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Agency and authenticity: Which value grounds patient choice?

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Abstract In current American medical practice, autonomy is assumed to be more valuable than human life: if a patient autonomously refuses lifesaving treatment, the doctors are supposed to let him die. In this paper we discuss two values that might be at stake in such clinical contexts. Usually, we hear only of autonomy and best interests. However, here, autonomy is ambiguous between two concepts—concepts that are tied to different values and to different philosophical traditions. In some cases, the two values (that of agency and that of authenticity) entail different outcomes. We argue that the comparative value of these values needs to be assessed.

Keywords Agency · Authenticity · Autonomy · Best interests · Kant · Mill

The problem

There is a type of ethical dilemma that consistently troubles clinicians and bioethicists alike. It arises when a clearly competent patient makes a choice that seems to be contrary not just to his interests but also to his own prior value commitments. In such cases, the patient seems to be acting in ways that do not make sense to his doctors or to his loved ones, because his decision seems inconsistent with his past decisions or with people's ideas of who he is.

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In such situations clinicians have to decide whether to accept the patient's statement about his desires or, if not, how to justify overriding a clearly stated choice. Often, they seek help from psychiatrists, ethics consultants, lawyers, chaplains, family members, and social workers. The role of these helpers is not well-defined. It is, in part, to change the patient's mind. It is, in part, to try to tell a story about the patient that makes sense. It is, in part, to defend the patient's right to make a choice, even if that choice seems troubling.

When these experts bring their skills to bear on a particular case, they often find ways out of the troubling dictates of the autonomy paradigm. Sometimes the patient's inconsistencies are interpreted as a sign of incompetence. This allows a procedural solution that ducks the ethical problem. In other cases the patient's statement of his own wishes can be so ambivalent or ambiguous that different interpreters draw different conclusions about what the patient "really" wants.

In this paper, we explore the implications of a third approach to this class of cases. We assume that the patient is clearly competent; we also assume that his stated wishes are clear and unambiguous, indicating a specific preference for treatment or non-treatment. In spite of these stubborn facts, we think it is sometimes justified for clinicians to wonder how to respect a patient's autonomy when the patient's own choices seem to be inconsistent with some idea of who he is and what they know about his beliefs and values.

In such cases, the physician is not trying to substitute her own values for those of the patient. Rather, the patient seems to be acting on a value that does not fit with the values he has long held. What worries the physician is an apparent conflict between a momentary but, by the standard criteria, competent choice of an end versus the ends that the patient has cared about through much of his life. In the type of case we want to discuss, the physician might actually agree with the patient's choice and even think that she would make the same choice herself. The problem is that she is not certain that the choice is a reflection of the patient's most deeply held values. If it is not, then the clinician wonders if it is a truly autonomous choice.

In general the right of competent patients to make choices is respected because it is thought that those choices have both instrumental and intrinsic value. It is thought that they have instrumental value because patients generally know best what is in their own interest. Allowing treatment to be guided by patient choice is thought usually to lead to the decision that is best for that patient. But choice is also said to have intrinsic value in the sense that, apart from whether the choice leads to good consequences for the patient, he is entitled to make his own decisions, to run his own life—even if he does so badly and makes choices that are not in his own interest.

These two types of values tend to reinforce one another. In cases where the physician does not believe that a patient's choice has instrumental value, she can fall back on the belief that it has intrinsic value. In these cases the physician behaves, in effect, as if the intrinsic value of autonomous patient choice is more valuable than life itself. We do not deny this thesis about value. Rather, our claim is that in clinical settings patient autonomy has two distinct components. Our focus is on cases in which these two components are in conflict. The question, then, is, which is most plausibly more important than life itself?

Two illustrative cases

Case #1

The first case that illustrates this dilemma comes from Jodi Halpern's book, *From Detached Concern to Empathy*. Halpern describes a patient, Ms. G:

> A medical-surgical team at an East Coast hospital requested a psychiatric consultation for Ms. G, a fifty-six-year-old white woman with diabetes mellitus who had just had her second above-the-knee amputation. She had a long history of kidney failure, was not a candidate for a transplant, and required dialysis three times a week. Although she had willingly come to the hospital for surgery, she was now refusing dialysis, even though she knew that without it she would die in a matter of days. She refused to tell the medical team why, so they wanted both a psychiatrist and an ethicist to evaluate her decision-making capacity. [1, p. 1]

Halpern, as the ethicist who was called to consult on the case, learns that, two years before, after her first amputation, Ms. G had been depressed and hopeless. With psychiatric treatment, however, she had recovered her optimism and energy. She had gone on to enjoy her work as an artist and to continue her active social life. But this time, something is different. Halpern explains that the difference is that Ms. G has just learned that her husband is leaving her for another woman.

Ms. G's psychiatrist and her internist both feel that she is competent, that she understands the decision she is making, and that her decision must be respected. Halpern thinks that it need not be respected because Ms. G's identity is distorted by the emotional trauma of her husband's decision to leave her. She is not herself, in the sense that she is no longer thinking in terms of the values that she has long lived by. Both groups appeal to Ms. G's autonomy in justifying their opinions.

Case #2

The case of Dr. Michael DeBakey's surgery for an aortic aneurysm was told in a *New York Times* article by physician–journalist Lawrence Altman [2]. Briefly, DeBakey, who invented the surgical procedure that is used worldwide for aortic aneurysm, and who was thus one of the leading authorities in the world on the diagnosis and treatment of this disease, developed the classic symptoms of a dissecting aortic aneurysm while he was at home alone one evening. Although he thought he was going to die, he did not call a doctor or go to the hospital. When his wife returned and doctors were summoned, they insisted that he go to the hospital. He refused, stating that he thought he would heal spontaneously. He continued to worsen, eventually agreed to be hospitalized, but continued to refuse surgery. He did not, however, request hospice or palliative care. At his insistence, a Do-Not-Resuscitate order was entered into the chart. He then lapsed into a coma. At that point, the doctors were not sure whether to operate. On the one hand, he had not given them permission to do so; on the other hand, he had stayed in the hospital under their care. His wife insisted that he should be operated on. Some doctors

refused; others agreed. All thought they were doing what DeBakey would have wanted.

Agency and authenticity

Philosophers have understood autonomy in many ways. We will focus on two elements of autonomy, each of which is tied to a basic human capacity. We start with the capacity to choose, to take something as a sufficient reason to act. At issue is not the capacity simply to pursue what one desires. Animals do that—but animals do not act for reasons. They do not judge that something is a sufficient reason for action. Nor are we talking about the capacity to act spontaneously, for instance, at a sporting event to jump up and cheer. There may be value to such spontaneity but, like the actions of animals, this is not something with the value that commands the respect that is accorded to autonomy.

The capacity *to make a choice* is, then, the capacity to decide on the basis of reasons (including bad reasons). The central idea is that the fact that I *desire* X does not entail that I must act on that desire and *pursue* X. That I desire X is *a* reason to pursue it; nevertheless, it might not be a sufficient reason. It is up to me to decide whether, overall, there is sufficient reason to pursue X. According to Kant in *The Metaphysics of Morals*, our capacity to make a choice, "to set ends," is what is distinctively human (separating *Menschheit* from *Tierheit*) [3, p. 154]. What Kant stresses there is our capacity to accept or to reject our desires, in some sense, to be independent of them. He stresses the capacity for *agency*.

One way to ground the respect that we, as a society, have for patient choice, to ground the value that we find in it, is to see it in terms of agency.[1] A patient who is competent to make a particular decision—who can understand and act on the basis of the pros and cons of the treatment options—is an agent. He can exercise his will. One way to understand why patient choice is so valuable is to see it as an instance of agency, something philosophers have often thought to be of enormous value because it is the way in which, unlike other animals, we are not merely creatures of desire.[2]

[1] A word should be said about Kant. There is an unfortunate tendency for bioethicists to appeal only to the Kant of the *Groundwork of the Metaphysics of Morals*. However, this is merely one book among several that are fundamental for Kant's moral thought. Limiting oneself to the *Groundwork* distorts one's understanding of that moral thought—and even of the *Groundwork*, itself. In the *Groundwork*, Kant claims that the good will is the only thing whose goodness is unconditional (*ohne Einschränkung*). This claim is often, correctly, tied to his use, in the *Groundwork*, of the term "autonomy": autonomy, in Kant's use, obtains only when one acts with a good will, i.e., from respect for the moral law. In his subsequent works, however, Kant came to see that autonomy and freedom are different. The latter can obtain even when the former is absent; otherwise, there could be no responsibility for one's immoral actions. In his books *The Metaphysics of Morals* and *Religion within the Boundaries of Mere Reason*, Kant stresses that what is distinctively human is the capacity to make choices, even immoral choices (indeed, it is the capacity to make choices that may not be treated as a mere means). In understanding Kant's contribution to the foundations of bioethics, it is vital not to restrict oneself to the *Groundwork*.

[2] Drawing on a different philosophical tradition, that of Aristotle and Aquinas, Philippa Foot has emphasized this point. See Foot [4, pp. 52–65].

However, "autonomy" can also have another meaning. It can refer to living one's own distinctive life, to constructing one's life in accordance with one's distinctive beliefs and values. This ideal—of the self-directed individual—goes back to the Renaissance but receives its canonical form in John Stuart Mill's book *On Liberty*.[3] Mill writes that "it is the privilege and proper condition of a human being, arrived at the maturity of his faculties, to use and interpret experience in his own way" [5, p. 58]. He stresses that we should not only make choices; we should form ourselves at the deepest level so that our very desires are things that we can endorse and that lead us to choices that consistently reflect those desires. "One whose desires and impulses are not his own," Mill writes, "has no character, no more than a steam-engine has a character" [5, pp. 60–61]. Beyond making choices, the idea is to be—or to become—oneself. Call this the capacity for *authenticity*.[4]

To see the difference between agency and authenticity, note that agency can be fully exercised at each instant. Each choice can completely exercise the capacity. Authenticity, by contrast, must be exercised over time, sometimes over a lifetime. Over time, my authenticity projects me, my individual *persona*, onto the world. Authenticity is a sustained achievement, agency a momentary one.

The point of authenticity is not just to make a choice, or even to make many choices, but to make a life. The value that we look for in an authentic life is that it is a life that *I* have made and made in a specific way because it is the life that I believe *fits me*. An authentic choice is one that makes sense within the framework of the beliefs and values that I affirm.

Note that autonomy does not preclude character change. A person may come to judge that her life has hitherto been misguided, that she needs to launch herself in a new direction. As long as she makes a change on the basis of her own beliefs and reflections, her life is as authentic as that of the person whose views have not altered over time. The unity of a life, on our view, is less in the constancy of its content than in one's leading it as the life that one has made and continues to make for oneself.[5]

Agency and authenticity are distinct and logically separable components of what clinical ethics dubs "autonomy." We suspect that, in practice, clinicians look for both components in order to judge whether a patient is acting autonomously. Agency seems to be the value behind the authority of decisional competence. If the patient can understand the options before her and can see a sufficient reason to choose option A over option B—that is, if the patient has the capacity to make a decision, to exercise her will, about the issue at hand—then, with respect to that issue, she has agency. We suspect that it is the value of agency that is tacitly

[3] See Mill [5, ch. 3]. See also Feinberg [6, pp. 32–33]. For a discussion of authenticity in clinical contexts, see Siegler and Goldblatt [7].

[4] Like "autonomy," the term "authenticity" has been used in many ways. Unfortunately, it is not possible here to detail the distinctions between our usage and the myriad others.

[5] It is also worth emphasizing that considerations of authenticity do not always point toward accepting treatment. Ms. W, described on the next page, is one such example. But even with Ms. G, her situation might have seemed to her so dire that the prospect of making for herself a new kind of life and, in effect, a new kind of self might have appeared not worth the trouble. Here, considerations of authenticity might have pointed toward refusing treatment. We thank an anonymous reviewer for pressing us to address this issue.

appealed to in the thought that a decisionally competent patient ought to be allowed to refuse treatment. On the other hand, when clinicians feel uncomfortable with allowing a decisionally competent patient to refuse treatment because that refusal seems inconsistent with who the patient is, then authenticity is at stake. In such situations, clinicians may intuit that mere decisional competence does not reflect a sufficiently robust value to justify going along with, say, the refusal of lifesaving treatment. As in the cases of Ms. G or Dr. DeBakey, they want to see such a refusal as part of a more or less stable and coherent set of beliefs and values, as flowing from who the patient is. *Then* they can more easily see that they ought to respect the choice to refuse treatment. At times, however, the powerful influence of a view of autonomy as grounded in agency alone may lead them to dismiss or distrust those intuitions.

We do not want to leave the impression that agency and authenticity usually diverge. On the contrary, they usually fit together nicely. Take Ms. W, a 35 year old Jehovah's Witness, who refuses a lifesaving procedure because it would involve a blood transfusion. She knows that to live she must have a transfusion but she chooses to die in accordance with the precepts of her religion. This is an instance of the exercise of *both* agency *and* authenticity. Ms. W understands her options and, as a competent patient, makes a choice. And that choice fits well with her deeply held and long-standing values and beliefs.

Which value is the crucial value?

In a common formulation of competing values, patient autonomy is pitted against beneficence, that is, against a focus on the patient's best interests. We have divided the patient autonomy side into two branches, leaving three values, rather than two, at stake in the clinical setting—autonomy-as-agency, autonomy-as-authenticity, and best interests.

In the current American system, best interest considerations stand a chance against autonomy only when the patient is not competent to make a decision and the patient's surrogate cannot say what the patient would have chosen to do. Limiting best interest considerations this way is based both on affirmation of the value of autonomy and on skepticism about doctors' practical wisdom. We could challenge this orthodoxy and ask whether a generally reasonable rule that limits best interest considerations might have exceptions. We put this question aside, however, in order to highlight the more fundamental issue of autonomy's competing interpretations. As noted, agency and authenticity usually point in the same direction yet in some cases, for instance, those of DeBakey or Ms. G, they seem opposed. What the patient says that he wants now seems inconsistent not with some conception of the patient's best interests but, rather, with who he is. Then the philosophical disagreement between Dr. Halpern and her superiors, or between Dr. Debakey's various specialists, comes to the fore.

We believe that the value of agency alone, that is, not conjoined with the value of authenticity, is insufficient to justify the refusal of lifesaving treatment. This is a philosophical thesis whose proper defense would require a different and longer

article. Still, the basic thought is straightforward. The mere exercise of a person's competent will, the mere exercise of choice, does not seem more valuable than human life—at least not *obviously* so. For Kant, agency is tied to a particular metaphysical picture. For him, our capacity to set ends distinguishes us from other animals and links us to other possible rational beings, such as God or the angels. Absent such a picture, it is not clear why we should think that agency has overriding value. By contrast, we find quite plausible the thought that a basic part of an acceptable human life is to live it in accordance with one's deeply held beliefs and values. Without agreeing with the content of her religious beliefs, we find plausible Ms. W's conviction that it is more important for her to end her life in accordance with those beliefs than to continue life at the cost of violating them.[6]

Our claims, then, are as follows:

(1) The moral justification for accepting a patient's decision to refuse lifesaving treatment is lessened to the extent that this decision, though made by a decisionally competent patient, is less than authentic.
(2) In cases in which the medical team believes that a patient's decision to refuse lifesaving treatment is less than authentic, the team should make additional efforts to talk to the patient, to try to understand her reasons for her decision and to try to see if those reasons fit into an adequate account of who the patient is. This should be done, when possible, in consultation with the patient's family, friends, or life partner.
(3) At the extreme, it is possible that a decisionally competent patient's decision to refuse treatment is sufficiently inauthentic that it would be wrong to accept that refusal of treatment.

Objections

Right off, one might object that an attempt to base clinical decisions on considerations of authenticity, rather than agency, is legally suspect. It might be pressed that, legally, a doctor must accept the decision of her competent patient. Even if Dr. Halpern wants to force treatment on Ms. G, she may not legally do so. This objection need not detain us. It correctly describes the current legal situation. Our question is whether that legal situation is as it should be. Furthermore, the legal situation is not always so clear, legal guidelines vary from state to state, and there are often ways to get around perceived legal requirements in complex cases.

More troubling is the objection that to compel Ms. G to have lifesaving treatment on the grounds that her refusal is not an authentic choice seems to open the door to

[6] Our sketch of the agency/authenticity distinction lacks adequate philosophical development. What is needed is a richer account of what the two values amount to. As a first step, one might compare the work of an agency advocate, Stephen Darwall (see especially [8, 9]), with that of Joseph Raz, who might be cast as something like an authenticity advocate (see especially [10]). One might also look at many of the essays of Harry Frankfurt in the collections *The Importance of What We Care About* [11] and *Necessity, Volition, and Love* [12]. Finally, in a quite complex way, Christine Korsgaard's discussion of agency and integrity is of relevance; see [13].

letting doctors ignore patients' refusals of treatment. This seems a slippery slope if there ever was one. Does not our proposal merely return to old-fashioned paternalism, now disguised as doctor-determined authenticity?

This is indeed a risk. However, it is a different risk than is usually involved in what is labeled "paternalism." Authenticity is not the same as best interests. The doctor who believes authenticity is important and tries sincerely to understand the basis for her patient's choice in that patient's deeply held beliefs and values is doing something very different from the doctor who decides based upon her own opinion about what is best for the patient.[7] The doctor who values authenticity is trying to respect what the patient—this person here, with a particular range of beliefs and values—really wants.

Nevertheless, we do not want to deny that our view has a troubling implication. Even if it is not paternalist in the sense of according the doctor independent authority to determine what is best for the patient, our view does entail that there could be cases in which a competent patient's liberty to refuse treatment is not the overriding consideration. No doubt such cases will be rare; moreover, they will likely involve additional considerations that warrant acceding to the patient's refusal (legal concerns, slippery slope concerns). What we are pressing is that in some cases the value of mere agency should not be seen as solely determinative, as unchallengeable, as a trump. Patient refusal involves a value-theoretic uncertainty that needs to be addressed.

Several other objections should be noted. First, talk of authenticity might seem to commit us to the suspect thesis that there is a "true me," some fundamental essence of the specific agent. As we use it, though, the concept of authenticity is normative, not metaphysical. It involves two claims: that people in fact tend to have (somewhat) stable and coherent sets of basic beliefs and values, and that living in accordance with those beliefs and values is usually a central good for that person. No doubt, a person's values can shift over time; what would count as an authentic choice might then also shift. But whether there is a pre-existing "true me" is not at issue.

Second, the ideal of authenticity might be challenged. One might reject reflection and/or self-determination as giving value to a life. Instead, one might give pride of place to whimsicality or to deference to authority. Authenticity is a substantive value. We invoke it both because it seems to play a role in clinical decision-making and because we think it is in fact of great value. Clearly, the latter claim needs philosophical defense.[8]

Third, in pressing for authentic patient choice over mere agency, we might seem to be advocating a form of "weak paternalism"—accepting the patient's values but attempting to instantiate them by means the patient has not chosen. The usual understanding of weak paternalism is that it involves interfering with a person

[7] It should also be kept in mind that one cannot vindicate the value of agency by appealing to the *epistemic* advantages of a rule that lets patients decide. The value of agency is precisely *not* tied to patient knowledge (beyond the minimum needed for legal competency). The thought that the patient knows best would put the stress not on the value of the exercise of the will (agency) but on the value of a good outcome (however that is construed).

[8] For a rejection of the ideal of authenticity, see Strawson [14].

because she has made a mistake about the facts rather than because she has made a mistake about values. As Gerald Dworkin puts it, "if a person tries to jump out of a window believing he will float gently to the ground we may restrain him" [15].[9] Actually, our focus differs from this. For us, beliefs about the facts are not in question. In the cases at issue, the patient is assumed to have correct beliefs about the facts. For us, the problem is that there appears to be a conflict in the patient's values—between his immediate preference, on the one hand, and, on the other hand, the values he has long held and that have been significantly constitutive of who he is.

Our view also raises worries that are purely practical. One might find something appealing about the concept of authenticity and yet think that achieving authentic patient choice is unlikely to be realizable in practice. To begin with, doctors simply do not have the necessary time. The ideal of authenticity seems to presuppose doctors who have known their patients over many years or who can spend many hours with a new patient. In a modern medical system neither seems possible. Moreover, to facilitate authentic patient choice and to judge when it obtains (and what to do when it does) seems to require a kind of practical wisdom that we have little reason to believe doctors possess. In terms of practicability, agency seems to have a big advantage. In practice, it is likely to be much easier to satisfy the conditions for being a competent agent than to satisfy the conditions for making an authentic choice. Perhaps more important, it is likely to be much easier for an ordinary doctor to know that the conditions for agency have been satisfied.

These are genuine worries. Still, to the extent that our arguments have weight, they suggest that accommodation ought to be made, at least in some cases, for practices that would promote authenticity. After all, medical practice has been made more cumbersome by the requirement to obtain and document informed consent to medical procedures. Because agency has been thought important, requirements (often quite onerous) to facilitate it have been put in place. Our society has been willing to change clinical practices in order to realize what it takes to be an important moral value. Surely, we should at least look into the possibility of practices that would promote authentic patient choice.

In any event, it is important to know one's ideal. Of course, the ideal of authentic choice cannot be reached. All ideals are unreachable. With any ideal, the most one can do is to take steps in its direction. But to figure out which steps to take, the ideal must first be identified.

If our medical institutions are to be regulated by the principle of patient choice, including the choice to refuse lifesaving treatment, it is imperative that we have a sufficient moral defense of that principle. If the value of agency does not provide a sufficient defense, it would be wholly inadequate, indeed ridiculous, to say that, nevertheless, it is a value that is practicable.

[9] Gerald Dworkin defines weak paternalism as follows: "A weak paternalist believes that it is legitimate to interfere with the means that agents choose to achieve their ends, if those means are likely to defeat those ends. So if a person really prefers safety to convenience then it is legitimate to force them to wear seatbelts…. Another way of putting this: we may interfere with mistakes about the facts but not mistakes about values. So if a person tries to jump out of a window believing he will float gently to the ground we may restrain him. If he jumps because he believes that it is important to be spontaneous we may not" [15].

We close with two hypothetical situations. Suppose that instead of needing long-term dialysis, Ms. G merely needs, but is refusing, one shot of a powerful antibiotic. Imagine, further, that she has drifted off to sleep. Imagine that the doctor has the syringe, it will take him barely a moment to inject her, and the injection will be done by the time she awakes and realizes what has been done. This is the only chance—inject her now or she dies. The agency advocate must hold that agency is so important that any violation of it is worse than death.[10] The authenticity advocate might inject Ms. G and feel that, on balance, he was more respectful of Ms. G's autonomy by preserving her opportunity to exercise it than he would have been by accepting her decision and foreclosing her future.

By contrast, imagine that the doctor could secretly, but against her wishes, give Ms. W, the Jehovah's Witness, a transfusion and so save her life. Some readers might think the doctor should do so, but some might think he should not. Our point is that in this case, it will seem morally more problematic to override patient choice—and that is because, unlike Ms. G, Ms. W is trying to exercise not merely her agency but *also* her capacity to live (and die) authentically.

Two values are at stake in patient choice. In particular cases, we may need to assess their relative value. So the debate about which is the more important value does have to be joined.[11]

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[10] In defending the value of agency in medical contexts, people often invoke the "right to bodily integrity." If someone keeps me from choosing what to do with my body, my agency is violated in an especially important way. On scrutiny, though, the issue turns out to be complicated. One way the bodily integrity claim is often spelled out is via the claim that it would be morally wrong to prevent me from taking a physical risk—to interfere with my body—as long as I am mentally competent and the proposed action does not harm or imperil any third-party. Yet this is not clearly right. If my child is in a burning building, I will want to rush in to try to save her. I would certainly be emotionally distraught, but I would not be incompetent or irrational. Nevertheless, the police are likely physically to prevent me from entering the building. Their reason will be that the risk to me is too great. (If preferred, the stage can be set more fully by assuming that the fire marshal has already ordered the fire fighters out of the building.) Libertarians might disagree with a law that requires the police to restrain me for my own good. However, most people would probably accept this as a proper constraint on my risk-taking. At any rate, the case is not *obviously* one in which the police would be morally wrong to restrain me. Bodily integrity is not *obviously* more valuable than life itself.

[11] One might think that *both* agency *and* authenticity are important values, and that in actual cases, they should be balanced against one another (maybe even sometimes along with best interests considerations). In the clinical setting one might favor value pluralism over value monism. This has some common sense appeal. Still, value pluralism requires that, in many cases, someone balance the values and decide what decision, on balance, is required. Authority must thus be put in the hands of a doctor or some other health care professional. Logically, pluralism involves denying that the patient's mere agency has overriding authority.

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