

# 9a

## Research as a challenge for ethical reflection

*Marcus Düwell<sup>#</sup>*

### Introduction

Research in the life sciences has different types of far-reaching impacts on the lives of human beings. Those impacts are partly intended but partly not foreseen when the research got started. Obviously, the relevant moral aspects of such developments go far beyond the moral responsibilities of individual researchers. It seems, however, a task for different actors in society to reflect on the moral dimensions of research and new technologies. But there is hardly any agreement on the question whether such an ethical evaluation of research is possible and in which way it should be done. We are faced with a plurality of moral convictions, a diversity of ethical theories and an increasing variety of technical, ecological, economic and social aspects constructing the context of modern research and the conditions of their application. In order to assess those possibilities I will have a look at the normative framework that can be found in our generally expected practice of ethical examination. I especially want to ask whether the instruments available are sufficient for an adequate moral evaluation of the new research developments. In that context it seems a crucial point of discussion to what extent the methodology of such applied ethics is able to deal with the insecurity of the future developments of research and the unclear options of future applications. Some scientific activities, for instance, are not directly harming individual rights but are ambivalent in their possible applications. The only thing we can expect is that these activities will obviously entail far-reaching consequences for our lives. Since we cannot foresee them, a moral evaluation of those scientific and technological enterprises is difficult. This difficulty is not only a (more or less) technical problem of the technology assessment, but it is also a question for the methodology and the theoretical framework of research ethics to what extent they are able to take those dimensions of research and new technologies into account. In this respect I want to examine the available normative frameworks, whether they are able to achieve an ethical evaluation of research that is able to take the social and political impacts of those scientific developments into account; an ethical evaluation that is appropriate to the complexity and importance of research and new technologies for modern society.

### Normative Framework

When the World Medical Association in Helsinki and Tokyo accepted the rights of the patient to decide at free will and well-informed about the treatment he or she would undergo, an important step was set for the protection of the individual. It was a

---

<sup>#</sup> Faculty of Philosophy, Ethics Institute, University of Utrecht, Heidelberglaan 8, 3584 CS Utrecht, The Netherlands. E-mail: marcus.duewell@phil.uu.nl

milestone in the transformation of the conviction and the self-understanding of medicine – a discipline the history of which was always accompanied by moral reflection. High moral expectations had been carried towards the profession of a physician, but at the same time the attitude of the physicians against the patient had been a very ambiguous one. Being in need of medical treatment, human beings were often in danger of becoming depersonalized by the knowledge of physicians, who saw themselves often as the administrators of the well-being of the patient. The high moral impact of the self-image of medicine has been one of the reasons for a latent paternalistic attitude in the medical ethos.

Nowadays, the notion of a patient's autonomy and self-determination has become intrinsically linked with our view of the medical ethos. Perhaps we are no longer really able to appreciate the importance of that change for the moral orientation, which took place in the 1960s and 1970s (see for the historical development: Jonsen 1998). If we look at the moral convictions to be found in the international declarations and conventions, we will encounter a central position of human rights. And mostly the content of human rights can be explained primarily by the right of the individual to decide freely about the treatment that he or she would undergo. If one examines the practice of ethical committees that evaluate experiments involving human beings, one can see that, in general, the central aspects of the evaluation include the expected result of the experiment, the risk for the subject involved and the protection of his or her decision to be taken at free will and well-informed. Moreover, the European Convention on Human Rights and Biomedicine considers the protection of the free decision of the individual as a core right to be protected. This position is even central to the whole structure of the convention, and correspondingly a great part of the convention deals with the question how to treat people who are not able to give consent (Council of Europe 1997, Art. 6, 7, 17, 20). In short, if the free and informed consent starts to become the cornerstone of the moral conviction, it becomes most important to challenge cases where the patient cannot give consent and where therefore the informed consent is not an option to protect the patient's interests. We are thus faced with a moral framework that puts great emphasis on the question how to secure the free decision of the individual against tendencies in medical practice to overrule the free will of the person. Taking into account the history of some physicians in the Nazi concentration camps during World War II, we cannot help of being glad about such a development. The same development is to be found if we look at the central importance of human rights in the secular moral convictions of Western societies. But it is the question whether such a normative framework of protecting the individual choice is sufficient for the challenge that ethical reflection has to face with respect to the new developments in the life sciences.

If we consider the most influential book on bioethics from the last decades, "Principles of Biomedical Ethics" by Tom Beauchamp and James Childress (2001), of which a revised edition is published every few years, we could get the feeling that the analysis I have offered is a bit too hasty. According to Beauchamp and Childress, autonomy is only one of four principles. Besides autonomy, beneficence, non-maleficence and justice are also part of that biomedical ethos of which the principles – according to the authors – are used by all participants in discussions about medical ethics, irrespective of the theoretical presuppositions they make. Although it falls outside my scope to give more detailed comments on this approach (cf. Clouser and Gert 1990), I would like to argue that the set of normative forces would not become richer via such additional notions. Beauchamp and Childress use the notion of non-maleficence to emphasize the need to protect the individual from suffering direct

harm. With the notion of beneficence they introduce an internal teleology of the acting of physicians. With the notion of justice they refer in the first place to aspects of equality in the treatment of patients and the general accessibility of the health-care system. But we can interpret the general approach of this set of *prima facie* principles as an expression of the protection of individual rights against inadequate treatment by physicians. In general their reflections remain within the context of the medical practice and try to secure the patient in that context. In fact, we can interpret it as the articulation of that ethos of autonomy and self-determination I have mentioned before. The long-term perspective of the impact of the life sciences on the life of human beings is not of central importance to them.

Viewed more generally, it seems to me that the compatibility of the right to self-determination with a contractualist perspective may explain its general acceptance in biomedical ethics. In a secular world it seems necessary for moral norms to be compatible with an ethos of the self-interested perspective of each individual to be accepted. Only those norms will be successful that are not asking for individuals with good moral intentions and that can (at least in the long run) be seen as an adequate interpretation of the interests we all have. This ethos is interested in fundamental security, which can be offered by a secular morality in the form of a social contract. Let me emphasize that I am not defending such a position, but that I am interested in understanding why it is successful.

If this assessment of the chances of moral reflections in a secular world is right, we have to interpret the central position of the ethos of free and informed consent as an articulation of a set of moral convictions concentrated around the idea that we all want a situation of general security, which can only be guaranteed in a society where the individual can be sure that his will is accepted and where the governmental institutions are in the first place legitimized by their ability and task to protect the security of the individual. In the concept of Thomas Hobbes, we are confronted with the idea that those institutions have to protect us against destructive tendencies of our anthropological constitution. In later discussions, contractualists have tried to become independent of such theoretical demanding and controversial anthropological presuppositions. In order to defend – with John Rawls – the priority of the right against the different notions of the good, it is sufficient to presume that we shall not from our very nature act in a peaceful way and that consensual solutions will not appear without specific regulations and institutions. To legitimate the need for moral regulations, we do not have to presuppose any bad intentions of the human being; we do not need a ‘negative’ anthropology, but it is sufficient to refer to the fact that moral conflicts are not avoidable without conscious decisions.

A moral protection of our right to self-determination can be interpreted from such a fundamental contractualist idea. It will limit the scope of a generally accepted morality to only those moral norms that are compatible with the negative rights of every agent, and it will assume that the rights that we concede to each other are strictly mutual. In most Western societies, this ethos of the protection of our negative freedom has of course been enriched with some ideas of a welfare state and of a government that acts supportively for its people. But this additional, positive or supportive ethos has an unclear position in the bioethical discussion. In the political debate concerning bioethics it disappears very easily. If the public bio-political discourse has the task to produce a minimal consensus, it is the normal procedure that only the protection of the right of self-determination of the individual will be consensual. Thus, only the negative right to self-determination will stay as a strong normative approach, and everything beyond that minimal ethos will be a matter of

choice between the conflicting convictions. One good example is, for instance, the European discourse about the treatment of human embryos. We are often confronted with the observation that there is a conflict between the European countries (whereby generally my native country Germany is mentioned explicitly in that context)<sup>1</sup>. Most of the people who look at these political processes with a realistic view, articulate the expectation that there will be no consent to be reached in the next future. The consequence is that tolerance for the position of the other is claimed. To avoid misunderstandings, I have to add that I do not hold the opinion that a human embryo has the same moral status as a person does, even though I believe that the embryo is to be protected in several respects (Düwell 2003). But the point that is important to me here is a theoretical one. If we ask for tolerance where it regards conflicting positions, we already assume that the point in question is answered, because if we ask for acceptance of a position we presuppose that that position is in principle morally acceptable. But, if the pro-life position is right, the destruction of a human embryo is a violation of human dignity and defending such an action cannot be acceptable at all. To my mind, the example clarifies how the creation of a minimal consensus is a way to reduce the possible moral convictions in the discourse to a more or less contractualist moral position.

More examples are found in bioethical theories. Tristram Engelhardt's *Foundations of Bioethics* (1996) for instance, illustrates the defence of the principle of autonomy and the principle of beneficence. Engelhardt attempts to explain a secular ethos that is to be understood as a minimal ethos. Very briefly stated, we are all members of groups that, although being different in several respects, share several moral convictions. We therefore have *moral friends* with whom we share a set of common values. For Engelhardt himself, the moral friends are to be found in some orthodox-Christian groups. But outside those groups of moral friends we are *moral strangers*. The minimal ethos is to be considered an explanation of that set of moral convictions that is necessary for the coexistence between moral strangers. Engelhardt explains that the ethos of acceptance of an individual's autonomy is a strong claim, even between moral strangers. If we are looking for a moral authorization of our action, we are looking for something that is not compatible with violence. The types of moral authorization may be different, we may have very different kinds of moral arguments, but looking for a moral foundation for our action always means that we do not want to solve our conflicts purely by the law of the jungle. In the centre of that minimal notion of morality we find the prohibition of 'unconsented-to force against the innocent'. This means that even between moral strangers that law is valid. And if we act against it, we shall be seen as a kind of outlaw, we are no longer members of a moral community at all. We can doubt whether Engelhardt is very successful in his reasoning why we are obliged to accept all norms that are to be regarded as a result of that minimal ethos that exists between moral strangers. Since he has no philosophical concept of a moral obligation, we can doubt whether that project is successful at all (A lucid critics is to be found in: Steigleder 2003; 1992). But Engelhardt goes further and claims that also a principle of beneficence has to be accepted within the minimal notion of morality. Even if we accept it, we can doubt whether a principle of beneficence has the possible impact of such a minimal ethos. In the logic of an ethos that is a kind of peace-making project between different communities of moral

---

<sup>1</sup> Of course it has to be mentioned that the disagreement within the European Societies is in general much bigger than the international disagreement.

believers, one can only argue for a cease-fire project, which is realized by a minimal ethos of autonomy.

### The liberal concept and its critics

I do not assume that a more or less liberal, minimal ethos is the consciously chosen theory, which is dominant in the politically influential bioethical discourse. I would rather be inclined to a direction in which the ethos of the biopolitical discourse can be best understood by a contractualist point of view. I have not said very much about that hypothesis until now, but I would like to refer to some central presuppositions in the concrete ethical debate, which I believe have far-reaching consequences for the structure of the discourse. I want to emphasize this point of view in two ways, firstly a more theoretical and secondly a more practical one. In doing so, I want to outline some desiderata of the ethical discussion.

To start with the theoretical aspects: In a pluralistic society we are used to thinking in terms of a fundamental difference between the right and the plural ideas of the good. There is a plurality of moral convictions and most of the more or less liberal concepts of moral and political philosophy want to defend the position that there are some fundamental ideas of justice and human rights that should have priority. We can interpret the right as an overlapping consensus between different ideas of the good, we can interpret it as a set of basic convictions that are implications of the idea of a human person, or we can see it as a sort of minimal consensus between all those different moral approaches. Against this contractualist or liberal perspective criticism from different approaches has been articulated. The conservative *communitarians* are afraid that reducing morality to such a liberal, minimal ethos will destroy the moral energies, which are found in our moral communities (MacIntyre 1981). Those communitarians are afraid that on the one hand the chances for a philosophical foundation of a liberal morality are not very good and that on the other hand the liberal criticism against the traditional moralities will destroy the only sources which are available for morality at all. The very influential *ethics of care* stresses the point that a broad variety of relevant moral aspects is ignored if we reduce the centre of moral convictions to the idea of the right. According to these critics, the attitude of caring for the other has a priority in relation to the formulation of individual rights, and the scope of morally relevant aspects cannot be restricted to those claims which are implications of the protection of the liberty of the free and rational being. Between communitarianism and care ethics we find a variety of other approaches that are critical against that liberal ethos. We can mention the critics of authors like Amartya Sen or Martha Nussbaum, who argue against the liberal reduced perspective by stating that the moral framework has to be described in a way that is different from the way the liberal perspective describes it. Nussbaum attempts to legitimize moral claims in a way that the basic needs and basic capacities for all human beings have to be protected (Nussbaum 1990; 2000). She can argue in that way for a hierarchy of basic goods which are forming the foundation of moral evaluations. In doing so, she defends the modern idea of universality and the idea that there is a difference between a set of moral convictions, which is strictly obligatory for everyone, and a plurality of moral convictions where a diversity of values can exist and has to be accepted. But she does not restrict the scope of a binding morality to the protection of the negative rights.

Another kind of criticism against the liberal concept is found in several attempts to reintroduce virtue ethics, perfectionist concepts or concepts of care in the debate. The

mentioned discussion criticizes the reduction of the liberal ethos to a concept of a person who is a strategically thinking, self-interested and atomistic individual. According to this criticism, we have to reintroduce emotions, motivations and meaning in the ethical discourse in order to enrich our moral universe. We have to deal with real persons and include their level of intentions and moral lives in our moral considerations, instead of drawing the 'veil of ignorance' over all concrete elements of life in the ethical discourse. The relation between those strategies and the liberal project is ambivalent. Some ethicists really want to present an alternative approach to the liberal society in an ethics of 'Lebenskunst' or in a new virtue ethics. Others see themselves in the framework of a pluralistic society and develop creative and stimulating moments in a liberal and pluralistic society. In that case the normative basic convictions of an ethos of autonomy, of free and informed consent are not touched by those reflections.

In such criticism of the liberal idea of a priority of the negative right for the different ideas of the good, a problematic confrontation will emerge. It seems that the liberal idea of rights is restricted to negative rights, which find a foundation in the liberal idea of a social contract. On the other side, we have a broad variety of moral convictions that are articulated against the liberal perspective, but which do not seem to have the pretension to be argued as morally right. My suggestion would be to criticize that alternative. Whether or not the scope of rights is to be identical with the negative liberal rights, is a matter of discussion. Here the role of moral philosophy in the concrete ethical debate becomes obvious. We have to ask why we are obliged to respect the rights of each individual. In doing so the question has to be put out in the open: what are the contents of the rights we are obliged to respect? The legitimization and the content of the moral rights will thus have some connection.

### **Ethical discourse and the complexities of new technologies**

The second consideration will be on a more practical level. If the ethical discussion concentrates on the protection of the self-determination of every individual, it has to be asked on what aspects such a moral debate will be focussed. It seems that the ethical debate is in this way restricted to those moral aspects that arise when a technology is on its way into practice. The question in that kind of moral debate will be: how can we protect the individual against possible harm through the application of a technology? But, the development of technologies itself seems to be morally neutral. To my mind, the key restriction of the bioethical discourse is the ignoring of central aspects of the social dimensions of those technologies. And that has to do with the theoretical problems I have mentioned above. Let me explain that by describing some issues.

If one describes moral questions that are connected with the research of a human being, one can start with either an analysis of the process of the research, with the targets that are the aims of that research, or with the expected outcome. If the ethical evaluation starts with the research process, one will be concentrating on the methods that are used and on questions that have to do with the responsibility of the researcher. One will furthermore examine from a moral perspective whether or not specific rights and values of human beings are touched; perhaps the protection of animals will be taken into consideration as well. Here it is possible to describe the relevant aspects, because the circumstances are known and in general the responsibilities are known as well. If, on the other hand, one is more focused on the possible outcome of the research, one is faced with many more insecurities and unknown aspects. The range of

research activities that are nowadays carried out under the label 'genomics', include a broad variety of research in biology, pharmacy, agriculture, veterinary medicine, human medicine and so on. It is not a research activity with a common methodology and a clear target. It is an ensemble of research activities, each with totally different application conditions. We only know that the expectations concerning the output are high. We expect that several fields in the life sciences can be changed, but we do not know precisely what the possibilities for application will be. We do not know what will change in medicine, pharmacy or veterinary medicine. We can also expect that some fields in practice will change although we did not have that in mind when the research got started. Since we do not have enough knowledge about the possible applications, we cannot know what will change in the different fields. If there are possibilities for creating pharmaceutical products that will cure a specific genetic disease, what will that mean for the whole idea of treatment in our clinics, for the perception of illness, for the self-understanding of patients and for the financing structure of the health-care system? What economic possibilities for agriculture will be connected with that research? In what way will our general concepts of illness, nature and bodily identity be changed? If the impact is so far-reaching, then we can expect that the consequences for several dimensions of life will be enormous.

For an adequate ethical framework for the evaluation of such scientific developments we have to wonder about the possible levels of moral regulation. In the framework of the ethics of an informed consent, we can first of all assure ourselves that no rights of human beings are touched or violated in the research process. Furthermore, we must ensure that in the application of the result of the research adequate control mechanisms are institutionalized to avoid harm to the people. Besides that, an ethics of free and informed consent, a liberal ethics, could fulfil its task in ensuring the possibility of autonomous decisions in dealing with the applications of such research. All of us, in our role as patients, consumers or citizens, have to be given the possibility to decide freely about the use of such developments. This means that measures should be taken to ensure that we are able to reject the use of such an outcome of genomics research if we want to. Furthermore, we should also consider the implementation of relevant measures in order to bring high-quality information to the public. If people shall decide freely, they have to be made competent to do so. This means that appropriate information materials have to be made available to ensure that competent decisions can be taken, and that infrastructures that give the consumer and citizen adequate access to all knowledge and information necessary for his free decision, have to be established.

What I have described here very briefly is the normal procedure in dealing with new scientific developments. It seems that the ethical approach has the advantage that it is not paternalistic. It is a liberal approach, in so far that it respects the different decisions of the citizen and the consumer and that it is compatible with different worldviews. It has the advantage of being clear concerning the responsibilities of the different actors in the field. The government has to take measures to support research, avoid harm and enable free decision-making. The consumer has to inform him- or herself, if he or she wants to decide freely. The scientists have to perform their job in a methodically correct manner, and have to make all scientific information available. Such an ethos is not burdened with high and idealistic expectations concerning the morality of different actors. The researcher only has to do a good job and be honest, that's enough.

All ethical reflections that go further are either a criticism of the fundamentals of a liberal society or deliberative considerations within the liberal framework. Reflections

of the first kind are easy to criticize; reflections of the second kind are deliberative considerations inside the liberal society. The critical attitude towards the liberal society was articulated, for example, in the debate around communitarianism, where the priority of the right and the plurality of the conceptions of the good were no longer accepted. That debate was able to articulate moral aspects in the evaluation of new developments only in the framework of specific moral convictions of particular groups in society. Therefore, they were either paternalistic in forcing their moral convictions to society or they were unable to deal with the plurality of moral concepts in another than a traditionalistic way. A convincing alternative to the liberal project cannot be found in that way.

### **Concluding remarks**

My sketch of the ethical landscape is aimed at explaining the problems for an ethical discourse that has to deal with the complex impact of new research. If ethics has the task to ensure autonomous decision-making, it will allow research to continue but will reduce the task of ethics to ensure free decision-making when dealing with the result of the research done. The moral evaluation of the question as to what impact that research has on our life will not take place. But, in fact, I think that, on the one hand, the task of ethical reflection goes further than ensuring autonomous decision-making, and, on the other hand, that it has to be seen within the framework of a liberal society. The question for the ethical debate should rather be what implications the protection of the rights of the individual and the respect we owe to each other has for new scientific developments. Is it enough to protect the possibility of free decision-making inside a room of alternatives and options that are already determined by the scientific development? In that concept, the alternatives between which the citizen can choose freely are already created by the scientific community. The structure of the room of decision-making will then not be the object of an ethical debate. The subject will find himself in a situation of decision-making where the options have already been structured in a way that the pathways of his choices are foreseeable. The question for an ethical reflection which wants to evaluate the scientific development, including the whole range of implications for society, economy and our private lives, thus has to be in what way an evaluation of research activities with their possible implications for our lives is possible, in order to avoid that moral reflection can only happen in a situation when the range of options and alternatives has already been decided by others.

In the framework of a liberal society I do not see an alternative to the exceptions of the priority of the respect we owe to each other for the different concepts of the good each of us can follow. But the question is what the content of those moral respects is. It is possible that we have to conceptualize it in such a way that research has to develop in its own inner logic and we have only to protect individuals against harm in the process of research as such. But it is also possible that our moral rights include much more. It is possible that the protection of the basic capacities of all has to be directed towards the hierarchy of the goods that should be protected. The range of moral rights has not to be restricted to negative rights, meaning that not only those measures are necessary that protect everyone against direct interference in the freedom of his acting. It is possible that there also are positive rights. This means that we owe to each other the support that we need in order to be able to live a good life. All the mentioned possibilities to interpret the content of the rights and obligations we have towards each other would have different impact on the moral evaluation of the

impact of scientific activities in a liberal society. The complexity of the impact that research has on our society and existence forces us to open the discussion about the normative framework of such an evaluation. Reducing that normative framework to an ethos of free and informed consent does not enable us to deal with the complexity of the new developments.

## References

- Beauchamp, T.L. and Childres, J.F., 2001. *Principle of biomedical ethics*. 5th edn. Oxford University Press, New York.
- Clouser, K.D. and Gert, B., 1990. A critique of principlism. *Journal of Medicine and Philosophy*, 15 (2), 219-236.
- Council of Europe, 1997. *The convention on human rights and biomedicine*. [<http://conventions.coe.int/treaty/en/treaties/html/164.htm>]
- Düwell, M., 2003. Der moralische Status von Embryonen und Feten. In: Düwell, M. and Steigleder, K. eds. *Bioethik: eine Einführung*. Suhrkamp, Frankfurt, 221-229.
- Engelhardt Jr., H.T., 1996. *The foundations of bioethics*. 2nd edn. Oxford University Press, New York.
- Jonsen, A.R., 1998. *The birth of bioethics*. Oxford University Press, New York.
- MacIntyre, A., 1981. *After virtue: a study in moral theory*. Duckworth, London.
- Nussbaum, M., 1990. Aristotelian social democracy. In: Douglass, R.B., Mara, G.M. and Richardson, H.S. eds. *Liberalism and the good*. Routledge, New York, 203-252.
- Nussbaum, M.C., 2000. *Women and human development: the capabilities approach*. Cambridge University Press, Cambridge.
- Steigleder, K., 1992. *Die Begründung des moralischen Sollens: Studien zur Möglichkeit einer normativen Ethik*. Attempto, Tübingen.
- Steigleder, K., 2003. Bioethik als Singular und als Plural: die Theorien von H. Tristram Engelhardt, Jr. In: Düwell, M. and Steigleder, K. eds. *Bioethik: eine Einführung*. Suhrkamp, Frankfurt, 72-87.