condition is an enabling/disabling factor. Despite the patient's autonomous request, euthanasia is only permissible if the patient's suffering is unbearable and hopeless." De Haan J. The ethics of euthanasia: Advocates' perspectives. Bioethics 2002;16:154–72, at 169.
- 5. The most common justification is that it violates the principle of nonmaleficence. Most physicians and bioethicists, for example, oppose amputations of healthy limbs for people with body integrity identity disorder. Arthur Caplan said, "It's absolute, utter lunacy to go along with a request to maim somebody," thereby appealing to nonmaleficence, though he also questioned whether someone requesting amputation could have capacity (https://www.salon.com/2000/08/29/amputation/).
- 6. This is not to say that the burden of proof is on the asymmetrical view, or that asymmetries are inherently problematic. However, if a survey of explanations produces no compelling reason for the asymmetry, and if there are reasons for symmetry, we have reason to believe that our intuitions for the asymmetry are mistaken.
- 7. Given this, our argument overlaps but is different in scope and approach to Jessica Flanigan's in *Pharmaceutical Freedom* (Oxford University Press; 2017), in which she argues that people have a right to self-medication by way of a similar pair of cases comparing refusal to treatment access. Flanigan's argument is, roughly, that broader access to pharmaceuticals ought to be permitted, whereas our argument is not, in the first instance, about what is permitted (or prohibited), but rather about how the various principles ought to be ordered when making such determinations in clinical contexts.
- 8. Those who might wish to impose further necessary conditions on an autonomous decision are invited to add these conditions to the description of the initial case. In most cases, the argument we make here will still go through. If not, then this might suggest that such a view of autonomy is so restrictive as to rule out far too many plausible cases, which would give us good reason to reject such a view.
- 9. Philosophers disagree on the extent that autonomy is part of welfare or distinct from it. For examples of theories of welfare that include autonomy, see Mill JS. On liberty. New York: Norton; 1859/1975; Kymlicka W. Liberalism, Community, and Culture. Oxford: Oxford University Press; 1989; Wall S. Liberalism, Perfection and Restraint. Cambridge: Cambridge University Press; 1998; Sumner LW. Welfare, Happiness, and Ethics. Oxford: Oxford University Press; 1996. Our view is that at least some of the time autonomy is distinct. This is because it is possible for someone to autonomously do what is prudentially bad for her by, for instance, acting altruistically. Therefore, "living according to one's values" is not always synonymous with "promoting one's welfare," which means that there is some important sense in which not getting the blood transfusion is bad for the patient. Her death is a great loss to her, but her values mean that she orders some things above the badness of death.
- 10. This is complicated by the fact that, in many cases, physicians defer to substitute decision-makers for deciding which treatment the patient ought to receive (or not). For a discussion of some of these difficulties, see Buchanan AE, Brock DW. Deciding for Others: The Ethics of Surrogate Decision-Making. Cambridge: Cambridge University Press; 1989. For a discussion on end-of-life substitute

- decision-making, see Appel JM. Trial by triad: Substituted judgment, mental illness and the right to die. Journal of Medical Ethics 2022;48(6):358-61.
- 11. The conditions of informed consent are generally agreed upon, though in practice there will be tough cases when determining capacity. See Faden R, Beauchamp T. A History and Theory of Informed Consent. New York: Oxford University Press; 1986; Beauchamp T, Childress J. Principles of Biomedical Ethics. 4th ed. New York: Oxford University Press; 1994; Beauchamp T. Autonomy and consent. In: Miller FG, Wertheimer A, eds. The Ethics of Consent. New York: Oxford University Press; 2010; and Berg J, Appelbaum P, Lidz C, Meisel A. Informed Consent: Legal Theory and Clinical Practice. 2nd ed. New York: Oxford University Press; 2001.
- 12. Examples both for and against include Howe EG. Should military care providers force-feed detainees? Military Medicine 2015;180(12):1203-4; Howe EG, Kosaraju A, Laraby P, Casscells SW. Guantanamo: Ethics, interrogation, and forced feeding. Military Medicine 2009;174(1):iv-xiii; Rubenstein L, Annas G. Medical ethics at Guantanamo Bay detention centre and in the US military: A time for reform. Lancet 2009;374(9686):353-5.
- 13. Those who value the sanctity of life over autonomy, as some defenders of force-feeding do, will likely also be against accepting Refusal. For the reasons we give above, we think this position is mistaken.
- 14. For a view of the former sort, see Savulescu J, Momeyer RW. Should informed consent be based on rational beliefs? Journal of Medical Ethics 1997;23:282-8. For a view of the latter sort, see Muramoto O. Bioethics of the refusal of blood by Jehovah's witnesses: Part 1. Should bioethical deliberation consider dissidents' views? Journal of Medical Ethics 1999;24:223-30.
- 15. Our aim here is not to defend this distinction. (Indeed, we disagree between ourselves on the extent of its application in moral theory.) Our point is simply to show that this distinction cannot explain why we should treat Refusal and Request differently.
- 16. For our purposes, what is relevant is that the act becomes permissible. Whether or not there is still something harmful about it—that is, whether there can be "consensual harms"—depends on one's definition of harm. Because our point stands either way, we will not try to settle this issue, but see Feinberg J. Harm to Others. Oxford: Oxford University Press; 1984; Lazar S. The nature and disvalue of injury. Res Publica 2009;15(3):289-304; Hanser M. The metaphysics of harm. Philosophy and Phenomenology Research 2008;LXXVII(2):421–50.
- 17. For those who think being consensually punched is still a harm, the symmetry point also applies in Request and Refusal. That is, if the physician unjustly harms the patient by acceding to the request for assistance in dying because dying is a harm, the physician also harms the patient in Refusal by letting her die.
- 18. Rachels J. Active and passive euthanasia. New England Journal of Medicine 1975;292(2):78-80.
- 19. McMahan, The Ethics of Killing Chapter 5, Section 2
- We have argued elsewhere that assisted dying is a legitimate goal of medicine Mathison E, Davis J. Value promotion as a goal of medicine. Journal of Medical Ethics 2021 47(7): 494–501.
- 21. One might object here that we are not plausibly talking about "care" in any standardly accepted sense in Request. On this view, the patient does not need this treatment and so does not have anything resembling a positive right to it. But this definition of care builds the well-being condition into it, which seems too tendentious for this discussion. Ultimately, we must either understand "care" in a way that is sufficiently broad such that it allows the requested treatment in Request to fall under it, in which case we can continue to discuss whether or not the positive-negative right distinction is of use in distinguishing Request and Refusal, or else understand "care" so narrowly that it rules out requests like Request. If we take this latter route, we have identified an important distinction between Refusal and Request—namely, that Refusal (and not Request) involves an important right. But we would still need a further argument to show why this right is enough to reorder autonomy and well-being. And, for reasons related to those we go on to discuss here, we doubt that this will be successful.
- 22. For a sustained argument in defense of this general idea, see Woollard F. Doing and Allowing Harm. Oxford: Oxford University Press; 2015.
- 23. Kass L. The end of medicine and the pursuit of health. Public Interest 1975;40:11-42, at 12.

- 24. Davis J, Mathison E. The case for an autonomy-centered view of physician-assisted death. Journal of Bioethical Inquiry 2020;17:345–356; Mathison E, Davis J. Value promotion as a goal of medicine. Journal of Medical Ethics 2021;47(7):494–501.
- 25. Notice that some of the most popular defenses of abortion in the philosophical literature are autonomy-based. See, for example, Thomson J. A defense of abortion. *Philosophy and Public Affairs* 1971;**1**(1):47–61.