Autonomy-Centered Healthcare

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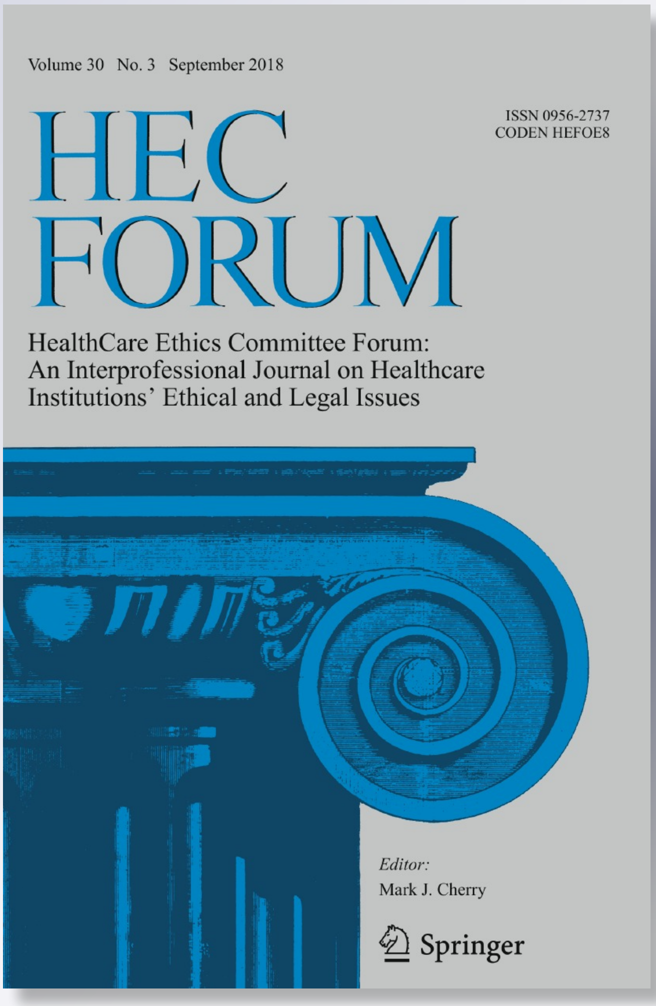

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Autonomy-Centered Healthcare

Maura Priest[1]

Abstract
In this paper, I aim to demonstrate that the consequences of the current United States health insurance scheme on both physician and patient autonomy is dire. So dire, in fact, that the only moral solution is something other than what we have now. The United States healthcare system faces much criticism at present. But my focus is particular: I am interested in the ways in which insurance interferes with physician and patient autonomy. (I do not consider The Affordable Care Act much of a change in this aspect of the system, for it still relies heavily on private insurance, albeit often subsidized.) I will argue in favor of an expansion of the traditional conception of what I call "medical autonomy" or "healthcare autonomy" and the usual role it plays in bioethical discussions. More generally, I show that in morally designing or evaluating any healthcare system, serious attention should be paid to how this system helps foster what I call active autonomy.

Keywords Insurance · Healthcare · Autonomy · Patient autonomy

Introduction

In the 1991 movie, *The Doctor,* there comes a dramatic point in the film where Dr. Jack MacKee (played by William Hunt) admits that he could have saved his patient, June Ellis's, (played by Elizabeth Perkins) life if only he had gone through with an MRI rather than a CAT scan. In a moment of terrifying honesty, MacKee explains the following:

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> They should've found your tumor. You were right. Somebody screwed up. You should've had an MRI. But the system stinks. Insurance companies tell us what tests we can and cannot do.[1]

While this is Hollywood and in the 1990s, this scene nonetheless brings to light an important bioethical issue that is deserving of greater attention in 2018. The issue I have in mind is the way in which health insurance schemes undermine physician and patient autonomy, and prevent them from exercising their judgment in accordance with the best interest of the latter. Although autonomy curtailing can happen in various ways, according to various insurance schemes, I will focus on the insurance grounded healthcare system in the United States, where the problem is especially severe. In this paper, I aim to demonstrate that the consequences of this health insurance scheme on both physician and patient autonomy is dire. So dire, in fact, that the only moral solution is something other than what we have now.

The United States healthcare system faces much criticism at present. But my focus is particular: I am interested in the ways in which insurance (and potentially government provided service as well) interferes with physician and patient autonomy. (I do not consider The Affordable Care Act much of a change in *this aspect* of the system, for it still relies heavily on the same types of insurance, albeit often subsidized.)

I will argue in favor of an expansion of the traditional conception of what I call "medical autonomy" or "healthcare autonomy", and the usual role it plays in bioethical discussions. More generally, I show that in morally designing or evaluating any healthcare system, serious attention should be paid to how this system helps foster what I call *active autonomy*. There is an ethical duty for all involved in healthcare to try and promote, as much as possible, the expansion and fulfillment of active healthcare autonomy. Although my paper does conclude with speculations concerning potential solutions, finding a solution is not the main aim of the paper. The main aim is to argue that the medical community within the United States (and nations which have similar insurance grounded systems) is morally obligated to do its best to find an alternative.

The plan for the rest of this paper will run as follows. I begin with a review of the history of autonomy in biomedical ethics. I hope to show that autonomy has commonly been understood through passive conceptual lenses. I then argue that while there is nothing wrong with this conception of autonomy, it is incomplete. A complete appreciation of medical autonomy will include an active conception which focuses not on what a patient can refuse, but rather on the ability of patients to choose between various healthcare alternatives. A similar discussion about autonomy and the role of the physician will follow. I then argue that given the ways health insurance limits patient and physician autonomy, bioethicists and those in the medical community have a duty to try and come up with potential alternatives. I propose a variety of such possible solutions. Variety is critical. The paper aims to show that

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[1] *The Doctor* (1991).

regardless of one's ideological views, healthcare systems that supports the active autonomy of patients and physicians have great moral potential.

What is Medical Autonomy?

What is Autonomy?

The right to *self-governance*, if not the definition of autonomy itself, is closely related or essential to the concept. But what might this "self-governance" consist of? This clearly depends on context. In the case of nations, *The Stanford Encyclopedia of Philosophy* explains, it means that no other nation creates the laws or controls the institutions.[2] In the case of individuals, it means something similar, that no other person or institution controls the behavior of this autonomous self-governing individual. The specific notion of autonomy that I will be working was put forth years ago by Tom Beauchamp and James Childress, who argued that personal autonomy is,

> …at a minimum, self-rule that is free from both controlling interference from others and from limitations, such as inadequate understanding, that prevents meaningful choice. The autonomous individual acts freely according to a self-chosen plan…A person of diminished autonomy, by contrast, is in some sense controlled by others… (2001, p. 58).

While Childress and Beauchamp have written much since then, their fundamental understanding of autonomy has remained, and it is commonly accepted as a standard definition within applied biomedical ethics. Admittedly, such an understanding is not a complete analysis and leaves much to work with within the theoretical realm. Notwithstanding, I believe the Beauchamp/Childress notion is sufficient for many applied discussions, including the philosophical discussions in my paper.

Autonomy then, as I understand it, means self-rule free from controlling interference. Like Beauchamp and Childress, I also believe that autonomy comes in degrees; that is, persons can have more or less autonomy depending on the amount of interference or control (Beauchamp and Childress 2001, p. 59). If certain types of controlling mechanisms, or other types of interferences, get in the way of an agent's self -rule, then they get in the way of personal autonomy. However, sometimes such interferences get in the way more than at other times; i.e., interference can be minor or substantial.

To be as clear as possible, I am working with Childress' and Beauchamp's understanding of autonomy as self-rule and the absence of controlling interference that prevents meaningful choice. With this in mind, we can make these general statements about the concept.

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[2] "Autonomous agents are self-governing agents… she, too, is denying that anyone else has the authority to control her activity within this sphere; she is saying that any exercise of power over this activity is illegitimate unless she authorizes it herself" (Buss 2016).

> Autonomous acts are ones where the acting agent had influence. (I.e. the agent's own choices, intentions, motivations played an important role in the act happening the way it did.)
>
> If an agent other than X prevents X from doing what X would do otherwise, that agent is undermining, diminishing, or violating X's autonomy. (This is not to say that such undermining is not justified. It might be.)
>
> Autonomous agent's rule (control) themselves, as opposed to being ruled by other persons or institutions.

None of the above features are necessary ones. And none of them are exhaustive. My paper hopes to grasp on to what many persons and scholars can agree is true about autonomy, and use that hold to have an applied discussion about autonomy in healthcare.

The History of Autonomy in Biomedical Ethics

Biomedical ethics has spent much time and energy delving into one aspect of self-rule: the right to decline medical treatment. It is easy to see how the right to refuse care is an important part of medical autonomy. (By "medical autonomy", I refer to autonomy concerning all aspects of healthcare, i.e., treatment, prevention, and everything in between. I will use the terms "medical autonomy" and "healthcare autonomy" interchangeably). If we are to be self-governing agents, then no other person should have the authority to force us to receive medical treatment. If another person did have this authority, then the person who received the unchosen medical treatment would not be governing oneself, the governor would rather be the authority figure who used coercive means to treat the patient against the patient's own will. Sometimes physicians might wish to violate autonomy for the sake of beneficence or non-maleficence; i.e., physicians might think the patient's self- rule will work against the patient's healthcare interests. The struggle of balancing autonomy against beneficence and non-maleficence is a repeated theme in the history of bioethics.

In spite of health benefits that might *sometimes* come from overriding a patient's own choices, autonomy is an important safe-guard against malevolent authority figures. Indeed, the emphasis on autonomy in biomedical ethics gains much force considering the terrible instances in which it was overridden for the supposed sake of medical research. The infamous Tuskegee experiments, for example, were a horrible display of what can go wrong when experimental subjects are treated as research pawns rather than self-governing agents. As these experiments demonstrate, crucial to agential autonomy is information access.[3] One cannot govern oneself without proper information. This need for proper information is the foundation of one of the most discussed bioethical issues in the contemporary era, i.e., *informed consent* (note that informed consent implies that one be *informed*).

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[3] For a quick overview, see Centers for Disease Control and Prevention (2017). Visit the CDC website at (https://www.cdc.gov/tuskegee/timeline.htm). For a more expansive account, see Jones (1993).

One of the most serious ethical problems displayed in the Tuskegee experiments was that the absence of information made it impossible for experimental subjects to make apt decisions about their own welfare. In other words, it was impossible for the experimental subjects to offer their informed consent. Just as a congress ignorant of its citizenry will unlikely prove effective governors, persons cannot govern themselves medically without medical information. Autonomy requires then, not only the right to make self-governing choices, but the tools (such as information) that aid one in the process. Governing oneself blindfolded and with one's hands tied behind one's back is not really governing at all. The horror of Tuskegee is that agents who should have been autonomous had so little information that acting in their own best interest was hardly a possibility.

Undoubtedly, the ability to act in accordance with one's best interest is a critical aspect of medical autonomy. However, having this possibility is a far cry from actualizing it. Simply because persons should have *the option* of acting in their own best interest, it hardly follows that persons thereby *must* do so. After all, if the purpose of autonomy was that persons ultimately act in their own best interest, self-governance would not be the foundational issue at all. What would matter would not be self-government but *proper, efficacious,* governance. And while bioethics clearly leaves room for the importance of effective medicine, this seems more properly the domain of the principles of beneficence or non-maleficence than the principle of autonomy. Tuskegee shows us *not* the horror of patients choosing to act against their own interest, but the horror of patients *lacking the choice* to act in their own interest to begin with.

Some of the most troubling ethical dilemmas of biomedical ethics arise when patients use their autonomy to act in ways that are perceived to be against their own interest. Let us consider a famous bioethical scenario in which a patient appears to make a choice which is detrimental to the patient's own health. Consider, for instance, a Jehovah's witness's refusal to receive a life-saving blood transfusion.[4] *Prima facie*, it appears that a patient is autonomously choosing to refuse salutatory (perhaps life-saving) medical treatment. This right to refuse has invited much controversy, but oddly enough the controversy rarely resolves around whether a patient should be permitted to make this autonomous choice, but rather *whether the choice is autonomous at all*. Many will admit, for instance, that a patient should be permitted to make autonomous medical decisions which result in self-harm, but they still will question whether the decision of Jehovah's witness is autonomous (and hence whether they should be allowed to refuse treatment). Critics might question whether the Jehovah's witness is unreasonably pressured to refuse a transfusion. Consider the following quotations from bioethicists who suggest *denying* the (medically dangerous) request of a Jehovah's witness adherent might be morally permissible (*Some quotations refer to a card that Jehovah's Witnesses often carry. This card indicates that the individual wishes to refuse emergency blood transfusions*.)

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[4] For a thorough summary of the ethical issues surrounding Jehovah's Witnesses and blood transfusions, see McInroy (2005).

> In an emergency, the doctor must be satisfied that a card carrying JW has been provided with the information necessary to make an informed decision. This is unlikely, as the WTS37 provides information about the risks but not the benefits of blood. In addition to the possible lack of information there is also concern about whether an individual's decision to carry a card is without external influence (crucial when considering autonomy). The WTS decides which products JWs may accept, distributes the "boilerplate" cards annually, and initiates the card signing process (Woolley 2005, p. 870).

> For patients to be truly autonomous, they must be free from undue organizational intimidation and fear of reprisal, and must be given sufficient information, including alternative views. The information presented here suggests a fundamental flaw in most physicians' assumption that JWs are acting autonomously in refusing blood (Muramoto 1998, p. 229).

> Whether an advance directive refusing treatment satisfies the intent requirement of autonomy depends on the individual's understanding of the consequences of refusing or accepting the particular therapy…A Witness's understanding of what an advance directive refusing blood means will necessarily be limited due to an absence of spiritual outcome data and a paucity of medical outcome data. Understanding will also be limited by foreseeability because it is unlikely that an otherwise healthy individual will unexpectedly need blood…evidence of an appropriate level of understanding of the risks, benefits, and alternatives to transfusion should be required before blood is withheld (Migden and Braen 1998, p. 817).

What is noticeable about the quotations above is that they all challenge respecting Jehovah's Witnesses' right to refuse a blood transfusion, but none question the right to *autonomously* make this choice. Indeed, each quote implies that *if* the patients were making autonomous decisions, *then* the physician should respect their wishes. Many other bioethicists argue that adherents to the Jehovah's Witness religion generally *are competent*, and that their decision to refuse blood transfusions *should* be respected. Few bioethicists argue that physicians should go forth with blood transfusions *in spite of a* patient's *autonomous* choice to the contrary. There seems then, to be fairly unified agreement within biomedical ethics that patient autonomy is (1) important, (2) that patients should have the information necessary to exercise it, and (3) that physicians ought also to respect patients' autonomous choices to act in a way that is *contrary* to this interest, but only if they have the ability to act "truly autonomously."

Passive and Active Medical Autonomy

For clarity, below I offer two loose definitions of what I mean by the terms "active" and "passive" autonomy:

> *Passive Autonomy*: An agent's ability to refuse certain activities, services, and treatments.

> *Active Autonomy*: An agent's ability to make choices about, and choose between, various activities, services, goods, and treatments.

Looking at the (loose) definitions above, we can imagine an agent with only passive autonomy and compare that agent to one who also has active autonomy. The former agent would never be forced to do something he did not want to do. However, this person could not seek out and choose which activities that he did wish to participate in. The person with active autonomy, however, *could* lead a life making choices about how he might spend his day, what he might be doing, and with whom he would do those activities. The person with only passive autonomy would lack these privileges, and hence it seems would not be self-governing in the fullest sense.

For the purposes of medical ethics, passive autonomy consists of the right to decline treatment (and other medical activates), while active autonomy covers all the ways an agent might seek treatment or choose between various healthcare related options. Admittedly, some might contend that declining treatment is a choice too. Hence declining treatment, one might argue, is just one of many possible choices. And hence by refusing treatment one is "actively" exercising one's autonomy. While I understand this viewpoint, all things considered, there seems purpose in distinguishing between the absence of treatment and treatment. If one has a certain medical condition, one can do various things to treat this condition. One can also do nothing. (This is true not only in healthcare, but in life. We have the option of doing something to change our situation, or not making any efforts and going on as we did before.) In any case, I call the former "active" and the latter "passive." These terms not only signify too distinctive types of self-rule, they are also less cumbersome than repeatedly saying, "not undergoing treatment" and "seeking treatment options." For these reasons, I will continue to use the terms "active" and "passive" autonomy.

Much discussion of patient autonomy in biomedical ethics appears focused on passive autonomy. For instance, there has been extensive focus on a patient's autonomous right to *refuse* medical treatment. However, deciding what treatment to seek or accept seems medically as important as the decision of which treatment to refuse. Once we open the door to the possibility that *seeking treatment* is as central to medical autonomy as refusing it, there is a world of possibilities for expanding bioethical discussions.

An Active Conception of Medical Autonomy

As explained above, patients who lack autonomy in the passive sense will lack the ability to refuse treatment. Patients who lacks autonomy in the active sense, however, will lack the ability seek out treatment options and make meaningful choices about which options they believe are best. Below is a list of ways an agent might exercise active medical autonomy:

1. Choose between healthcare specialists.
2. Choose between medical facilities.
3. Choose to try one medication over another.

Active medical autonomy, I would argue, is the most complete sense of the term in relation to healthcare ethics. If an agent's only medical options are to either say yes or no to treatment, there is only a weak sense of self-governance at issue. Passive medical autonomy gives patients very little control over their health. Perhaps the only control one has is to say no to an option that is so obviously bad few reasonable persons would consider saying yes. In most areas of life, however, we do not consider autonomy the mere ability to avoid disaster. Let us consider an example. Most modern liberal democracies consider the ability to pursue choice of career a basic right (even if rarely enshrined in a constitution or legal document). Only countries with dictators or fascists force individuals into particular careers. Now imagine that the right to choose one's career was only seen in a passive light. For instance, suppose that career autonomy in an imaginary society consisted of the following choice:

1. Career as a firefighter or starvation

There is a sense in which individuals faced with the above career choice indeed have autonomy. After all, they are not forced nor coerced to become a firefighter. However, it is obvious to all who are fortunate enough to live in a liberal society that this career autonomy so offered is grossly inadequate. This is a mere passive choice, as one does not have even two choices of career. Rather it is a take it or leave it situation: one can choose a single career offered, or one can choose to do nothing, i.e., no career at all. In the medical world, this is equivalent to the option of having treatment (perhaps treatment you do not believe is best or treatment from a provider you distrust), or declining that treatment altogether. The ability to choose one option when the other is terribly undesirable (for instance, starvation), is not much of an option at all. If an agent decides to be a firefighter because his other option is starvation, it would be silly to assume his career is one that comes from his own judgement about which career is best for his needs and interests. Rather, such an individual lacks autonomy; i.e., he lacks the ability to make a meaningful choice. Likewise, if an agent decides to take a certain medication (or to see a certain physician) because it was the *only* option covered by insurance, it would be silly to assume such choice represents true self-governance.

There are many ways in which the option to choose one's own career is empowering for both the person seeking employment and the employer. The former can balance her desires and preferences against the potential benefits and detriments of each career. She might, for instance, choose to become an artist knowing that the financial payout is less than a career as a lawyer. She might be happy to accept the lower salary, because her preferences are for creativity over wealth. Such an agent is truly self-governing. Knowing her skills, needs, and desires, she uses this information to seek employment that fits her preferences. Yet, it is not only the careerist herself that will reap the benefit of such autonomy, but society as well. When everyone can pursue a career choice that best matches their needs and abilities, and is also something that is needed in the market place (which must be the case, otherwise the person would not be hired), then the community is better off.[5] This is the full sense of autonomy that is sparsely applied in the healthcare world.

Let us imagine that medical autonomy became akin to career autonomy. Imagine that medical autonomy is understood as the ability to go out into the world and seek the healthcare treatment that best fits needs and preferences. Just as a person seeking a career would look at the available employment positions in one's general location, a patient would search for the most appropriate healthcare facilities. Patients would choose between a variety of possible procedures, physicians, clinicians, etc. A physician which is a perfect match for one individual might be a terrible choice for another. One benefit of this active medical autonomy is that a patient can seek the physician that is that perfect (or at least acceptable) match. In the current healthcare environment grounded in private insurance, the relationship between physician and patient is often brushed aside. And the situation is no better with government insurance provided for the poor. Indeed, things are usually worse. Many physicians, for example, refuse Medicaid patients because the reimbursements are so low. *The New York Times* tells the story of Carol Vielt, a 53-year-old cancer patient who in 2010 learned her physician will no longer accept Medicaid. In Vielt's own words,

> When you build a relationship, you want to stay with that doctor. You don't want to go from doctor to doctor to doctor and have strangers looking at you who don't have a clue who you are (Sack 2010).

The above quotation illustrates much of which is wrong with both government and insurance programs that provide few options for patients to make their healthcare decisions. Not only are patient and physician relationships less personal when the latter does not seek out the former, but sick patients are often forced to go from doctor to doctor in hope of finding one that will accept their form of payment. This is not a story of medical freedom but one of despair and restraint. There is a clear paucity of autonomy in such scenarios. When it comes to career choice, it is *obvious* that the availability of only one or two employment positions leaves little room for individual autonomy. But in healthcare, we have come to accept that patients may see only one or perhaps two physicians. And this is hardly the only limitation imposed on patients via traditional insurance and Medicaid/Medicare. For instance, a patient may desire one operation over another, but have no ability to seek the desired operation for it is out of network. An individual recovering from surgery, addiction, or disease, might strongly desire to visit one recovery center over another but be thwarted in any attempt at choice due to insurance restrictions. Things are especially bad when it comes to mental health treatment, one of the most limiting areas of insurance coverage.[6] Absence of medical autonomy has become so common it is not only unsurprising, it is what we expect.

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[5] This is not always true. Sometimes, for instance, persons are hired due to nepotism even if they are unqualified. Notwithstanding, the general course of things in most liberal democracies is that persons are hired because they are at least minimally qualified to do work that in some sense needs doing.

[6] For an article documenting the difficulties of receiving mental health treatment via private insurance, Medicaid, and Medicare, see Bishop et al. (2014).

The Importance of Physician Autonomy

As bad as the picture for active medical autonomy appears, there is even more to the story. The opening of this essay described a case in which the *physician's* autonomy (not the patient's) was infringed. As much as there has been a just focus on patient autonomy throughout the history of biomedical ethics, one might argue that physician/clinician autonomy is every bit as important. In line with our earlier description of autonomy, let us understand an autonomous physician as one who is self-governing and free to make meaningful choices in the absence controlling interference. Self-governing physicians are ones who make their own decisions about how best to treat patients.

Unfortunately, rather than governed by the self, physicians are sometimes governed by bureaucracy or corporations. While it may be appropriate for hospitals or other institutions to lay down some ground rules, these restraints should not interfere with the ability of the physician to evaluate each patient on a case by case basis. This, after all, is the point of one physician encountering one patient.

One of the greatest values of physician autonomy is it allows for what we might call "particularized judgements." This is something like what Aristotle referred to as "practical wisdom." Virtuous individuals recognize the complexity of life and that there are not always stable ethical rules that can be used across circumstances.[7] The Aristotelian picture is importantly different than other philosophical views in which a single rule or principle can be applied in a variety of distinct scenarios.[8] Biomedical ethics has, perhaps more than many other areas of ethics and applied ethics, recognized the value in something like practical wisdom. Maybe this is because it is especially obvious in the bioethical context that every person has unique needs, that there is no template that can replace individual judgement.

The modern Hippocratic Oath states that medicine is often as much of an art as a science.[9] Yet, the problem landscape that I have been painting is that the insurance system drives a deep wedge between patient and physician that prevents each from making particularized judgements according to circumstance. In other words, the insurance system can leave little room for practical wisdom and the physician as artist.

Despite the difficulties just discussed, sometimes patients will luck out and find a physician that is not only covered by their insurance, but also someone with whom they like and feel connected to. Sadly, these beneficial patient/physician relationships are too often short-lived due to expiring or changing insurance plans. The trust between doctor and patient that has built over the years can evaporate in an instance. *The New York Time*s recently ran a story of this kind, featuring a very young girl with an ongoing heart problem. Luckily the family liked their daughter's physician.

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[7] See Aristotle (2009, Book VI).

[8] In the beginning of *The Nicomachean Ethics* (2009), Aristotle sets the stage for particularized judgments by noting that, "We must not expect more precision than the subject-matter admits of" (1094b, pp.13–15).

[9] See http://www.pbs.org/wgbh/nova/body/hippocratic-oath-today.html.

As so often happens with insurance plans, however, this family's contract was on the verge of expiring. And as much as the parents bonded with and would have liked to maintain their relationship with their daughter's physician, they did not know if he would be covered under their new plan. Worse still, many insurance plans (including plans on the Affordable Care Act exchanges in the U.S.) will not inform patients which physicians are covered before purchasing the policy. Because of this lack of information, these parents understandably felt both hopeless and frustrated; they could not even make efforts to keep the physician whom they liked. Speaking to *The New York Times*, the father lamented, "Sienna's situation is such that it makes us very nervous…You don't know who the doctors are on different plans because there are no lists" (Bernard 2013).

In this situation, we have an insurance system that is undermining self-rule in important ways. Both the physician and the patient wish to continue seeing each other. But the insurance system has controls in place which makes this wish very difficult to achieve. What is important here is understanding autonomy/autonomous action on a spectrum. While there might still be some conceivable way for the physician and patient to continue to see one another (they are not being physically restrained, after all), the practical interference is significant. This significant interference does not shut-down autonomy full-stop, but it gets in the way, and hurts autonomy to a degree that does undermine self-rule to a certain extent. Suppose this patient (as seems to be the actual case) is forced to find another physician. At this point, the parents are asked: "Why did they change physicians?" Notice that their answer will not be an explanation that appeals to personal judgements about why they believed that choice was best, or expedient, or anything of this sort. Rather the reasons they offer will be something along the lines of: "The insurance system refused to pay for the physician we knew and loved." This is an answer which suggests control and interference from an outside agent.

What Next?

Having seen the many ways in which health insurance undermines both patient and physician autonomy, what might we take away from this discovery other than despair? In one sense, despair is just the sort of reaction which I would hope to illicit, for despair is an attitude that appreciates the seriousness of the situation. The wrong of autonomy violation in the healthcare context has been brushed aside or ignored for far too long. On the other hand, we should not fool ourselves. Discovering that a widely accepted medical practice (in this case, limiting patient autonomy via insurance coverage) violates ethical principles has a familiar history in biomedical ethics (I would argue in all of ethics). Today, for instance, it is hard to imagine that physicians themselves advocated the horribly unethical and autonomy violating experiments of The Holocaust.[10] (Relatedly, the idea of informed consent was underappreciated for many decades.) Perhaps

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[10] For accounts on the role of physicians in The Holocaust see Barondess (1998) and Lerner and Rothman (1995).

then, the medical field overlooking the importance of active autonomy is unsurprising. Let us admit this accident of the past and start a correction that is anything but accidental. The focus should be on developing healthcare systems which thoroughly respect active autonomy. This new system (whatever it might be) should above all aim for *improvement* over the current model which so commonly and severely restrains physician and patient active autonomy.

Possibilities for an Autonomy Maximizing Healthcare System

Better, Not Best

This second endeavor of the paper is meant to be exploratory. It is also speculative insofar as the ideas are admittedly fresh and will undoubtedly need adjustment. It is open-ended for my hope is that other ethicists and medical professionals will continue to brainstorm in accordance with the ideas I lay out in this paper, so we might derive a system that is better than before. This “better than before” is critical to my argument. It is obvious that no system will allow an endless array of healthcare possibilities and any healthcare system will have some restrictions on active autonomy. However, by bringing attention to the paucity of active autonomy in many insurance-grounded healthcare systems, much can be improved.

Let us return to the analogy used earlier about career autonomy. The United States is a society that allows significant career freedom. As children come of age they might attempt to become a firefighter, butler, architect, accountant, or business owner. Neither law nor bureaucracy nor businesses prevents young adults from pursuing any of these vastly differing career paths. However, this does not mean that all will achieve just what they sought. The dream career must be compatible with the freedom and autonomous choices of others. Whether an aspiring firefighter becomes an employed firefighter depends (among other things) on manifesting the skills for the position. Similarly, if the young wish to pursue part-time work as a butler this necessarily depends (among other things) on another individual willing to hire a butler. So while there is a sense in which persons have *abundant freedom* to autonomously pursue their career of choice, there remains many *limitations*. We can admit that such limitations are present while recognizing that the typical career environment of a liberal democratic nation respects autonomy to a far greater degree than a planned economy which limits one worker to one job. We should say something similar about healthcare: we can admit there will be limitations to active autonomy in any healthcare system, notwithstanding, some systems are much better than others. We are aiming for the sort of difference in autonomy between a direct command economy where individuals have no choice over career, to a system largely like most liberal democracies where persons have great but not complete career freedom. The relevant improvement is both substantial and terribly imperfect.

The "Deal-Breakers" and "Must-Haves" of Autonomy-Centered Healthcare

Our alternative healthcare system can come in a variety of flavors. But all should meet the following conditions:

1. Allow patients to choose between a variety of healthcare professionals/physicians.
2. Allow patients to choose between a variety of treatment options.
3. Allow patients to seek a variety of preventive healthcare resources.

What is so important with (1)–(3) is it puts patients in the driver's seat of their own healthcare. Patients then become governors of their own health, and can make choices for themselves in particular, when evaluating a range of competing options. This system gives patients a large incentive to research information about their own health. It is common sense that when persons have little control, they have far less desire to seek information.[11] What, after all, would be the point of knowing what healthcare option is best if those options are not covered by one's insurance? Surely this research would be done in vain, and may only cause heartache insofar as a patient suffers with the knowledge that the treatment they are getting is not what is best for their needs. However, when patients *do* have control over healthcare treatment, their research is matched with reward. Few of us are motivated to work without reward, but once the reward becomes available many are willing to put in the effort.

Other than the patients themselves, the class that might benefit the most from informed patients are clinicians and physicians. It is much easier to treat patients who are informed about their own health than ones who are not. Although a trained physician cannot take the word of his amateur patient without reflection, a patient who has previously researched treatment possibilities can greatly aid the physicians task by providing a helpful starting place. Even more, a healthcare system that gives patients greater choice and control over providers is far more likely to create compatible patient/physician partnerships.

As far as physician autonomy is concerned, our system must avoid the tale laid out in our earlier discussed movie scene. What must be avoided at all costs are situations in which a physician knows that a particular treatment is what patients need, and yet does not go forward due to external restrictions (like insurance). More specifically, physician freedoms which are especially important include the following:

1. The freedom to recommend whatever treatment the physician believes is best for the patient's needs.

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[11] Most study in this area has revolved around voting, in particular, whether the small impact one has via voting is worth the cost of becoming informed. There is strong reason to think that acquiring information is not worth the cost. For example, see Martinelli (2006). It would not be surprising if there was a similar effect when it comes to making medical decisions. When patients have very little control over their medical treatment, many patients will deem the cost of acquiring information unworthy of the reward, if there is a reward at all.

2. The freedom to recommend the patient to other treatment centers or other providers/physicians if the physician does not believe that her own treatment center is best for the patient's needs.
3. The freedom to recommend preventative care and diagnostic resources to patients without fear of external restrictions.

When looking at (1)–(3) above, what we see is a list that allows a physician the simple privilege of fulfilling the oath sworn to defend upon becoming a licensed practitioner. The modern Hippocratic oath asks that physicians gladly share scientific knowledge and avoid both over and under treatment.[12] When restricted via insurance limitations, physicians might not share scientific knowledge, seeing no purpose in raising a patients' hopes only to tell them the treatment is out of network. The oath also asks that physicians avoid both under and over treatment. This is something which points (1)–(3) above encourage physicians to fulfill, while many insurance schemes encourage physicians to do *the opposite*. Physicians might undertreat a patient due to lack of coverage, and overtreatment might also be a problem because a physician may seek to overcompensate with various treatments that *are* covered by insurance but strictly not necessary. The modern oath also asks physicians to admit their ignorance. The problem when admitting a lack of knowledge is that a physician might be unable to refer a patient elsewhere knowing there are no other in-network physicians. Any alternative healthcare scheme should make it easy for a physician to admit ignorance, by making it easy for a physician to refer patients elsewhere.

Step (3) above is an important part of the modern oath, which notes that "prevention is preferable to cure." As important as is prevention, there is little good in recommending preventive measures if the patient cannot afford them and if they are not covered via insurance. Lastly, perhaps the most important part of the Hippocratic oath (for our purposes) is the part which encourages physicians to recall that "there is art to medicine as well as science." This is a reminder that the discerning judgement and moral practical wisdom is a necessity. To exercise practical wisdom in the medical sense physicians should be able to explore the widest possible variety of treatment options for the unique needs of the patient. Our alternative healthcare system must keep this mind, and strive as much as possible to leave expansive room for the physician to practice the autonomous art of medicine.

The Health Savings Plan System

One potential way to improve healthcare coverage is through a large-scale form of a health-savings plan. The general model would involve persons putting away tax-favorable or tax-free contributions to a saving or investment fund. When an individual has a need to use healthcare services, they pay through a debit of such fund. This system is advantageous insofar as it solves one of the major problems of health insurance, i.e., the principle agent problem. In this system, a patient would be using

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[12] Again, see http://www.pbs.org/wgbh/nova/body/hippocratic-oath-today.html.

direct funds to pay for the service, and thus would be aware how much the service costs and how great of a percentage of the health-savings plan is being dwindled away. If the patient doubted that the service was worth the monetary loss in the health savings plan, the patient might seek an alternative service. Patients would have no restrictions as to what treatment, hospital, physician, or preventive health care resources they might seek (other than some cost limitations, which is unavoidable in any system). Healthcare providers could no longer count on the guarantee of patients that come to their practice because they have little choice to go elsewhere. In addition to the increased patient freedom, *physicians* would no longer be forced to worry about making recommendations in line with health insurance, but would be free to exercise their practical wisdom and make the recommendation that best fits the unique needs of the patient.

Health savings plans can be voluntary or government mandated (an example of the latter might involve automatically deducting money from paychecks, etc.). The degree of government funding, and whether to make health savings accounts voluntary, are important discussions which must take place before any government would implement such a system, but it is not a debate that should be solved in this paper. What matters for our current purposes is that these plans would enable both patients and physicians to exercise their active healthcare autonomy in a way that was previously unimaginable under traditional health insurance systems.

One clear drawback to a health savings plan is the inevitable circumstances in which there is not enough funding to pay for the needed treatment. Indeed, this problem is one that will show up in all speculative solutions. However, let us not forget that this is a problem which is inevitable under *any* healthcare system. Lower income insurance customers, for instance, are commonly unable to afford a policy which covers all costs that need to be covered. Medicaid is in many ways a successful program. However, we have already seen that many physicians refuse to take it, which greatly limits the medical choices of the most vulnerable patients. In all these varying healthcare systems, there is the creeping problem of a lack of financial resources to cover all costs. However, I do believe a large part of the solution is separating *non-emergency* and preventative care from *emergency* and life-threatening care. This is discussed in the next section.

Catastrophic Care

Let us return to the health savings model. It might not be plausible for any such plan to have enough funds to cover catastrophic health crises. For instance, if we look at the medical costs involved in a serious car accident, cancer, or degenerative disease, only the richest of the rich could afford to put away enough money to pay for these serious ailments. So even though this paper is focused on changing the current insurance system, there is room for a separate insurance program or government supported emergency fund. Either program could pay for catastrophic care without limiting medical autonomy in substantial ways. This emergency fund would pay for life threatening illness or injury, and would be entirely divorced from the rest of the healthcare system, which would fund non-emergency services. From here on out I will refer to this type of emergency funding as "catastrophic care."

What makes catastrophic care importantly different from other types of care has at least three dimensions. First, the costs of catastrophic care are drastically higher than preventative care, check-up care, and care for minor illness and ailments. Second, the nature of catastrophic care itself lends to less possibility for choice. Often in times of crises, the best care is the most immediate. If, for instance, one is hemorrhaging from a car accident, there is little sense in the patient sorting through various treatment alternatives. The best treatment is simply the fastest treatment. Hence a special program for catastrophic care need not be focused on active autonomy, for active autonomy bears little relevance in most catastrophic circumstances.

Besides the difference in active autonomy, catastrophic care is importantly different from other medical expenses insofar as resource scarcity is more salient. In the case of organ transplantation, for example, the mere scarcity of resources means there are few choices for those in desperate need of an organ. Due to resource scarcity, patients must be grateful to take whatever help is available. This is the third way in which active autonomy plays a different role in the case of catastrophic care.

Admitting that either insurance or government support is necessary for catastrophic care does not undermine the more general need for an insurance alternative. Consider, for instance, typical home owner's insurance. Most minor repairs and other home expenses are paid by the homeowner directly, *not* via insurance. If, for instance, the toilet is backed up, the light bulbs need to be changed, the sprinkler system enhanced, a shower head replaced, etc.—one does not appeal to a home owner's insurance policy to cover these costs. Indeed, many customers of home owner's insurance are all too aware that if they use their insurance for anything other than a catastrophic even they are at risk of losing the insurance. Homeowner's insurance corporations could never survive by insuring the basic upkeep and repair needs of the average home. If *they were* to cover the basic home needs, homeowner's insurance companies would likely impose great restrictions on the particular services home owners might use. This is exactly the downfall of traditional health insurance. Because even minor medical costs are covered via insurance, corporations impose strict coverage limitations to maintain a profit.

It is obvious that coverage for minor home repairs goes against common sense while coverage for catastrophic home repair is a necessity. Few can afford to rebuild their home after a hurricane, but most can indeed afford a plumber. Along these lines, we do not *want* insurance companies to mandate the brand and model of our toaster, nor do we *need* them to do so. We are perfectly capable of purchasing a toaster on our own. This paper contends that the healthcare industry should take careful note of the home insurance model, and recognize that an all-inclusive insurance system is both impractical and imposes unethical burdens. On the other hand, what is practical is a large-scale insurance system (whether privately or publicly funded) that covers catastrophic needs alone.

This is an appropriate time to note that any potential healthcare system can come with greater or lesser degrees of government support. This paper purposely avoids a discussion of the degree to which healthcare should be publicly funded, for resolving this argument is not necessary for the point of this paper. The point of the paper is that insurance systems limit autonomy, and thus the medical community has an ethical obligation to derive an alternative system with less severe limitations. In addition to the health savings plan, I offer three more potential solutions discussed below.

The Active Insurance Model

Thus far we have spent much time criticizing the way in which insurance limits patient autonomy. However, it is possible to imagine an insurance system where active healthcare autonomy stays in tack. Consider, for example, the model of most car insurance companies. When there is an injury or accident, the driver and car are both respectively "treated." And there are rarely strict limitations on where either might receive care. Indeed, in most cases consumers have a right to use a mechanic of their choosing. Liability coverage, similarly, typically does not insist that patients' injuries are treated at a particular hospital.[13]

Recently, I was in an accident and in need of a rental car. My insurance covered the cost of the rental, and posed almost no restrictions on where or from which company I might receive the car. I also had no problem reaching out to my trusted mechanic of over 10 years to repair minor damages to my vehicle. The only insurance limitation was that the cost of the rental and the repairs was deemed "reasonable." I can tell a similar story about my home owner's insurance. Recently, a water pipe broke and flooded my home, resulting in the need to stay at a hotel. My home owner's insurance had a limit on how much they would pay, but there was no restriction on *which* hotel. The point is this: it is not a matter of necessity that the health insurance coverage policies are as restricted as they are today. One problem with traditional health insurance is that it must cover all health costs, from the smallest of ailments to the largest. Neither car nor home insurance works in this fashion. If catastrophic care was covered via a distinct system as it ought to be, this opens up the possibility that health insurance too could allow more choice while maintaining a profit.

Imagine an alternative health insurance system where members pay premiums to receive a strict dollar amount of coverage for all healthcare excluding the catastrophic. What would *not* be part of such insurance model are rules that limit or dictate what clinicians, facilities, and treatment options a patient might seek and receive. Achieving this outcome might come via weakening restrictions on which healthcare companies can enter the market. Another solution might involve regulatory measures mandating how private insurance companies may or may not provide care. It is empirically possible that regulating health insurance in this way is not economically viable. This seems hard to know without trying this model. If it is not viable, then it would remain the duty of bioethicists and others involved in the healthcare industry to design a system which allows for the widest possible scope

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[13] For one example of the coverage freedom offered via car insurance see (Connecticut Insurance Department 2018; http://ct.gov/cid/cwp/view.asp?a=1272&Q=483962). The state of Connecticut is not exceptional.

of patient and physician autonomy yet remains economically viable. Below are three more possibilities for a healthcare system that supports and encourages active autonomy.

The Kaiser Permanente Model

Another alternative to the traditional health insurance model is far different than a health savings account. One benefit of this second alternative is that it already has a relatively strong track record. This system would be modeled according to the healthcare non-profit Kaiser Permanente. The Kaiser system, in turn, is similar to "pre-paid physician groups" that existed in the U.S. before insurance took over the healthcare system. Today, the system generally works as follows: individuals become members and membership opens access to a network of centers, resources, and medical professionals.[14] The advantage to patients is they have freedom to choose their own doctors, treatments, and preventive care as long as they are within the network.[15] Another touted advantage is that a variety of services, including pharmaceutical services and specialty care, are available at one location. For those with busy lives and schedules, this is an important advantage, which increases the chance that patients will seek the services they need.

One of the obvious downsides of the Kaiser system is that patients would be limited to seeking treatment within the network (although Kaiser covers some out of network services, this does not come without difficulties). Likewise, while physicians could recommend out of network providers, there would be an obvious incentive to limit referrals to other in-network professionals. The seriousness of this problem depends on the size of the network and the extent of their available services. If the network is sufficiently large, there will be room for a large degree of active patient autonomy. Encouragingly, Kaiser Permanente itself emphasizes the importance of patients making their own healthcare choices, and finding clinicians who are a good fit for them personally. Kaiser's website notes the following:

> We know that having the right doctor can make all the difference in the world. That's why you choose your primary care physician based on qualities that are important to you. Looking for a doctor who speaks a certain language? We can help you find him or her. Have a condition where your physician is referring you to a specialist? We can point you in the right direction.[16]

Now even though Kaiser is a non- profit company, they have an obvious incentive (like all of us) to display a strong public image. Hence like all self-testimony, their

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[14] A thorough description of physician groups, their history, and the start of The Kaiser Permanente story can be found in Christy Chapin's recent (2015a) book, *Ensuring America's Health: The Public Creation of the Corporate Healthcare System* (pp. 10–38). Please see Part I, "Early Attempts to Organize Healthcare".

[15] Kaiser does provide reimbursement for certain types of care received outside of the Kaiser Permanente network. This seems a good addition to the model, but a relatively minor part of it.

[16] See https://individual-family.kaiserpermanente.org/healthinsurance/why-kaiser-permanente/affordable-health-insurance.html.

words should be taken with a grain of salt. But it remains promising both that Kaiser recognizes the importance of patient autonomy and in addition makes efforts to give patients choice over their healthcare decisions, especially going so far as to find physicians who speak multiple languages and can be sensitive to a variety of cultures.

While admitting the limitations of the Kaiser model, let us again remember that every system is flawed, and all systems will have some limitations. The relevant litmus question is the following: *Does the alternative system of networks and providers leave more room for medical autonomy than the health insurance system?* Arguably, The Kaiser model, although it imposes limitations, imposes *less limitation*s than the traditional health insurance model. A strong national model of this kind might consist in a variety of companies like Kaiser, each which offers an expansive array of physicians and treatment centers within their network. We can even imagine that these networks receive public understanding to varying degrees, or that patients have an option of joining a public conglomerate modeled of the Kaiser system.

The Direct Consumer Model

The last two possibilities I will discuss are in direct opposition to one another. I do this to suggest that there is a wide range of systems that improve upon a health-care system grounded in traditional insurance. It is important that healthcare systems can be adapted by persons with diverse cultural beliefs, ideologies, and values. If a solution is strongly biased toward one ideological system, it faces problems if its implementation is suggested to a group who rejects such ideology. This cultural conflict might then maintain the status quo when changes are greatly needed. It is easy to imagine the health insurance model persisting, despite its infringement on autonomy, simply because no one can agree on an alternative solution. Hence when speculating about potential solutions, it is best to try and come up with a range which will appeal to various ideological and cultural groups while having one important factor in common: each system respects the active autonomy of both patients and physicians.

Perhaps our healthcare system would improve if we turned to the same model used for most other consumer products. When we need a new car, dishwasher, carpet, or carton of eggs, we find ourselves at a retail shop, in a position to directly exchange our money for the desired product. This is also true for most services like home cleaning, car repair, plumbing, gardening, haircuts, etc. In all these cases, a direct transaction occurs between the individual who needs the service and the person who provides it at a cost. There is generally no middleman. And it is easy to see why not. Not only would such middleman be unnecessary and inefficient, it would also be extremely intrusive. We neither need nor want a third-party who imposes rules about who should mow our lawn or what color we should paint our cabinets. If most consumer transactions took place via universal insurance, our everyday life would be greatly complicated and our autonomy severely infringed.

Since the direct consumer model works so well for so many things, it is worth considering how it might work for healthcare. Transactions in the direct-consumer healthcare model would usually take place between two individuals, a buyer and seller. Below are examples of what might become common transactions.

Consumer	Provider	Service
1. Patient	*Primary Care Physician*	*Annual Physical*
2. Mother	*Nurse Practitioner*	*Urgent Care for Child's Fever*
3. Patient	*Emergency Care Physician*	*Cast for Broken Arm*
4. Average Joe	*Local Hospital*	*Preventative Colonoscopy*

There are various ways the direct consumer model might work. For instance, a patient might pay a physician directly. The physician, in turn, pays a fee to maintain his practice within a particular hospital. Another model is one in which the patient pays the hospital and the physician receives a salary. What matters is that the person receiving the service (or their guardian) is the person paying for the service. This system is much like the health savings plan, except there is no special tax-privileged account. It would be up to each individual to save for healthcare as they choose, or simply to budget for healthcare as part of monthly expenses.

Now the obvious problem with a direct consumer model can be illustrated in the following question*: What happens when persons lack the appropriate funds?* Now, this problem is much less of a concern when catastrophic care is already covered, notwithstanding, there remains reason for worry. Some will choose to take the risk of not saving money for healthcare, and then end up in need of treatment without the means to pay. Others might want to put money aside for healthcare, but will lack the income stream to do so. (Something similar is bound to occur with health savings plans, especially when they are not mandated.)

Persons lacking income to pay for health treatment is not a new problem: it is again a problem that arises in nearly any system. The potential solutions are also familiar. Healthcare of the poor could be subsided via the government or via private charities. Because caring for the low income is not an issue unique to this paper's discussion, there is no need to spend much time investigating. What can be said is that whatever healthcare alternative system is chosen, and to whatever extent lower income persons are subsided, they should be subsidized in a way that allows them to have the same healthcare autonomy that those of higher income have. We have already discussed the unfortunate ways that Medicaid system in the U.S. restricts the healthcare options of the poor. We can return to our *New York Times* article quoted earlier, and hear the frustrated words of a Medicaid patient trying to find care, "I called four or five doctors and asked if they accepted our Medicaid plan…it would always be, 'No, I'm Sorry', It kind of makes us feel like second class citizens" (Bernard 2010). A healthcare system should not leave anyone in this position.

Single Payer System

At least in theory, we can imagine a government funded healthcare system that allows extensive patient and physician autonomy. Through taxation a government might fund both physicians and hospitals which are free for all residents. What is key in this imagined government funded system is that there be few restrictions on where a citizen might seek care. It would also be important that there be a wide range of treatment options across the nation.

One problem with a government controlled healthcare system is imagining how to fund it. In a world with unlimited funds, it is easy to envision a nation where each town or city-center has an expansive array of hospitals and specialty treatment centers. When citizens become ill they can then exercise their medical autonomy, consider the many government-funded treatment options, and then go seek the care which best fits their particular needs. In real-life, such a system would be terribly costly, and to fully fund national healthcare, choices are often made which restrict healthcare autonomy.

Depending on the seriousness of the funding problem, some government funded systems might be much like traditional private insurance insofar as patients are left with few options and physicians feel pressured to treat particular persons. However, it is also possible that a government funded system falls far short of an ideal scenario and nonetheless significantly improves upon a system grounded in traditional health insurance. Since a significant increase in both patient and physician autonomy is what we should be working towards, this possibility should be on the table. We can also imagine hybrid systems. For instance, a system might have private hospitals that are publicly funded. This might allow the efficiency of the market while respecting the sentiments of those who see healthcare as a right. As long as such hybrid public–private hospitals could be used without restrictions, this would greatly improve upon the traditional health insurance model that limits active autonomy.

Conclusion

The current healthcare model in the United States, which relies on a mix of private health insurance, and subsidized insurance for the elderly and poor, is immoral insofar as it infringes on the autonomy of physician and patient. We have become so accustomed to this system that we have also been accustomed to viewing healthcare autonomy in a largely passive light. When bioethicists and philosophers think of medical autonomy, what often comes to mind is the right to refuse treatment.

And indeed, this sense of autonomy is critical to a morally grounded healthcare system. But it is not nearly enough. A healthcare system that truly values autonomy will be one in which a patient not only has the right to say “no”, but one in which the patient can make a range of “active choices” concerning his or her own healthcare treatment. In addition to the importance of active patient autonomy, this paper argued that a moral healthcare system is also one which values *physician* active autonomy. That is, it is a system in which physicians can consider a wide range of particularized options for individual patient needs.

There is a moral duty for all involved in the United States healthcare profession to seek out an alternative healthcare model which does not impose severe autonomy infringing limitations on physician and patient. I offered a few exploratory possibilities. The solutions I offered were varied, for I wished to stress that a healthcare model focused on active autonomy can be realized under a wide-range of systems that respects multiple ideological viewpoints. In addition, no possibility I offered would allow complete active autonomy (whatever that might mean). Yet, any system which offers significant improvement over the traditional health insurance model is one worth the effort. Further work must be done to both design and implement such system, and this paper argued that taking part in this endeavor is a moral imperative for the bioethical community.

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