Limits of Autonomy in Biomedical Ethics? Conceptual Clarifications

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In biomedical ethics the principle of autonomy is closely connected with the moral and legal claim to *informed consent*. After World War II and the dramatic misuse of medicine in Nazi Germany, informed consent regulations were expected to help avoid similar misuse in the future, to help overcome the traditional medical paternalism, and to advance the liberty rights of patients and human subjects of research. With the rise of the new field of bioethics in the 1970s, the traditional beneficence-based model of medical ethics shifted in the direction of an individual autonomy model. "Respect for autonomy," according to the standard work *Principles of Biomedical Ethics*, means "respect for the autonomous choices of other persons."[1] Autonomy on this account means individual liberty or self-determination, that is, the shaping of our own lives according to our own aims and values, which may be different for different individuals. "Persons should be free to choose and act without controlling constraints imposed by others."[2]

Meanwhile, many objections have been formulated against informed consent claims and against the underlying liberalistic and individualistic ideal of liberty. Beginning with a short overview of these criticisms, I argue in this article that this critique should be taken seriously but that we should not adopt the widespread opinion that the principle of autonomy should be restricted or abandoned in favor of other ethical principles such as beneficence or public interest. Rather, what we need is a more precise, broader, and more differentiated understanding of the concept of autonomy and of its relation to other ethical principles. This will allow us to understand that, and how, the principle of autonomy has unconditional and universal, but not exclusive, value. Rather, it is not respected and applied adequately unless—in any situation—the other principles are respected and applied as well. Only under this condition are we able to deal with moral conflicts between the principles that arise only in exceptional situations.

Should Autonomy Be Limited or Substituted by Other Ethical Principles?

Typically, objections against the principle of autonomy and informed consent regulations are being raised with regard to the limits of autonomy, respectively of individual liberty.

Regarding the limits of the mental capability of making autonomous choices, it is argued that ill people may, due to their illness, vulnerability, and weakness, be partly or totally unable to understand the information given to them and incapable of making rational decisions based on the information. Onora O'Neill, for instance, says:

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> Consent cannot be given by children, at least not by younger children; it cannot be given by patients who are seriously deranged . . . ; it cannot be given by those with learning disabilities . . . ; it cannot be given by patients with dementia; it cannot be given by patients who are traumatised or unconscious; it cannot be given in medical emergencies.[3]

Considering these restrictions on autonomy in medical practice, the model of the patient as a savvy consumer of healthcare, capable of making rational choices in his own best interest, appears to be based on unrealistic illusions. Rather, real patients seem to be in need of the help, support, and beneficence of others who have to make decisions on their behalf.

Regarding moral or legal limitations of individual liberty, the use of liberty may be opposed to other moral rights or values such as solidarity or public interest. Those arguments can be found in discussions about euthanasia, organ transplantation, human subject research, genetic databases, or biometric databases, to mention only a few of innumerable examples. In these debates we find a mixture of utilitarian and Aristotelian notions of the common good, which appears to be threatened by the liberalistic conceptions of individual liberty. In his article "When Self-Determination Runs Amok," Daniel Callahan, for example, argues against the right of physicians to perform assisted suicide and voluntary active euthanasia. He criticizes the practices of using medicine as a mere instrument to help individuals "achieve their private vision of the good life"[4] while at the same time endangering common goods, like the relation of trust between doctor and patient or the vocation of medicine to preserve life. Similar arguments are to be found in debates about organ transplantation. Utilitarian as well as Aristotelian and clerical proponents of an *opt-out* regulation—which regards every person as a potential organ donor unless they explicitly reject it—also argue for the primacy of a moral duty to solidarity and altruistic help for those in need of organs over the right to autonomy of the donors.

Regarding anthropological limitations on individual liberty, some people—particularly communitarians—argue that autonomy is conditioned and limited by the social and bodily constitution of human existence. From this point of view, the ideal of an autonomous and independent subject as an atomistic, "unencumbered self" (Michael Sandel) appears as a mere illusion. Rather, the human being has to be seen as a biological and social being dependent on nature and fellow human beings.

If this criticism is right, what conclusions are to be drawn from it? Should beneficence and public interest become more important than respect for autonomy? Should suffering and dying patients be forced to go on living against their will? Should potential organ donors be regarded as morally obligated to donate their organs and forced to fill out an organ donor card? Should we all be compelled and obligated to participate in research projects that others find to be of great value for medical progress and common welfare?

No, I do not think so. The critique is to be taken seriously. Especially in the field of medicine, the limits of individual liberty in all three aforementioned respects have to be taken into account carefully. But the criticisms mostly draw the wrong conclusions by requiring the right to autonomy to be limited or even abandoned and substituted by other ethical principles. The danger this strategy implies is, in my view, a relapse into the old paternalism and moral heteronomy that was

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criticized and rejected with strong and convincing arguments by John Stuart Mill as well as Immanuel Kant. They both defended the self-determination and moral autonomy of the individual person against external authorities, not only those of church and tradition, but also the more modern authority of the state as well as science and technology experts. Therefore the problem is not the principle of autonomy itself, but the conceptual understanding of it as well as the concrete realization and institutional implementation of informed consent procedures under conditions of modern medicine. The influence of science and technology as well as law and bureaucratic institutions poses just as much or perhaps even more of a threat to the principle of autonomy as did the traditional paternalism of medical ethics. The patient-doctor relationship has become highly constrained, formalized, and regulated instead of being a personal and communicative relation of interpersonal respect. All these conditions are great obstacles to the development of genuine respect for autonomy, instead of enabling, promoting, or facilitating it. If one only has to read and sign a long paper with a good deal of information and is otherwise left alone with the final decision, one does not get the feeling that one's autonomy is being respected.

But what is genuine respect for autonomy? In order to clarify this ethical principle, we need, as I mentioned in the beginning, a more precise and differentiated analysis of the ethical meaning of autonomy, which I now outline roughly.

Unconditional Respect for Autonomy: A Kantian Approach

The main thesis I want to defend here is the following: Respect for autonomy should not be reduced to "respect for autonomous choices" and, thereby, to respect for the mental capacity ("competence") to make such choices through informed consent procedures. Rather, it has to be understood in a much broader sense as respect for the *will* of the person. This will must not be identified with actual wishes or preferences, because these, first, may be unjust and immoral, and second, they may be irrational and not really in the best interest of the person. Faced with these possibilities, one could think that autonomy has to be restricted or overridden by public interest in the case of immoral preferences and by beneficence in the case of irrational preferences, as well as in the case of total "incompetence." In the following I show that this cannot be the case, that respect for autonomy has unconditional and universal value if we take into account the Kantian sense of autonomy as *moral* autonomy and if we take into account the close connection and interdependence between respect for autonomy and beneficence.

Moral Autonomy and the Common Good

Kant, as well as John Stuart Mill, defends the idea of individual liberty and self-determination against the infantilizing paternalism of external authorities such as the church, the state, science (including medicine), or our fellow beings who want to educate us according to their own ideals.

Respect for individual liberty, of course, can only extend to the point at which the other person does not interfere with the liberty of others in order to pursue her own happiness. To the contrary, we are obligated to interfere with any immoral use of liberty, to force the other person to stop or at least to appeal to his or her moral insight with regard to the interest of others or to what may be called

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the common good or public interest. But even in these cases, the right and obligation to coerce or force individuals to change their behavior has to be limited. First, the power of punishment has to be restricted to the *external actions* of an individual; she cannot be coerced to change her *moral attitude*. Second, it has to be restricted to serious cases of violation of negative duties, such as not to kill, not to steal, and so on. Finally, even in these cases, punishment must not mean a violation of autonomy. As in the case of error, in which one has to respect the other person as a rational person who, by being rational, is able to detect and correct her own error, we have to respect the other person as a moral agent who is able to understand her moral vice as a vice and to accept her punishment as legitimate. Thus, even the person and autonomy of the criminal has to be respected.

But this understanding of respect for autonomy obviously presupposes a different meaning or aspect of the concept of autonomy, namely, autonomy not as individual liberty, but as moral autonomy, which is fundamental for Kant's moral philosophy. Whereas individual liberty in Mill's sense or "Willkür" in the Kantian sense means self-determination according to one's own notions of happiness, moral autonomy means *self-legislation* or *self-commitment*, according to moral norms that are to be followed not because of external command or authority but because of one's own rational insight. This insight cannot and must not be forced or compelled—even in the case of the criminal. Moreover, the punishment must not be unjust but adequate and in accordance with the degree of the moral failure, in order to make it possible for the criminal to gain moral insight.

Just as an error presupposes the possession of rationality as a capacity to realize the error as such and to correct it, a moral failure presupposes the possession of practical reason or, as Kant says, a "rational will" that enables the individual to realize his moral fault. Typical moral conflicts consist, for Kant, in a conflict between one's *individual* will in terms of actual preferences, and one's *rational* will, in terms of insight into the legitimate claims and rights of others. This practical reason is not something private and individual, but a common, shared reason insofar as we expect from each other the acknowledgment of fundamental moral norms. The rational will is one's own will, not an egoistical will, but a general will, which is concerned not only with one's own liberty and happiness, but also with the liberty and happiness of others.

In accordance with this understanding of a rational will, Kant speaks of "general happiness," that is, the happiness of every human being. What this general happiness consists of remains, in my view, an open question. It should not be reduced to the mere sum of individual states of well-being or fulfilled wishes. In this respect it is right and necessary to criticize Kant's account of happiness—which he shares with Mill and others—as being too individualistic. It would be a good idea to combine the Kantian approach with a more objective Aristotelian account of happiness as a common good that includes justice and moral virtue. Kant's non-individualistic notion of moral autonomy could be a bridge between ancient and modern ethics.

But the main point I wish to emphasize here is that the Kantian notion of autonomy as moral autonomy cannot and must not be substituted, replaced, or in any way overridden by such a notion of a common good, either in a utilitarian or in an Aristotelian sense. General happiness is the object of moral action, not its foundation. What is good and what is right in a concrete situation, in the end, cannot be decided from an external standpoint; it depends on individual

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preferences and autonomous moral judgment, on self-commitment as opposed to heteronomous commitment. Observing the duty to respect one's own autonomy in this moral sense forbids one to blindly follow the pretended authority of external institutions such as the church, the state, or the sciences. The individual cannot and must not be regarded or treated in any way as a mere means for a common good or for public welfare.

Let us apply these Kantian insights to the objections to the principle of autonomy discussed previously. In the case of euthanasia the individual cannot expect the physician and society to fulfill all of her wishes whatever they are and to use others as a mere instrument to "achieve their private vision of the good life" (Callahan). The individual herself and others have to distinguish between legitimate and non-legitimate wishes. But the cases for which the legalization of active euthanasia and assisted suicide is discussed are cases of serious suffering. The will to die in those cases may be desperate and understandable; thus the moral decision of doctors to help the patient to kill herself has to be respected in those exceptional situations of emergency. It is right, of course, to maintain that killing as such is bad. We have good and strong reasons against legally permitting such acts, in order to protect other individuals from being killed without or against their will. Therefore, the exceptional emergency cases imply a kind of unsolvable dilemma or conflict. On the one hand, individual will and moral autonomy in those cases has to be respected. On the other hand, killing in itself is something bad and cannot (easily) be legalized. The public interest of protection against killing has to be fulfilled, especially in the field of medicine. We must find a manner to deal with this conflict, which cannot be resolved in the strict sense.

In the case of organ transplantation, no one can be forced to donate organs or even to state one's position by filling out an organ donor card. One could try to persuade someone to become a donor, but one cannot force others to behave altruistically, just as one cannot force anyone to donate money in order to fight hunger in the world. On the one hand, duties to help others are positive duties. The fulfilling of these duties, except in some extraordinary cases, cannot be forced by law, strong social sanctions, or moral pressure, unlike negative duties such as the duty not to steal or not to kill. In both cases the decision has to be based on the individual's explicit free will. On the other hand, the relation of a person to his own body is a much closer and more personal relation than the relation to one's property or money. Therefore, only a strict opt-in regulation for organ donation would be morally acceptable in terms of respect for moral autonomy, which cannot be delegated to relatives and which has to be defended against the moral heteronomy of the state and society as well as against the heteronomy of medicine.

In the case of human subject research, respect for moral autonomy means that scientific investigators as well as possible participants have the moral right to know as well as the moral duty to be concerned about the scientific quality, moral acceptability, and worth of the experiment for humanity or society. They should be able to identify with, approve of, and support the goals of the research. The more this is the case, the more it can be expected that participants would be willing, at least afterward, to accept and consent, if necessary, to a certain degree of deception or risk. But this is a balancing of different aspects that does not imply that the respect for autonomy could be or has to be outweighed or

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overridden. The purpose of an experiment can never be so useful or important that it would really justify any violation of autonomy that also has to be defended against the pretended authority of science.

By now, I have argued only for the unconditional validity of autonomy insofar as it is not to be overridden by reference to public interests or altruistic duties of solidarity. But what about so-called incompetent persons who are incapable of autonomous decision and action? Can the principle of autonomy be sensibly applied to the case of newborn, unconscious, or dead persons, or to persons suffering from dementia? In order to understand this, the close connection between the respect for autonomy (in the sense of individual liberty) and beneficence has to be reflected on more thoroughly, in order to show that both principles not only do not exclude or contradict each other, but imply and need each other. This can only be done through an anthropological reflection on all morally relevant features of the human situation.

Autonomy and Beneficence

Reason and autonomy are, indeed, specific features of human existence, but they are not the *only* features. They are inseparable from the *sensual-bodily* constitution of humans as a necessary condition for any execution of our reason and autonomy. Without this condition we would be godlike and not limited in our possibilities of knowledge and action in the way that we in fact are. Therefore, autonomy means, indeed, that everyone can and has to lead their own life, but no one can do this alone, without the help and support of others. To be able to lead our own lives, we need good education, medical help, and a great variety of support by other people in *any* situation of our life, not only in special cases of emergency. But what is true for daily life is even more true for medical practice: To be able to act as an autonomous agent, I am dependent on a great deal of support and assistance by others through real communication, for instance, instead of a mere transmission of information from one person to another, as found in informed consent procedures.[5]

This anthropological consideration leads Kant to the insight that the categorical imperative and respect for human dignity do not only imply negative duties of not interfering with the liberty of our fellow human beings, not killing, not lying, and so on. Human dignity, rather, also implies the duty to help and to support others to lead their life and to shape it by caring, educating children, or helping others in need. Kant calls these duties the duties of (practical) love for other human beings. Based on the categorical imperative, "the maxim of common interest, of beneficence toward those in need, is a universal duty of human beings, just because they are to be considered fellowmen, that is, rational beings with needs, united by nature in one dwelling place so that they can help one another."[6] In this respect, the Kantian moral philosophy obviously shows, in spite of his widely individualistic conception of happiness, some tendencies toward a more objective, anthropological, and Aristotelian conception of a common human good.

The inseparable connection of reason and sensuality, autonomy and dependency, agency and patency, and so on constitutes the common, shared background for all human beings in any situation. It enables us to argue with someone, motivated by beneficence and care for the well-being of the other person, in order to convince them that their wishes and preferences are not really

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in their best interest, that they should, for example, agree to a life-saving surgery. But arguing with the other person still implies respecting her as an autonomous person. Therefore this care has to be non-paternalistic; it has to abstain from one's own individual ideals and ends, and one has to put oneself in the shoes of the other person and try to comprehend her possibly very different will, ends, and situation. Ultimately one even has to respect decisions that appear to be highly unreasonable. Even if, in extreme situations, we feel obliged to interfere with the actual preferences and actions of a person—because she obviously acts on the basis of wrong information or in a state of strong mental aberration—paternalistic action in this sense has to be only temporary, and we must have good reasons to assume that, in the long run, we act in accordance with the will of the person, so that she will be able to endorse our actions at least in retrospect. Thus, respect for autonomy cannot and must not imply being indifferent to the consequences and impact of the other person's decision regarding her own well-being. This would be a form of autonomism that is the reverse of paternalism, and equally bad. Nevertheless, the principle of respect for autonomy can in no way be overridden. Paternalism in the sense of interfering with the will of someone can never be morally right.

The anthropological background also enables us to regard even unborn and newborn children as well as dead persons as our fellow beings, with whom we share the same form of existence. Without regarding them as persons, we would not be able to distinguish a dead person, in respect to his corpse, from a lifeless piece of material or from a dead animal, or to identify the corpse as a human person with an individual history. That a person is dead does not imply that he is a completely different kind of being. Being dead is different from being inanimate or lifeless, like a stone or a machine. The actual situation of a dead person can only be adequately understood in the broader context of his whole biography and of his social relation to others; even the bodily appearance still shows traces of the personality. When we encounter dead people, as opposed to mere lifeless things, our intuitive reactions are different, and, thus, our conscious behavior has to be different. We cannot and we must not treat lifeless things and dead persons in the same manner. We can only treat persons *as if* they were mere things, but that would mean that we are violating their dignity.

This implies that, in the case of dead persons, it in fact makes sense to speak of respect or disrespect for their will, autonomy, and dignity, of humiliation, violation, or defense of their rights, and so on. Thus, throwing away the body of a person as we throw away useless instruments, using it for scientific experiments, or conducting an autopsy or an organ transplantation without the preceding consent of the dead person, for instance, would mean violating the person's dignity. In a moral and legal sense, respect for the dignity of dead persons implies, as Kant argues in his *Doctrine of Right*, that they have rights toward us and that we have duties toward them, for instance, the duty to defend their reputation against defamation after their death.[7] This duty is in a sense even stricter than duties toward living persons, because dead persons cannot defend themselves. They are dependent on others to do this on their behalf.

What applies to dead people is all the more valid for situations of dementia, coma, and so on. We should, of course, as far and as much as possible, try to communicate with the patient in order to inform them and thereby enable them to make autonomous choices according to their individual situation. But declared will is not the patient's only means of expressing her will, and for others it is not

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the only source for determining the will of the patient. The rejection of food in the state of dementia, for example, is not necessarily but *can* be an expression of the will to die, like the cry of a child may be an expression of the will to be cared for. Kant writes, "everyone who finds himself in need *wishes* to be helped by others."[8] Therefore, the two persons neglecting the need of the robbed and wounded victim in the parable of the good Samaritan cannot excuse themselves by saying that they could not ask the victim if he wanted to be rescued. It can and should be taken for granted in such typical situations of need, without asking for declared wishes, that this is the will of the victim. It is only against this background of a *general* will that *individual* wishes, needs, preferences, and so on that may modify or change this general will can be understood and respected—as, for example, the will to die in exceptional cases of suffering. In cases such as death or coma, in which the other person is not able to express her will, there may be numerous possibilities and indications that still enable us to determine or presume the individual need, wish, or preference of the other person.

Thus, respect for autonomy, especially in the cases of so called incompetent persons, obviously implies beneficence and caring for the other person, because we have to consider and realize their ends on their behalf. But even in these cases, the principle of autonomy can in no way be outweighed by other principles.

To summarize: If we understand adequately the broad meaning of autonomy as individual self-determination and moral autonomy, as well as the close connection of autonomy with other principles such as beneficence, public interest, or the common good, then we are able to understand the unconditional and universal validity of the principle of autonomy, and we are able to defend it against its critics. But how should we deal with moral conflicts?

Dealing with Moral Conflicts

We are all well aware of situations in medical and scientific practice in which different ethical principles are in conflict. What should a physician do: Should he conduct a lifesaving operation with little risk against the clearly competent and durable will of the patient? Or should he respect the will, thereby letting die a patient who could have easily been saved?

Regarding such conflicts, Kant's thesis that moral principles or duties cannot be in conflict with one another has often been rejected and misunderstood. But the anthropological and ethical considerations about the close connection between the rational and the sensual aspects of human existence as well as between autonomy and beneficence make this thesis more reasonable. Usually, the principles depend on each other; we cannot apply one of them without applying the other: Beneficence without respect for autonomy would imply an unacceptable paternalism; respect for autonomy without beneficence would imply an inhumane lack of care and thereby an unacceptable autonomism. Precisely because of this inseparable connection of the principles, the situation can become a possibly unsolvable conflict or dilemma between two indispensable claims in exceptional situations.

The situation is similar in the case of the conflict between autonomy and public interest, as we have seen in the case of euthanasia. Autonomy as moral autonomy implies respect for the interests of others and of society. Because of this close connection, the conflicts in medical practice become unsolvable dilemmas in exceptional and desperate end-of-life situations.

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Thus, the conflicts that we encounter in special situations are not conflicts between the principles or duties themselves, but conflicts between different and excluding alternatives of action, each of which is equally necessary and justified by the principles. The conflict can be experienced and adequately described as a conflict only because all the principles are equally valid and applicable to this situation. This insight implies that not all conflicts—especially in the typical borderline situations that are discussed in the ethics of medicine—are solvable conflicts. To acknowledge the limits of ethical deliberation is a much better way of dealing with those conflicts than any illusionary and enforced attempts to solve them.

Notes

1. Cf. Beauchamp TL, Childress J. *Principles of Biomedical Ethics*. New York/Oxford: Oxford University Press; 1994:120.
2. Faden R, Beauchamp TL. *A History and Theory of Informed Consent*. New York/Oxford: Oxford University Press; 1986:8.
3. O'Neill O. *Autonomy and Trust in Bioethics*. Cambridge: Cambridge University Press; 2002:40.
4. Callahan D. When self-determination runs amok. *Hastings Center Report* 1992;22(2):52.
5. Cf. Manson NC, O'Neill O. *Rethinking Informed Consent in Bioethics*. Cambridge: Cambridge University Press; 2007.
6. Kant I. *The Metaphysics of Morals. Part II: Metaphysical First Principles of the Doctrine of Virtue*. Cambridge: Cambridge University Press; 2009:202 (§ 30).
7. See note 6, Kant 2009:76–77 (§ 35).
8. See note 7, Kant 2009.

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