

ARE PATIENTS' DECISIONS TO REFUSE TREATMENT BINDING ON HEALTH CARE PROFESSIONALS?

PETER MURPHY

ABSTRACT

When patients refuse to receive medical treatment, the consequences of honouring their decisions can be tragic. This is no less true of patients who autonomously decide to refuse treatment. I distinguish three possible implications of these autonomous decisions. According to the Permissibility Claim, such a decision implies that it is permissible for the patient who has made the autonomous decision to forego medical treatment. According to the Anti-Paternalism Claim, it follows that health-care professionals are not morally permitted to treat that patient. According to the Binding Claim it follows that these decisions are binding on health-care professionals. My focus is the last claim. After arguing that it is importantly different from each of the first two claims, I give two arguments to show that it is false. One argument against the Binding Claim draws a comparison with cases in which patients autonomously choose perilous positive treatments. The other argument appeals to considered judgments about cases in which disincentives are used to deter patients from refusing sound treatments.

When patients refuse to receive medical treatment, the consequences of honoring their choices can be tragic. Significant unnecessary suffering and even death can result if health-care professionals honor the wishes of patients who, for example, refuse to be resuscitated, refuse to have blood transfusions, or refuse to be fed.¹ And this is no less true of patients who *autonomously* choose to refuse treatment.

¹ For a multidisciplinary dialogue on the general issue of patient refusals, see C. Wong & S. Swazey (eds.). 1981. *Dilemmas of Dying: Policies and Procedures for Decisions Not to Treat*. Boston, MA. G.K. Hall Medical Publishers.

It is very plausible to think that health-care professionals should respond to a patient who makes a perilous choice like this by explaining the detrimental consequences of their refusal. Once this is done, the patient can have another opportunity to make a choice. In some instances, though, this can't be done, and in others it does not achieve the desired result: there may not be time for the patient to deliberate again, the patient may refuse to deliberate again, the patient may deliberate again only to make another perilous choice, or the patient may deliberate again but fail to settle on any of the other options. For all of these reasons, decisions not to be treated that are both autonomously made and perilous are going to persist.

Ethical issues regarding these decisions can be organized in terms of what claims do, and do not, follow from the fact that a patient has made an autonomous choice. Here, I will consider three possible implications, paying special attention to the third. According to the 'Permissibility Claim,' such a decision implies that it is permissible for the patient who has made the autonomous choice to forego medical treatment. The second claim is the 'Anti-Paternalism Claim.' It says that it follows that health-care professionals are not morally permitted to treat the patient.² The main focus here will be another claim, one that has not received as much attention. I call it the 'Binding Claim.' It says that it follows that these decisions are binding on the health-care professionals working with the patient. My aim is to establish two things. First, I will argue that the Binding Claim is importantly different from the Permissibility Claim and the Anti-Paternalism Claim. Then, I will give two arguments against the Binding Claim, and offer an alternative view.

I. DISTINGUISHING THE CLAIMS

Each of the three claims says something follows from the fact that a patient has autonomously decided not to be treated. However, these claims are importantly different. The Permissibility Claim differs from the Anti-Paternalism Claim and the Binding Claim, because the Permissibility Claim only asserts that something about the patient follows, namely that she is permitted to forego treatment. It simply does not assert anything about anyone other than the patient. By contrast, both the Anti-Paternalism Claim and the

² For a full discussion of paternalistic claims in health care, see J. Childress. 1982. *Who Should Decide?: Paternalism in Health Care*. New York, NY: Oxford University Press.

Binding Claim assert that something about other people – namely, health care professionals – follows.

This gap between the Permissibility Claim, and the Anti-Paternalism and Binding Claims is reinforced by cases. Consider a case which suggests that in general it is *not* true that if an agent is permitted to pursue some option (as the Permissibility Claim asserts), then other agents are not permitted to do anything that will interfere with her chances of executing her option (as the Anti-Paternalism Claim asserts). Though I am permitted to buy the last piece of cake that is for sale at the coffee shop, it does not follow that my fellow patrons are not permitted to do things that will decrease my chances of buying the cake. For they too are permitted to buy the cake; and if one of them does so, this will ruin my chance of buying it. This case suggests that until we are given reasons to think there is something special about patient decisions to refuse treatment, we should hold that the Permissibility Claim does not imply the Anti-Paternalism Claim. In addition, this case also suggests that the Permissibility Claim does not imply the Binding Claim. For while it is permissible for me to buy the cake, even if I decide to buy it and I express my intention to others, this does not bind others to clear the way for me to buy the cake.³

What about the relationship between the Anti-Paternalism Claim and the Binding Claim? The obvious difference between these claims is that the Binding Claim, but not the Anti-Paternalism Claim, is about forging an agreement between two parties. Recall that the Binding Claim says that when a patient makes one of the decisions that we will be concerned with – an autonomous decision to not be treated – this is sufficient to bring about an agreement between the patient and health-care professionals, an agreement that morally binds the health-care professionals. Now, while there can be, as we will see, different things that such a decision might bind a health-care professional to, even if it only binds a health-care professional to not treating the patient against her wishes, there is an important theoretical difference between the Anti-Paternalism Claim and the Binding

³ The fact that the Permissibility Claim does not imply either the Anti-Paternalism Claim or the Binding Claim should not be taken to suggest that the Permissibility Claim is somehow more likely to be true. In fact, there are good reasons for thinking that it is not true. Though the issues largely hinge on one's overall ethical theory, familiar versions of consequentialism, Kant's deontological theory, and classical virtue ethics all leave plenty of room for self-regarding actions that are not morally permissible.

Claim. The difference lies in the fact that only the latter invokes the notion of a contract.

Not only does the Anti-Paternalism Claim not include any contractual language, anti-paternalist claims are typically not established by arguments that invoke anything about contracts. Instead, they are arrived at more directly. Their proponents typically argue that such claims follow from a pair of premises, neither of which invokes the notion of a contract. The first premise reports that a patient's decision to forego treatment was made autonomously; the other premise says that if this patient foregoes treatment, no harm will thereby come to any non-consenting party. So contractual notions do not appear in either the Anti-Paternalism Claim or the standard justification for anti-paternalist claims.

As I have said, there is a contractual notion at the center of the Binding Claim. Indeed, the claim can be understood in terms of the historical nature of contracts. Contracts run through three main stages: they are entered into, they continue for a while, then they end. There are separate conditions for each stage. We can call the conditions that must be met if the parties are to initiate a morally binding contract, 'entry conditions.'⁴ The Binding Claim states a sufficient entry condition that when met initiates an agreement between a patient and a team of health care professionals. In the next two sections, I will give two arguments against the Binding Claim. I will attempt to show that not only is making an autonomous choice to forego treatment *not* sufficient to initiate a binding agreement, but that some such choices entail that a binding agreement has *not* been initiated. According to the second, stronger claim, such a choice constitutes a failed entry.⁵

Distinguishing between the Anti-Paternalism Claim and the Binding Claim allows us to be more careful when thinking about respect for patients' autonomy and patients' rights of self-determination. Many articulations of respect for autonomy fail to make clear whether such respect entails the Anti-Paternalism Claim, or the Binding Claim, or both. For instance, the Council

⁴ Entry conditions are contrasted with continuation conditions and exit conditions. Continuation conditions must be met if the morally binding nature of an agreement is to continue; exit conditions must be met if a morally binding agreement is to end.

⁵ For more on taking the relationship between patients and health care professionals as being importantly contractual, see R. Masters. Is contract an adequate basis for medical ethics? *Hastings Center Report* 1975; 5: 24–28; and J. Childress & M. Siegler. *Metaphors and Models of Doctor-Patient Relationships: Their Implications for Autonomy*. *Theoretical Medicine* 1984; 5: 17–30.

on Ethical and Judicial Affairs of the American Medical Association offers a principle of patient autonomy, which 'requires that physicians respect a competent patient's decision to forego any medical treatment.'⁶ This characterization is ambiguous. Is it the Anti-Paternalism Claim that follows from the requirement to respect such decisions, or does the Binding Claim follow, or do both? The Council does not say. Nor does asserting that the right to refuse treatment is basic or fundamental tell us anything about what this right implies.⁷ As we will see, the correct view on this matter is important for theoretical reasons, since it will tell us how central contractual notions are to such widely held principles. Also, as I will argue later, it bears on certain practices.

II. THE PARITY ARGUMENT

Since the Binding Claim is most closely associated with theories of informed consent, I am going to set out my first argument in terms of one of the chief problems that theories of informed consent must satisfactorily solve. This problem is posed by cases where there is a tradeoff between promoting a patient's well being and respecting her autonomous choice. In the tradeoff cases that I will focus on, a patient autonomously chooses a course of action that ranks poorly in terms of well being.⁸

Among general approaches to medical ethics, there is considerable agreement about the nature of these cases. To see that this is so, we can think of general approaches as giving agents aims. Among the approaches, we find single-aim theories and multiple-aim theories. The former include the consequentialist aim of promoting overall utility, and the deontological aim of treating people as ends, and not merely as means. Multiple-aim theories prescribe aims such as acting in ways that are beneficent, non-maleficent, respectful, and just. There are, then, a wide variety of approaches in circulation. Fortunately there are also some compelling standards of adequacy against which we can assess the approaches. Among the most compelling, we find the simple

⁶ Council on Ethical and Judicial Affairs. *Decisions Near the End of Life*. *Journal of the American Medical Association* 1992; vol. 267, no. 16: 2229–2233; 2229.

⁷ One place where we find the assertion that the right is basic and fundamental, without a view about what the right consists in, is the court case, *Bouvia v. Superior Court*, 225 Cal Rprt 297. 1986.

⁸ Of course, it has to be verified that a choice is both autonomous and perilous, especially given the provisional assumption in favor of taking autonomous choices as being non-perilous.

demand that the moral aims of health-care professionals include the promotion of the overall well-being of patients and respect of patients' autonomous choices. An approach that does not include these two aims is *seriously* defective. Without the aim of promoting the overall well-being of patients, an approach is without the obvious means for explaining why health-care professionals are not to intentionally and unnecessarily neglect their patients. And without the aim of respecting patients' autonomous choices, an approach is unequipped to explain, again in the most obvious way, why health-care professionals cannot simply ignore the choices of their patients. The aims of promoting patient well-being and respecting patient autonomy, then, are indispensable to any plausible medical ethical theory.

Of course, different approaches have different specific conceptions of these aims. Fortunately, for present purposes, we can remain neutral and allow approaches to employ their favored conceptions of these aims. We can do this because the main competing approaches agree with the following basic claims about autonomy and well-being, and it is only these claims that will be employed in the ensuing argument.

Consider, first, autonomy. Here our interest is in autonomous *choices*, and the following basic claims. What makes a choice autonomous are facts about the process by which a person comes to make that choice. Various facts about this process determine the degree to which the decision is autonomous. The exact determinants and their relative weights are controversial. Proposed determinants include the extent to which a patient is informed about her options, the extent to which she comes to her decision free of external coercive pressures and distorting internal pressures, and the extent to which her choice reflects her deep values. At least some of these determinants admit of degree, and thereby make the autonomy of choices also admit of degree.⁹ This gets us a continuum along which some processes of deliberation clearly manifest autonomy, others clearly fail to manifest autonomy, and others fall in a gray area because they neither clearly manifest, nor clearly fail to manifest, autonomy. In what follows, I will focus on choices that belong to the first of these classes – choices that clearly manifest autonomy. I will refer to these simply as 'autonomous choices.' We have, according to the

⁹ It is important that not all determinants of autonomy have to admit of degree for autonomy itself to do so. A theory that exemplifies this is endorsed in R. Faden & T. Beauchamp. 1986. *A History and Theory of Informed Consent*. New York, NY. Oxford University Press: chapter 7.

standard approaches, a *prima facie* duty to respect autonomous choices.

Consider next well-being. Considerations of expected well being are based on comparative facts. Choices that do poorly are choices in favor of options which, among the options, rank poorly in terms of the well-being that they are expected to bring about. Along a ranking of available options, we can also expect to find three classes: some of the options are clearly much better than the rest when assessed for the well-being that they are expected to bring about; some are clearly inferior to others; and some are neither clearly much better than, nor clearly inferior to, the rest. The cases I will be focusing on belong to the second class: they involve chosen options, which are clearly inferior to others. I will call these 'perilous choices.' These include choices in favor of high risk treatments, choices in favor of unproven methods of treatment, and choices in favor of drugs and medical practices that have with good reason been deemed illegal.

Now since the Binding Claim says that *all* autonomous patient decisions to forego treatment are binding on health-care professionals, its truth requires that the perilous subset of these choices be binding on health-care professionals. To show that this second claim is false, I offer a three premise argument.

The first premise has us start with a different set of cases. These are the subset of perilous autonomous choices that are choices *for positive courses of action*. These are just courses of action besides refusing treatment. These include cases where health-care professionals perilously engage in unnecessarily high risk treatments, unproven methods, and other unnecessarily harmful courses of action.¹⁰ The first premise asserts that choices of this kind are not binding on health-care professionals. This premise has the status of a strong considered judgment. Health-care professionals have as one of their uncontroversial aims, the promotion of patient well being. This aim implies that they are not morally obligated to carry out the wishes of patients who want perilous positive treatments.¹¹ And this is no less true for wishes that are arrived at autonomously. In fact, an even stronger claim seems correct: in many cases, health-care professionals are *morally forbidden* from treating these patients as they wish to be treated. All of this makes

¹⁰ If there is no defensible distinction between positive courses of action and cases of foregoing treatment, then the Binding Claim relies on an illegitimate distinction, and is therefore false.

¹¹ This claim does not imply anything about whether it is permissible for health-care professionals to go ahead and treat the patient in some way that she did not authorize.

for a strong, considered judgment that few people will seriously question.¹²

The second premise in the argument uncovers the ground for the first premise. Exactly why do the choices circumscribed in the first premise fail to bind health care professionals? The answer to this question must appeal to an aim in one's overall ethical framework. The answer, however, cannot appeal to respecting patient autonomy, since respecting patient autonomy would require carrying out the patient's perilous choice, a choice that *should not* be carried out. The judgment that these wishes do not bind must be grounded, instead, in a duty to promote patient well-being. This, of course, is just what we should expect, since it is the fact that these choices are perilous that makes them fail to bind; and this fact obviously concerns well being.

An alternative explanation of the failure of these choices to bind invokes the professional autonomy that can be exercised by health-care professionals. According to this explanation, when patients make such choices, health care professionals can exercise their autonomy and refuse to facilitate such choices. This explanation has a serious drawback, though. It comes with health-care professionals who *do not* refuse to facilitate patients' perilous choices. On this explanation, these professionals *are* bound to facilitate such choices. It would then be permissible for them to facilitate these choices. This, however, goes against the view that the promotion of patients' well being constrains, in a more significant way, what health-care professionals are, and are not, permitted to do. So an appeal to professional autonomy yields the wrong result in these cases. However, an appeal to the perilous nature of the choices does not. On this appeal, it is not permissible for professionals to facilitate perilous choices even when the professionals agree and go along with these choices.¹³

The argument's third premise builds on the second premise. Since autonomous perilous choices fail to bind health-care professionals precisely because they are perilous, this premise asserts that any other patient choice that is similarly perilous is a choice that, for just the same reason, fails to bind. This premise can be thought

¹² The cases I describe include instances of all three limitations on the exercise of patient autonomy identified in R. Schwartz. *Autonomy, Futility, and the Limits of Medicine*. *Cambridge Quarterly of Health Care Ethics* 1992; 2: 159–164. The limitations are a function of (1) patient choices to be treated by non-medical means, (2) patient choices to be treated in a way that is scientifically futile, and (3) patient choices to be treated in ways that are inconsistent with the ends of medicine.

¹³ For more on appeals to professional autonomy, see my *Competing Deep Justifications of Professional Autonomy in Medical Ethics*. Manuscript.

of as demanding consistency. Fully spelled out, it says that if autonomous perilous choices for positive treatments fail to bind health-care professionals because of facts about patient well-being, then autonomous perilous choices to forego treatment also fail to bind health-care professionals, when similar facts about well-being are in place.¹⁴ This gets us a parity argument. From considered judgments that certain choices for positive courses of treatment are not binding on health-care professionals, and the further thought that these choices fail to bind because they are perilous choices, it follows that equally perilous choices to forego treatment must, for just the same reason, fail to bind health-care professionals.¹⁵

The line of reasoning embodied in this argument allows us to see an alternative to the Binding Claim. On the alternative, patients who decide on a perilous course of positive treatment and patients who decide on a perilous course of foregoing treatment *both* fail to meet an entry condition that must be met for there to be a morally binding agreement between patient and health-care professional. Since this article asserts a parity between these two kinds of perilous patient choices, I call it 'the Parity Claim.'¹⁶

III. THE ARGUMENT FROM SUBSEQUENT CONDITION CASES

In this section, I provide a second argument for preferring the Parity Claim to the Binding Claim. This argument also allows reveals that the Binding Claim and the Anti-Paternalism Claim

¹⁴ This claim can be thought of in terms of what philosophers call 'supervenience.' If the fact that certain choices in favor of positive treatments are not binding supervenes upon, or follows upon, their being perilous, then whenever the same facts hold – that is whenever, a patient makes a perilous choice – that choice fails to bind.

¹⁵ There are some approaches to medical ethics on which there is a more direct argument against the Binding Claim. These are approaches that restrict the set of genuinely autonomous choices to choices that meet some level of adequacy in promoting patient well being. On these approaches, a sufficiently perilous choice to forego treatment is not a choice that can be made autonomously. Since these choices do not even count as autonomous, there is no initial reason to think that they might be binding on health care professionals.

¹⁶ A different parity claim concerns the permissibility of coercive measures. It says that unless some special supporting reasons are offered, if patient choices in favor of perilous positive treatments make some alternative coercive courses permissible, then patient choices to forego treatment make the same coercive courses permissible. And, similarly, if patient choices in favor of perilous positive treatments do not make any coercive treatments permissible, then neither do patient choices to forego treatment. Here, I do not take any stand on these claims.

have different practical implications. In outline, the contention is that the Parity Claim provides a better explanation of considered judgments about a certain set of cases than the Binding Claim does.

The kind of case I have in mind involves a patient with a condition for which there is a highly effective and inexpensive positive treatment. The patient deliberates and autonomously decides to forgo this treatment. Suppose that as a result of not receiving the treatment, health-care professionals are able to predict with a high degree of accuracy that a subsequent condition will develop, one for which all the available treatments are burdensome and expensive. They tell the patient this. In response, the patient autonomously decides that she wants to receive the further treatment once the subsequent condition has developed. However, she is still unwilling to avoid that second condition by having her present condition treated.

In these cases, it is plausible to think that it is morally permissible to impose disincentives. For instance, the patient might be put further down the waiting list for the subsequent treatment, or her insurance premiums might be increased.¹⁷ There are several ways of supporting these disincentives. One looks to the overall well-being of the patient. Since the patient would be much better off if she underwent the treatment now, and she has some obligation to do what she can to promote her own well being, she ought to undergo treatment now. So as long as it is morally permissible to provide encouragements for people to do what is both in their own self-interest and morally required of them, there are good grounds for providing disincentives to increase the probability that the patient will elect to receive treatment.

Another way of supporting the disincentives makes an appeal to the well-being of others. Since the treatment for the subsequent condition is expensive and the need for it is avoidable, it wastes crucial resources that could be better spent in other ways. On the quite plausible view that it is permissible to set up incentives that discourage squandering resources in this way, the disincentives are again permissible.

The Parity Claim does a nice job of helping to explain why disincentives are permissible. For a view that incorporates the

¹⁷ The exact nature of the available disincentives depends on the institutional framework in which medical care is delivered. On a different note, notice that this claim is *not* a paternalistic claim; it is not the denial of the Anti-Paternalism Claim that we have been following. That claim says it is permissible for health care professionals to treat the patient for her initial condition. The claim here says nothing about the permissibility of treating the patient. It says, instead, that putting disincentives in place for certain choices is permissible.

Parity Claim can point to the stretch of interrelated medical problems that begins with the initial condition and eventuates in the subsequent condition, and call on the fact that the patient failed to meet the entry conditions in the initial stage of this stretch of medical problems. Because she failed to do this, when (as a result) she develops the subsequent condition and elects to have it treated, one who adopts the Parity Claim can point out that the subsequent condition stems from the earlier condition and that the relevant health-care professionals have not yet been morally bound to deal with this stretch of problems. And the fact that they have not been bound is due to a failure on the part of the patient. Because the failure lies with the patient, health-care professionals are justified in adjusting the entry conditions that the patient must meet in the later stage if she is to bind the health care professionals in such a way that they are obligated to provide her with some expensive and burdensome treatment. For instance, the entry condition may be adjusted by putting the patient further down the waiting list for this treatment; or it might be adjusted by increasing the patient's insurance premiums.¹⁸

Contrast this with a view that incorporates the Binding Claim. On this view, the patient's refusal to be treated in the initial stage is morally binding on health-care professionals. This creates two difficulties. First, it may make the health-care professionals complicit in an imprudent response to a condition that is sure to develop into a much worse condition. And, second, it does not make available the resource that the Parity Claim does. This is the claim that the patient failed to enter into a binding agreement with health-care professionals. As we have seen, this claim is valuable, since it allows us to justify reasonable disincentives focused on the later stage in the stretch of problems. Views that incorporate the Binding Claim lack this advantage, since they state that there is a binding agreement in the initial stage.¹⁹

¹⁸ Again, the nature of the added entry condition depends on the institutional framework in which medical care is delivered.

¹⁹ An anonymous referee suggested that what supports the disincentives is an obligation to use scarce medical resources efficiently. But this suggestion provides no support for the Binding Claim. In fact, if there is this obligation, then the Binding Claim is false, since a patient's autonomous decision to forego treatment would not be sufficient to bind a health care professional. Instead, they would only be bound if, in addition, no inefficient use of resources followed. More importantly, since subsequent condition cases whose initial stage involves refusing treatment and subsequent condition cases whose initial stage involves positive treatment are not *per se* any different with regards to the inefficient use of resources that they entail, the Parity Claim stands.

In addition to showing that the Parity Claim is superior to the Binding Claim, these last considerations also sharpen the difference between the Binding Claim and the Anti-Paternalism Claim. Earlier, we saw that the presence (or absence) of contractual language allows us to differentiate these claims. This difference is sharpened into one with practical implications when we compare a view that conjoins the Anti-Paternalism and Parity claims with a view that includes the Binding Claim. As we have seen, the former view can handle subsequent condition cases better than the Binding Claim. This makes for a difference in practical implications: while the Anti-Paternalism Claim is able, by being conjoined with the Parity Claim, to figure into a view that justifies disincentives, the Binding Claim is not able to do so.

IV. DIAGNOSIS

Why would someone find the Binding Claim attractive in the first place? Presumably, it is the moral importance of autonomy and rights of self-determination, privacy, and bodily integrity that make the Binding Claim attractive. It is crucial, though, to see that what these kinds of appeals really support is not the Binding Claim, but the Anti-Paternalism Claim. For the Anti-Paternalism Claim that it is not permissible for health-care professionals to treat a patient who autonomously decides to not be treated captures what is correct about all of these appeals, since it implies that the patient's autonomous wishes ought to be respected, and that the patient's autonomy and rights of self-determination, privacy, and bodily integrity should not be violated. This means that proponents of the Binding Claim must recognize that the Binding Claim is significantly stronger than the Anti-Paternalism Claim; therefore, they must appeal to something else to support their view.

V. CONCLUSION

A move away from the Binding Claim to the Parity Claim can be seen as part of a counter-reformation in medical ethics. Historically, the Hippocratic Oath put a strong, almost exclusive, emphasis on the value of patient well being. In more recent times, there has been an emphasis on patient autonomy.²⁰ The discussion here

²⁰ For a good overview of the history of informed consent doctrine, see R. Young. 1998. *Informed Consent and Patient Autonomy*. In *A Companion to Bioethics*. H. Kuhse and P. Singer, eds. Malden, MA: Blackwell Publishers: 441–451.

suggests that the recent emphasis has been overplayed. The failures of the Binding Claim, and the successes of the Parity Claim, imply that the scope of what patients can bind health-care professionals to with their autonomous choices is importantly constrained by considerations regarding patient well being.²¹

Peter Murphy
Department of Philosophy
University of Tennessee
801 McClung Tower
Knoxville TN 37996-0480
USA
pjmurphy469@yahoo.com

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