Responsibility for Health and the Value of Choice
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In this lecture I will discuss two kinds of claims of responsibility that arise in regard to health and medical care, and discuss some connections between claims of responsibility of these two kinds. Claims of one kind are obligation-limiting claims about individuals' responsibility for coming to need health care. The economist Julian Le Grand, for example, has argued that individuals who need care for injuries they suffer as a result of risky activities such as mountain climbing or sky diving, or who become ill as a result of smoking, do not have a claim to state sponsored health care. Because *they* are responsible for what has happened to them, others are not obligated to help them. So they are not entitled to state-funded medical care.[1]

In different context, it is commonly thought that because patients are, or should be, responsible for the kind of treatment they receive, they need to be informed about the treatment options available to them so that they can decide which of these treatments if any, they will undergo. This is what I will call a claim of responsibility as decision-making authority.

Cases of both of these kinds involve claims about the importance and moral significance of individuals' choices. But these cases differ in important ways.
In the first kind of case, the idea of "taking responsibility for one's health" is appealed to as a ground for denying some individuals state funding for the treatment they want. In cases of the other kind, the idea of responsibility in an argument for giving patients a kind

[1] Julian Le Grand, "Individual Responsibility, Health, and Health Care," in Nir Eyal, *et al*, eds., *Inequalities in Health* (Oxford: Oxford University Press 2013), p. 300.

of control over what happens to them that they generally wish to have. Another difference is that in cases of responsibility for risky activities what is appealed to is the (supposed) moral significance of a choice that a person *has made*, whereas in cases of the other kind what is at issue is the importance, for a patient, of *having* a choice of what treatment he or she will receive. It seems, however, that we should be able to give a unified account responsibility that explains its role in cases of both kinds: one that explains the significance of choice in determining the validity of individuals' claims to treatment and the importance for individuals of having a choice about the treatment they receive. To foreshadow the content of this lecture: I will seek to explain the former in terms of the latter—to explain the moral significance of the choices individuals make in terms of the value for individuals of having such choices.

I will begin by explaining more clearly what I mean by the value of having a choice. I will apply this idea first to the question of the responsibility of patients in determining their own treatment, and then return to the question of the responsibility of individuals for their need for medical care.

By having a choice, I mean having what happens to one depend on how one reacts when presented with certain alternatives under certain conditions. The value of having such a choice lies in the reasons a person has for wanting what happens to him or her to be determined in this way. These reasons depend on the alternatives that are made available to him or her and on the conditions under which these alternatives are presented

The most obvious reasons for wanting to have a choice in this sense are *instrumental*: they lie in the degree to which having this choice makes it more likely that the result will be something one has reason to want. To take a simple example, one

normally has reasons of this instrumental kind for wanting the food one is served in a restaurant to depend on how one reacts when presented with the menu. But these reasons vary: they depend on the alternatives that are made available—whether the menu includes anything one would want to eat—and on one's ability to make good use of it. Choosing from a menu may be of little help if it is written in a language one cannot understand, or if one is too drunk to read it, or too distracted to think clearly.

A second class of reasons for wanting to have a choice might be called "representative" or "expressive" reasons. These reasons arise from the fact that an outcome can have a different meaning if it results from, and therefore represents or expresses, one's feelings and attitudes. For example, I have a reason of this kind to choose a gift for my wife myself, rather than delegating it to an assistant, or to a professional shopper, even if such a person might do a better job of selecting something she would like. If the shopper would select a better gift, perhaps my reason for choosing the gift myself is not conclusive. The point is just that something would be lost if I don't make the decision myself. Similarly, I have expressive reasons to want to choose the décor of my own apartment, and to decide for myself what clothes to wear. It matters to me that these things should express my own tastes, even if they would be more stylish and impressive if chosen by an expert.

The strength of these expressive reasons depends on the outcomes that are being chosen and the particular significance they have for us. These reasons vary in strength, and can even be negative. One has reasons of this kind not to be the one who decides which of one's friends is to be fired, for example, and in William Styron's novel, Sophie

had very strong reasons of this kind not to be the one to decide which of her children was to die and which to be spared.

In addition to instrumental and expressive reasons, there is a third class of what might be called symbolic, or status-based, reasons for wanting to have a choice. If it is generally held in one's society that it is appropriate for people in one's position to make certain decisions for themselves, then failing to make such a decision for oneself or being denied the opportunity to make it, can be embarrassing, or even humiliating. In the United States, for example, at least among certain classes, the decision about which university to attend is generally seen as one that young people are expected to make for themselves (often as the first important decision that they must make about their lives.) As this example illustrates, these reasons depend on the society in which one is placed, and they can conflict with reasons of other kinds, particularly with instrumental reasons. Reasons of all three of these kinds often count in favor of "having a choice," but for reasons of all three kinds having *more* choice (over a wider range of alternatives) is not always better than less. Being faced with a wider range of alternatives may simply be distracting, and there are some alternatives it would be better not to have.

To sum up this discussion, consider the reasons a person has for wanting to choose his or her own marriage partner, rather than having the choice made by his or her parents. A person has instrumental reasons for wanting to make this choice insofar as this makes it more likely that one will choose a partner with whom he or she will be happy. These reasons may not be conclusive, however, if the parents are less likely to be swayed by fashion and immediate sexual desire and to have a better understanding of the problems and challenges of adult married life. On the other hand, there are strong

expressive reasons for making the choice oneself: a marriage proposal has a very different meaning if it reflects a person's heart's desire rather than merely obedience to parental authority. Finally, in a society in which people normally choose their own spouses, it would be embarrassing to have to accept the dictates of one's "old fashioned" parents.

Note that these reasons for valuing choice do not depend on whether we have free will. The choices we make are significant for us in these ways insofar as they reflect our attitudes and our capacities for judgment, whether or not these attitudes and faculties themselves can be explained in terms of "outside causes" such as our heredity and environment.

Reasons of all three kinds are relevant to patients' choices about their medical care. That this choice is "up to them"—that they have what I called decision-making authority—follows in many cases from the more general right to have authority over what happens to one's body. Since most medical treatments involve touching or intervening in the body in some way—through surgery, medication, or in some other way—patients have a right to say no, just as they have a right to object to any form of unwanted touching. But beyond this basic right to say no, there is the question of the conditions under which patients are to make this decision. Reasons of the kinds I have mentioned explain what these conditions should be.

Patients facing a decision about medical treatment can have instrumental reason to want to decide for themselves what treatment to have because they know their own preferences about the relative importance of pain, ability to function, risk, expense, and length of life. In the case of end of life decisions in particular, they also have expressive

reasons to want the shape that their life has and the way that it ends in a way that expresses their own values, and they may have symbolic reasons to object to being judged incapable of making such choices for themselves.

But as I have said, reasons of these kinds vary in strength. They can count both for and against having a certain choice, and they can conflict with one another. I once asked a doctor whether having surgery for suspected lung tumor would be the wisest course. When he said, "It depends on your attitude toward risk," I regarded this response as unhelpful, even evasive. I didn't care about whether my decision expressed my attitudes toward risk. I was interested only in my chances of living longer. Believing that the surgeon knew more about this than I did, I saw no instrumental reason for making the decision myself. (I also suspected that the doctor might have "expressive" reasons for wanting the choice not to be his.)

Claims about reasons for having a choice are not, in themselves, moral claims about how we should be treated. They are just claims about what we have reason to want, and the conditions under which we have these reasons. But norms and policies that require others to give us a choice and to respect the choices we make are justified only if they take these reasons into account, along with other factors involving costs to ourselves and others. If a policy holding that patients must be given a choice about what treatment to have is justified in this way, then moral conclusions follow. Patients ought to be given this choice and they may be "responsible for" the result—that is to say, they may have no complaint if they find this result unsatisfactory.

The points I have made about the different reasons for valuing choice, and about the possibility of conflicts between these reasons, provide the basis for understanding

objections to what is called “paternalism,” an idea that in my opinion is often given more importance than it should have. Paternalism in the clearest sense occurs when individuals making a choice are denied certain information, or the range of alternatives over which they can choose is restricted, on the ground that if they were to have this information or this wider range of choice they would make choices that would make them worse off. In the terms I have used, what is claimed is that the individuals have instrumental reasons not to want broader or more informed choices. Laws requiring motorcyclists to wear helmets and automobile drivers to wear seat belts are commonly cited examples. In the area of medical care, some object to laws that bar medications from being sold until they have been tested and at least found not to have harmful side effects on the ground that these are paternalistic. And I once knew a healthy man in his early fifties with no signs of prostate trouble who complained about the fact that he could not, while having surgery for other reasons, also have his prostate removed as a preventive measure.

If the main reasons for wanting to have a choice are what I have called instrumental reasons, this may seem to give strong support to paternalism. I said that one has instrumental reason for wanting what happens to one to be determined by the way one reacts when presented with the alternatives under certain conditions insofar as this is more likely to result in an outcome that affects one in ways that one has reason to want. This makes the reason for having a choice depend on what the facts are, not on what one believes them to be, and on the reasons one actually has to prefer certain outcomes rather than on what reasons one takes oneself to have. So if others know more about the facts, or if one is likely, when deciding under certain conditions, to underestimate the significance of important reasons, then one has no instrumental reason to have the

outcome depend on one's own choice rather than on the judgment of another person who is more likely to get these things right.

When this is so, it would follow on the account I have offered that paternalistic restrictions on one's range of choice are justified unless one has sufficient reasons of the other two kinds I mentioned to object to these restrictions, and insist on having a wider range of choice despite the costs of doing this. These reasons for objecting to paternalistic restrictions can be strong, however. One can have good reason to want to have control over the way one's life ends, for example, and over whether one leads an exciting life in which one takes certain risks or follows instead a path of caution. Perhaps this is the kind of reason that the surgeon was calling my attention to when he said that whether I should have surgery depended on "my attitude toward risk."

Still, it is worth asking whether there are reasons for objecting to paternalism that I have missed. I do not have an idea of what these reasons might be. However, the way I have formulated the class of instrumental reasons may have made the case for paternalism appear stronger than it is by focusing attention on cases in which instrumental reasons are stronger than they often are. I stated these reasons in an "objective" form, as depending on the facts about what the outcome of my choice are likely to be and the facts about the reasons I actually have to prefer some of those outcomes to others. But it is often not entirely clear what is likely to result from various forms if treatment. Even more important, in many cases there is reasonable disagreement about the values in question—about, for example, the reasons one has to engage in risky activities, or to endure pain and discomfort for the sake of living somewhat longer. Where disagreement is reasonable, a person can have strong expressive and symbolic

reasons to want to be the one who makes decisions affecting one's life and, especially, reasons not to want such decisions to be made by others with whom one disagrees about these matters.

Expressive and symbolic reasons for making one's own choices seem to me to be strongest in these cases of reasonable disagreement, and they do not apply only against paternalistic restrictions. For example, some arguments against giving people aid in ending their lives are paternalistic—based on claims that people are likely to use this opportunity unwisely. But objections to assistance in dying are often also based on claims about the intrinsic value of human life itself, apart from the benefits of additional life for the person who lives it. Speaking for myself, I find these arguments more objectionable than paternalistic ones. Being prevented from doing something "for my own good," is less objectionable than being prevented from doing it on the ground of some other person's judgment about what I have reason to do, for reasons that have nothing to do with my welfare (or with the claims of others.)

This analysis of reasons for caring about the conditions under which one has a choice casts some light on the controversy about what Cass Sunstein and Richard Thaler call "libertarian paternalism."[2] This is a policy of presenting choices in a particular way in order to make choosers more likely to select alternatives that they have reason to want. A leading example cited by Sunstein and Thaler concerns saving for retirement. Like many economists, they believe that most Americans do not save as much for retirement as they should. They present evidence that workers put aside more for retirement when a

[2] Richard H. Thaler and Cass R. Sunstein, *Nudge: Improving Decisions about Health, Wealth, and Happiness* (New York: Penguin Books, 2009)

monthly deduction for retirement saving is presented as the default state that they can opt out of if they wish rather than as an alternative they must "opt into." Sunstein and Thaler describe the policy of structuring employees choices in this way as "libertarian" because it still gives workers that choice about whether to contribute regularly to their retirement fund, but also as "paternalistic" because the justification for doing this is that individuals would be likely to choose badly if the alternatives were presented in a different way. Similar cases no doubt arise in medical contexts. For example, patients might make better decisions about whether to have PSA tests every year, or, in cases like the one I faced, decisions about whether to have surgery or "wait and see" what develops, if these alternatives were presented in one way rather than another.

Insofar as structuring a choice in the way that Sunstein and Thaler propose increases the likelihood of outcomes that the choosers have good reason to prefer, this increases the instrumental value of having that choice. Why, then, should structuring choices in this way be regarded as at all objectionably "paternalistic?" Improving the conditions under which choices are made by requiring the provision of relevant information, or insisting that choosers be given time to understand and reflect on this information puts them in a better position to choose, does not seem paternalistic. What is different about the "choice architecture" that Sunstein and Thaler are talking about may be that it affects individuals tendencies to choose in ways other than by enabling them to better understand the alternatives they are choosing between, and effects their choices in ways that the individuals themselves are not aware of.

This last feature, in particular, may give rise to the complaint that the policies that Sunstein and Thaler recommend amount to an objectionable form of manipulation. Their

response to this complaint is that any choice will be presented in *some* way, and the way it is presented will affect the decisions that people make in ways that they are not aware of, whether these features are designed to have these effects or not. Given that unnoticed influences are inevitable and pervasive, they argue, why object to having choices structured in ways that lead to better decisions?

Choosers do not, it seems to me, have expressive reasons to object to choices structured in this way, since the choices they make under these conditions reflect their attitudes at least as well as the choices they would make when presented with a different structure. Nor do they have symbolic reasons to object. The rationale for structuring choices presumes that people make mistakes, but everyone is presumed to do this; no one is being labeled as inferior.

I suggest that the objections to "libertarian paternalism" flow from concerns about disagreement of the kind I discussed above. Sunstein and Thaler focus on examples like retirement saving in which they claim there is no disagreement about the value of various outcomes. They even say that structuring choices in the way they recommend leads to outcomes in which choosers are better off "by their own lights." When this is literally true—when there is no disagreement at all about the relative value of the outcomes in question—"libertarian paternalism" may seem not only justified but perhaps too weak. There is evidence that even when choices of retirement saving are presented in the way Sunstein and Thaler recommend, employees tend to save less than they should "by their own lights," and saving more would make them better off as judged by their own

preferences regarding present and future consumption. If this is true, why not make saving mandatory, rather than giving employees the chance to "opt out" of contributing?[3]

But choices about which there is this little disagreement are a special case. I suggest that people are reluctant to grant bureaucrats the general power to design "choice architecture" in ways that will produce what the bureaucrats judge to be better outcomes because they are worried about how this power will be exercised across a broader range of cases in which the bureaucrats judgements about which outcomes are to be preferred, even if sincere and confidently made, will not coincide with their own.

I will turn now to the question of individuals' responsibility for their need for medical care. In the paper I mentioned earlier, Julian Le Grand takes it as obvious that people are responsible for something that happens to them just in case they have control over whether it happens or not. He writes,

> If an individual's health state depends on factors entirely within his or her control, then he or she is responsible for (paying for) any health care that she might need. The health care should be financed either through the taking out [of] private insurance or through paying directly out of pocket. If, on the other hand, his or her health state has arisen entirely from factors beyond his or her control (an inherited disease, say), then he or she is not responsible, and there is a prima facie argument for his or her health care to be financed by the state or the wider community, funded through taxation or some form of social insurance scheme. If his or her health state has arisen partly from factors within her control and partly from factors beyond his or her control, then the answer is a mix of public and private insurance."[4]

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[3] A question asked by Ryan Bubb and Richard H. Pildes, "How Behavioral Economics Trims Its Sails and Why," New York University Law & Economics Research Paper Series, Working Paper No. 13-29.

[4] Le Grand, "Individual Responsibility, Health, and Health Care," in Nir Eyal, *et al*, eds., *Inequalities in Health* (Oxford: Oxford University Press 2013), p. 300.

This policy may seem harsh, and as far as I know it is not frequently followed to the letter. But the idea has some plausibility.[5] What I am interested in doing is uncovering the idea of responsibility that underlies its (at least partial) appeal, and explaining why this idea may not have the full force that Le Grand gives it.

It is important here to distinguish between different kinds of claims of responsibility. Le Grand seems to be making what I called a claim of responsibility in the obligation-limiting sense: a claim that we do not owe individuals help in dealing with illness and injuries that they had control over. My view will be that claims about responsibility in this obligation-limiting sense are conclusions about what we owe to each other that depend on the costs and benefits to all concerned of the relevant policy alternatives. The value, for individuals, of having various forms of control over what happens to them figure in such a justification, but only as one element among many. And they figure not as moral conclusions about responsibility but rather as claims about the reasons that individuals have certain opportunities and to have outcomes depend on their choices. In Le Grand's argument, by contrast, an idea of responsibility—the idea that individuals are responsible for the things that happen to them that are under their control—enters at the very beginning, as a moral claim from which other conclusions then follow.

The fact that a given outcome was under a person's control can make it the case that he or she is responsible for that outcome in the blame-justifying sense. If a person knew, or should have known, that heavy smoking brought a high risk of lung cancer and

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[5] Amy Gutmann, for example, considers a milder version of the idea in "Justice Across the Spheres," in *Pluralism, Justice, and Equality*, David Miller and Michael Walzer, eds. (Oxford: Oxford University Press, 1995), pp. 111-114.

decided, foolishly, to smoke anyway, then that person is responsible for smoking in the sense of being properly subject to criticism, or even blame, for doing so. But moral criticism is not what is at issue in the justification of policies about access to medical care. It would be objectionably moralistic to make a person's access to state supported health care depend on his or her moral faults.

A person's blameworthiness for smoking depends on two factors: smoking was something that was under the person's control and he or she had good reason not to smoke: the decision to smoke was a foolish one. These two factors are also relevant to the question of who should receive state-supported health care. What we need to consider is *how* they are relevant if their relevance does not come by way of a conclusion about the person's blameworthiness.

As Le Grand says, smoking is not a perfect example of an outcome being "under a person's control." An individual might have gotten lung cancer even without smoking, although smoking greatly increases the risk. Insofar as a person could have refrained from smoking, however, he or she could have avoided getting lung cancer *and having smoked*. Other examples are clearer: individuals can avoid suffering injury in mountain climbing accidents by choosing not to climb mountains, and they can avoid suffering head injuries in motor cycle accidents by not riding motor cycles, or by wearing helmets when they do so.

Taken alone, however, the idea that individuals are responsible for—and must therefore bear the cost of—injuries resulting from any activities that they could have chosen not to engage in would prove too much. People could, after all, choose not to drive or ride in automobiles, and not to walk on sidewalks near fast moving traffic. So

responsibility as control, understood as avoidability, does not render a person ineligible for state supported health care. The question of who is to receive such care, and who, by contrast, is to be "held responsible" for the consequences of the choices he or she has made--the question of responsibility in the obligation-limiting sense—is a question of social policy, the answer to which depends on a comparison of the reasons individuals have for wanting to have the opportunity to engage in activities involving certain kinds of risk, and the costs to others of providing care for those who suffer illness or injury as a result of these activities. The apparent difference, just noted, between the claims of individuals who need care as a result of sky-diving and those who need care only as a result of more "normal" activities such as walking along a busy street, lies in the difference in the strength of the reasons individuals have for wanting to be able to engage in these activities.

Le Grand, by contrast, suggests that individuals' entitlement to state supported health care should depend on the *degree* of control that they had over the circumstances leading to their need for this care. But putting the matter in that way conceals the value judgment I have just described, about the reasons people have to engage in certain activities, in what seems like an empirical question about the factors that caused the injuries in question. Putting things in this way tries to make the idea of control do more work in justifying social policy than it can actually do.

This does not mean, however, that choice and control play no role at all in the justification of these policies. To see this it will be helpful to consider first a case involving scarce resource such as the case of people in need of kidney transplants. Suppose the supply of organs available for transplantation is limited and less than the

demand. One way of dealing with this situation would be simply hold a lottery among those in need of transplants, giving them all the same chance of getting a kidney. An alternative would be make people who engage in behavior that leads to kidney failure ineligible for transplants (or even for the lottery.) I am assuming that this policy would be forward-looking: it would put people on notice that if they engage in these forms of behavior in future they would lose their eligibility for kidney transplants when kidneys are scarce.

Insofar as announcing this would reduce the number of people who come to need kidneys, by discouraging kidney-damaging activities, it would also reduce the number who need kidneys and are unable to obtain them. But this deterrent effect also makes the policy one that individuals themselves have reason to prefer to a pure lottery for their own personal reasons. The deterrent effect just mentioned also makes it the case that having the choice of decreasing their probability of dying of kidney failure by avoiding certain risky activities has instrumental value for the individuals in question. They have instrumental reasons for preferring having the choice of refraining from kidney-damaging behavior or engaging in it at the cost of losing the chance for a transplant insofar as this makes it more likely that that they will avoid an outcome that they have good reason not to want, namely needing a transplant but being unable to get one. Similarly, being given the opportunity to choose my meal from the menu has instrumental value for me by making it less likely that I will wind up being served something containing liver, which I hate. Like the latter choice, however, this instrumental value is limited and variable: it depends on the likelihood of my paying attention and choosing wisely when I have this choice.

This rationale for making eligibility for benefits depend on an individual's choices differs from the rationale offered by Le Grand. Le Grand's view rests on the moral claim that, independent of any particular social policy we might adopt, individuals whose need for medical care is due to activity that was under their control have a reduced moral claim on state resources to supply this care. This claim may have some intuitive appeal, but it seems to me objectionably moralistic. On the view I am proposing, by contrast, a policy that makes eligibility for benefits depend on individuals' choices can be justified because of the instrumental value for individuals of having the choice that *such a policy itself* presents them with, namely the choice between retaining entitlement to state-supported care by living carefully or foregoing it in order to have a different life style.

I have just been discussing cases in which I have assumed there to be an unavoidable shortage of medical resources: there are not enough kidneys available for transplant to those who need them. Of course, other things might be done to increase the number of kidney donors. But, given the shortage some have to be denied treatment. I have explained how the value of having a choice provides a reason for preferring a policy that makes access to health care depend on prior choices over a policy that relies only on a lottery. In cases in which the supply of resources not limited in this way, and care could be provided (at greater public expense) to all who need it, there is the prior question of whether to provide care to all, or only to some. In these cases, the argument for a policy that denies care to those who need it only because they chose to engage in risky activities rests on two ideas: first a claim that the reasons for allowing individuals to engage in these activities are not sufficient to justify the additional expenditure of public money, and second the importance, if such a policy is to be adopted, of giving people an

instrumentally valuable choice by warning them that they will forfeit their claim on publicly supported care by engaging in these activities.

Earlier, in discussing responsibility in the blame-justifying sense and rejecting the moralistic rationale for "holding people responsible," I said that although this rationale is mistaken, it calls our attention to two factors whose relevance needs to be explained: the fact that certain outcomes can be avoided by choosing in certain ways and the reasons individuals have to choose in those ways. We now have that explanation in hand. The choices I have been discussing have positive instrumental value for individuals only because the bad outcomes are ones that they can avoid by choosing appropriately. The relative weakness of the reasons individuals have for engaging in these risky activities is relevant not as a ground for holding that individuals who act on these reasons are foolish and blameworthy, but instead as a basis for assessing the importance of giving people the option of engaging in these activities without loss.

To conclude: I have appealed to the value of choice—the reasons that individuals have for wanting what happens to them to depend on how they respond when presented with the alternatives under appropriate conditions—to explain the ideas of responsibility that arise in regard to patients' control over the treatment they receive and in regard to their need for health care to begin with. I have argued that by attending to the various reasons that underlie the value of choice we can understand the importance for patients of having control over their treatment and can understand both the appeal of paternalism and the reasons for objecting to it. The value of choice also enables us to understand the role of individuals' choices in determining their claims to state-supported health care without exaggerating that role in a way that involves implausible moralism.