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# Informed Consent

Jean-Pierre CLÉRO<sup>1</sup>

**Abstract:** Informed consent is one pillar of the nowadays' medical relation; it is a main element of the Copernican revolution of the care ethics: where the doctor was at the centre of the system, the patient has now taken the place at the focus of the care's process. The new deal with the doctor goes through the informed consent.

The change is not always easily accepted. French people which just have a quiet revolution in endowing the patient with a large autonomy in the medical act – nevertheless speak of *refus de soin* (word for word: refusal of treatment) when the patient wants his treatment to be stopped; whereas English-speaking people rightly draw a distinction between *to waive* <to renounce, to let, to abandon> and *to refuse*. There is no a slight difference between *to waive* and *to refuse*, between a *waiver* and a *refusal* even though a quick translation can take a word for another. A patient may decide to stop the treatment prescribed by the doctor, a treatment that he so far followed, without his waiver be a refusal. He is not necessarily somebody who is spoiling to a fight with the nursing staff.

Even when they are Republican, the States are not at ease with the consent they try to restrain by all possible means. Caught between liberalism and republicanism, ethics seem, on the field of consent, prevented by the politics to take its autonomy.

**Keywords:** anosognosy, authority, autonomy / heteronomy, balance risks / benefits, benevolence, choice, contract, decision, deliberation, fiction, freedom, *habeas corpus*, happiness, gestational surrogacy, information, knowledge, liberalism, non-malevolence, paternalism, person, pleasure, republicanism, understanding / misunderstanding, psychiatry, will,

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## I. Apparent simplicity of the notion of *informed consent* and its real difficulties

At first sight, the notion of “informed consent”, which is an ethical, legal and political question, does not seem to pose any problem. Except in French: in this language, the notion of «consentement éclairé» reverses the grammatical order of the English phrase, which might also imply reversing the logical order in which the operations take place. For there seems to be two moments in the notion. *First* comes the moment when the patient is

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given information concerning his state of health, the medical examinations, tests and treatments available to overcome a possible illness. *Second* comes the moment when consent is needed –when the doctor has to obtain it from his patient and negotiates with him or her. He needs to persuade the patient, to present him or her with an option or a set of options (such as a medical protocol) that he or she is supposed to have chosen, after having weighed the risks and the benefits of his or her choice in full knowledge of the situation. In other words, the patient gives the doctor the right and the authority to cure him or her; she or he empowers the doctor.

However, though this approach seems simple enough, there are numerous difficulties when it comes to putting it into practice, or when it needs to be explained in theory. These difficulties are twofold. *First*, as is well-known, there may be an opposition between the understanding a person has of a situation and what the person wants to *make of* this situation, or wants *in* this situation. In other words, the understanding and the will do not always work together. To what degree is it necessary that the patient should be informed in order to be taken seriously when he is supposed to make decisions regarding his own cure? Is it necessary to wait until the patient knows as much as the doctor about the illness to begin treatment? The patient is seldom in a position of knowledge; therefore it is necessary for someone with authority –the authority of the will– to suppress the hesitations that he or she cannot fail to have, not being doctors themselves. Nevertheless, when hesitations are overcome by authority, does the expression of will have as much value? We can acknowledge that the patients freely expressed their will, but in such circumstances, in which a misunderstanding is always possible, can we presume that the decision would have been different if they had been better informed and had therefore understood better? Many philosophers (Spinoza, 1999) think that a misinformed will was nothing but an illusion and a mask of ignorance. Others (Descartes, 1982) believe that we should recognise freedom of choice even when the subject misunderstands the situation in which he is asked to express his will, but they easily admit that an ill-advised choice has less value than a better informed choice, though it is not necessarily more free. When the choice follows from a misunderstanding of the situation, does the doctor have an obligation to obey a decision that may be disadvantageous for the patient though he has been unable to convince him to take a better one? Moreover, there are psychiatric cases in which, for instance, patients who (in case of *anosognosy*) are absolutely unable to

understand what happens to them when they are ill, who think they are not ill, even at the highest point of their illness, and who believe that the hospital staff ought to be treated but not themselves. How, in those circumstances, shall we take into account such a misguided will? Is it not right to ignore the expression of a will when it is asserted in such unfortunate circumstances?

This first set of difficulties arose from the disjunction between the will and the understanding. In the ethics of care, a *second line* of problems appears. Focusing on the will, whether it be expressed with full knowledge or not, often goes together with praising *autonomy*. Autonomy may be accompanied by fictions and contrivances that allow it to be used in a large number of situations, included those in which people choose reluctantly. In situations of illness, autonomy can conflict with values such as benevolence or non-malevolence, which imply *heteronomy*, that is to say imposing a decision on someone in their best interest. Indeed, one cannot assert that the patient should always be regarded as an autonomous agent. The duty of care extends to everyone, even if they cannot pose as heroic partners playing an active role in their own cure, as informed agents.

Therefore, the notion of *consent* brings into focus a series of acute oppositions. But what I want to demonstrate is that, far from only revealing acute oppositions, this notion invites us to understand knowledge, will, autonomy and heteronomy not as absolutes but as open to degrees. In all cases, it seems that we lose sight of the notion of *consent* when we imagine the will as an absolutely free instance, independent from the situation in which it is expressed. This is also the case when the will is conceived, to take up Hobbes's phrase, as the "last appetite" preceding an action (Hobbes, 2010). And yet, we will see how difficult it is to truly draw the consequences of a gradual understanding of these notions. The legal and political concepts that underpin the notion of *consent* constantly bring into being new and more violent oppositions which soon transform the continuum we hope to construct into a conflict in which theses are set against antitheses.

Let us begin with exploring the way in which informed consent enables us to bypass the violent oppositions between, on the one hand, the understanding and the will, and on the other hand, heteronomy and autonomy. Is it entirely possible to forget these oppositions? As we shall see, I do not believe so.

## II. A definition of the notion of *consent*

First, it is clear that the notion of *consent* has to do with the will. “I consent to such or such thing” means that I want this thing such as I understand it. This is true even if I hesitated or calculated in forming my will. If, being ill, I consent to a treatment, of course I accept the treatment the doctor offers me, but it is no less clear that I should have preferred not to have to take it and not to be ill to the point of needing treatment. Consent always includes a counterbalance of reasons and motives: they were not strong enough to lead me to the opposed decision but they do not cease to exist when I have made my decision or just after. Indeed, what I have *not* consented to continues to inform my consent, even afterwards. To consent is not as final as many other types of decisions. Consent requires mature deliberation. Contrary arguments remain in the mind. Consent requires me to assess the situation; in some circumstances it forces me to separate or distinguish myself from my personal will. *To consent* is not as direct as *to want*; *to will*, *vouloir*, in English as in French, is a transitive verb: I want something; *to consent* is intransitive: I consent *to* something.

It may be said that I am attaching too much importance to grammar, and that grammar does not impose any order on our relations with others. However, it highlights an important characteristic. If it is possible to want anything, it is because, rightly or wrongly, I believe I am the principle from which the will issues, with nothing coming between I and myself. This is not true of consent. *I cannot consent in the same conditions*. I cannot say that I consent to anything without taking into account a check to my will, without experiencing a restriction of my impulse, without introducing degrees. On the contrary, when I exercise my will, these degrees do not exist – at least – I take no notice of them. If I *want* to marry somebody, using the famous English phrase *I will*, I suggest that I am entirely in love with the person, or that I am so interested in this union that there is no counterbalance to it, or that the feelings expressed by the formula will break any resistance. This is not the case if, following the French pattern, I answer *yes* to the question of whether I consent to the marriage. It lacks enthusiasm but it is perhaps less hypocritical. There is no consent without counterweighing, debating, perhaps without intimate splits, though the consenter would not go so far as to set out his reasons. Unlike volition, consent implies degrees; these degrees range from resignation, which is the inferior degree of reluctant acceptance, to the degrees just below a full and entire will. So, there is a fraction of the volition which implies that, in circumstance where many options were

possible, the option I consent to is presumably the best one or the least bad, considering all other possible choices.

Therefore, the misfortune of consent is that it accepts degrees in its quest for happiness or pleasure (Ricoeur, 1984). Besides this, it may be said to have degrees in another sense. When I consent, I am not the single and undivided principle of my volition. When the matter is to consent –the etymology is clear: in Latin, *consentire* is not only *sentire*, which implies some passivity, but it is *cum sentire*, *sentire* with, agreeing with. This is important: it is not the same as feeling the same thing as the person with which I am supposed to feel-, my will is implied among an interplay of many other wills. Maybe others do not want for themselves what I want for myself, but they want what I consent to, just as I include their volition and enclose it in mine. When the doctor prescribes a treatment he or she asks me to consent to, he or she draws for my will a path that someone else has –and particularly I have– to follow. I may find my own path through a sort of second degree autonomy (an autonomy of adhesion not of production). Unable to provide by myself the rule of my action, because the circumstances do not give me the opportunity, I take it upon myself to obey the rule of another, which is a way of recovering some lost autonomy or of pretending that I am autonomous.

In a text entitled *Of Human Nature*, Chap. XII, § 7 and 8 (Hobbes, 1840), Hobbes makes clear that it is not necessary that, in *consenting to something*, the actors or the authors of this style of alliance actually want the same thing. They only want the same consequences. All parties agree to contribute to the effect, effectively dividing labour between themselves, for reasons that none of them has to declare to the other. When I consent to something, I conceive that those with whom or with regard to whom I consent may have a different volition from mine, and that they will do what I want by composition with them. This difference does not prevent us from consenting to the same thing. In consenting, I do not examine the intentions of those with whom I consent to anything. I am conscious that they have different wills from me. I do not confound my will with theirs. In consenting, I agree to a common project, which is mine as well as someone else's; sometimes more the other's project than my own. That situation is exactly that of informed consent in medicine: "In the core of the notion of informed consent, there is the idea that decisions about the medical cure a person will receive, if any, are to be made in a collaborative manner between patient and physician. The concept also implies that the physician must be

prepared to engage in –indeed to initiate– a discussion with the patient about the available therapeutic options and to provide relevant knowledge information on them” (Katz, 1984). I do not want something that I can make true by my own will; I want what someone else wants for me as long as this agrees with the ends I set for myself. I want something that becomes intertwined with the other’s will and which changes constantly.

### **III. An interesting “French” problem: the case of gestational surrogacy**

During illness, it is mistaken to use the notions of *understanding*, of *will*, of *autonomy*, as if they were steady, independent and isolable categories. In fact, the boundaries are unclear. But to limit ourselves to that statement would be forgetting another component of *informed consent*, which also has a political dimension. In France, several years ago –in 2009– there was a fierce controversy about informed consent, especially as applied to gestational surrogacy (it is called *gestation pour autrui* – gestation for another person). This medical act did not pose any problems in some democracies similar to France. But there, it was rejected by the Conseil d’État “in the interest of the child and of the surrogate mother”. This led to media debates between those who thought that the decision of the Council was well founded (Agacinski, 2009), and the others who thought that the State would appear paternalist and condescending if it followed the Council’s recommendation (Ogien, 2009). Paternalist in treating the citizens like children, whereas they could know and realize by themselves what they desire, and they, if it came to the worst, harmed themselves if the notion of “doing harm to oneself” means anything at all from a legal point of view. That debate was interesting because, on both sides, the same notion of *consent* was put forward. The ones thought that the contract of gestational surrogacy was a good contract which the State had no reason to forbid when all consenting parties agreed to it. It did not injure anybody, i. e. without producing any displeasure to others, except the symbolic displeasure aroused by the disgust felt by those who reproved commercial surrogacy. The others suspected that the consenting parties were not equal in that false contract; that no woman would ever decide to be a surrogate mother except if extreme circumstances made her depend on the money; that, consequently, the consent of two parties was not enough to authenticate a contract. Therefore, she concluded, the State is right when it interferes in the contract. In rejecting the legal validity of such contracts, it does not encroach on the rights of the contracting parties. If we

follow that line of argument, it may be illegal to commit oneself by mutual consent even in cases when this does not cause apparent harm to anybody. This is only true, of course, if we forget the foetus, and the child. But are they truly given a say in a more classical birth?

This highlights a powerful antinomy which is relevant to examine *consent* in general. The question is to know whether mutual consent, which is at the core of the debate, may be sufficient to constrain both parties or whether the consent, which, as it has been demonstrated, is part and parcel of a contract, may by itself validate the contract, provided, of course none of the parties intends to cheat the other. Does the notion of *freedom*, meaning *autonomy*, provide a way out of this antinomy by saying who is right and who is wrong? May the State interfere in a covenant in which each party is considered as autonomous? May the sovereign be authorized to decide that the parties are not autonomous, even if they claim they are? On what grounds would the State have the right to estimate that the autonomy of one of the parties, in the matter of the surrogate pregnancy, is not real? Can this not be said to be abusive? Can the claim that the party entirely agrees with the terms of the covenant be dismissed?

Everybody will understand that we enter a sphere in which ethics and politics are hard to distinguish. Conflicts on matters such as gestational surrogacy, euthanasia, payment for transplanted organs or free medical care for example, fall under *habeas corpus*, the legal principle that establishes the property of one's body and one's person. They therefore have to do with politics. In these circumstances, reason may feel humiliated when it fails to extricate ourselves from such difficult situations. For how can we know which decision is best? Is it the *first* one, the "liberal" one, which places consent first and derives rules from the free interplay of contract? Or is it the *second*, the "republican" one, which insists that rules are valid only if they are enacted by the sovereignty, even at the cost of paternalism, that is to say making citizen believe that the State knows what is best for them, included in their private lives. This option implies that individuals need a supreme authority to decide in their place, and abandons the word *autonomy* and the values attached to it. Calling fictions into play to help autonomy out of these dire straights can also imply that it is legitimate for the State to lecture citizens on what privacy should mean for them.



#### **IV. A possibility of conflict between politics and ethics. A new version of the “correct usage of illnesses”**

The reason why the problem of informed consent has led us to political positions and not strictly ethical ones is that, even though one should admit that ethics has intrinsic characteristics, there are also notions – including, significantly, *informed consent*– that fall under the control of the State and cannot be separated from politics. The conflicts dividing the political world inform ethical debates, on top of the internal contradictions I have highlighted. Informed consent is a notion that leads us to suppose that it is not unambiguous for the sovereign to trust the nursing staff in such matters. In this respect, politics seems to impose its law to ethics. Anyway, ethics, on this point, is subject to the two political oppositions that we have already seen. Consent may be an alibi for refusing the right of the understanding to explain a behaviour and for concealing some disturbing elements as far as the circumstances are concerned. It may also be the case that the pretended explanation can substitute itself to the will, which ends up being discredited as a mere illusion of transcendence. I do not mean that there is no *rationale* to politics and ethics; but I wanted to say that here, on this subject, they conflict. My position on a given matter can be righteous, but I cannot convince everybody of its validity, for demonstration is impossible here.

My ultimate conclusion to that research on informed consent is this one: care ethics is not simply general ethics applied to care, but it is an ethics which questions general ethics and allows us to place classical problems in a different light. So consent, which has very often been understood as a heroic challenge or the adhesion of freedom to necessity, may not here be discussed in traditional terms. The modern fashion of the “correct usage of illnesses” allows to shift the meaning of freedom as autonomy and to dissolve the necessity that was ordinarily bound to causality (Stuart Mill, 1996), so that nearly nothing is left of the matter. In medical ethics, philosophy should not only impose knowledge but collect elements that allow people to shift their categories and challenge the traditional oppositions.

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