

Biobanks and the Rights to the Human Body

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Introduction

This article will investigate how to protect the rights to the body in the perspective of the Western legal, ethical and religious tradition. The new commodification of the human body represents a major challenge to this tradition¹. On this basis I will discuss who has property rights over the human body and the individual's rights to dispose over body parts.

Modernity and commodification of human bodies

In a historical perspective the use of the human body as medical resource or research object is not new but a part of the social and cultural life of the Western world. According to cultural anthropology our conceptions of the body are characterized by the tension between “the grotesque and the sacred”. Western culture is marked by the conflicting conceptions of the body. It distinguishes between the dead body, independent body parts and the lived body that is an integrated part of the human person.

The French legal philosopher Jean-Pierre Baud has argued that instead of only focusing on the lived body of the person we should examine the cultural status of the dead body². The dead body can both be described as 1. an object and a material thing. 2. a sacred object indicating the spirituality of the human person. The feelings of the grotesque and the sacred in the dead body are determined by the fact that the dead body expresses the presence of mortality in human existence. The grotesque character of body parts reminds us of the fact that the lived body in reality is a thing and that the person is an abstraction from this objectified way of being.

In modernity, medical technology and science are no longer restoring the body to a natural condition. Today we are also remodeling the body³. However, the tension between person and thing remains central in the industrial use of human bodies and body parts. Medicine does not teach us how to die. Death seems to be something very strange and far removed from human existence. In an increased technological culture, the body might be seen as “La part maudite”, the inescapable other of human personal existence. In technoscience the body is considered as a machine that we in principle could repair and change indefinitely. We live in a close interaction between humans and machines. The body has become an object among other objects⁴. Many of the visions connected with biobanks are based on this idea of the human body as mere object of production.

This can be illustrated by the famous case of John Moore, the man with the golden cells⁵. John Moore who lived in Alaska had been treated for a very rare leukemia. His physician lived in California, and he continued to come for check-ups by his doctor. After a number of years he realized that the physician was very interested in his cells and that they

had been used to create a medical product. Moore discovered that he had become MO-cell-line and that the physicians had earned millions of dollars on his cells, but they refused to give him a share of the earnings.

Accordingly, Moore sued the physicians at the California Court. The Court judged that he had the rights to his own body and should have a share in the economic gains. The physicians appealed the decision to the Appellee Court. This Court came up with the opposite judgment. It stated that it should be considered as contrary to the dignity of Moore to sell his own body. However, he should have compensation for malpractice because the physician had not informed him about the use of his cells and he had had no possibility of refusing the development of the cell-line.

The John Moore Case is interesting because it displays many of the central problems with regard to biobanks. It illustrates the possibilities of commercial gain and profit when using human biological materials. It raises the difficult problem of whether the human body should be subject to scientific patents. But the case also shows the vulnerability of research being dependent on Moore's informed consent in order to use the cells for research and development of new medicine. The dilemma of commodification of the human body is a tension between individual rights to dispose over bodies and respect for freedom of research and commercial production.

Ethical principles and protection of human individuals

Classical principles are the ethical ideas of protection of autonomy, dignity, integrity and vulnerability. These principles are founded on philosophical and anthropological theory of the human body.

i) Autonomy should not only be interpreted in the liberal sense of "permission", instead five aspects of autonomy should be put forward⁶: i) the capacity of creation of ideas and goals for life, ii) the capacity of moral insight, "self-legislation" and privacy, iii) the capacity of rational decision and action without coercion, iv) the capacity of political involvement and personal responsibility, v) the capacity of informed consent. However, autonomy remains merely an ideal, because of the structural limitations given to it by human weakness and dependence on biological, material and social conditions, lack of information for reasoning etc.

On this basis, autonomy defends the rights of the individual to dispose over his own body. This includes a right to refuse a certain use of body parts. However, autonomy as an ethical requirement excludes individuals who do not have this capacity, dead bodies, including minors, incapacitated persons, fetuses etc. In these cases it is necessary to find alternative representatives for making the decision.

ii) Dignity should not be reduced to autonomy⁷. Although originally a virtue of outstanding persons and a virtue of self-control in healthy life – qualities which can be lost, for instance by lack of responsibility or in extreme illness – it has been universalized as a quality of the person as such. It now refers to both the intrinsic value of the individual and the intersubjective value of every human being in their encounter with the other. Dignity concerns both oneself and the other person: I must behave with dignity, and I must consider the dignity of the other person; I must not give up civilized and responsible behavior, and the other person should not be commercialized and enslaved. Defined as an intrinsic value and as an intersubjective dimension of respect for the living person, the dignity of the human body mainly refers to what it can be dignified to do with human beings.

We should recognize the respect for the dead as an essential requirement. This limits the use of dead bodies in biobanks. Here religious traditions, the ethical worldview of the deceased and his or her family might play a role in their decision-making. But dignity in

general demands respect for the person in using the material. This means that confidentiality, respect for autonomy etc. is a part of the treatment of tissue from dead bodies.

With regard to living persons, respect for their dignity implies the use of their material for medically and scientifically justified purposes. This might mean that certain purely commercial uses are contrary to the dignity of the person. Some research aims, such as genetic enhancement, creation of human animal hybrids and cloning have been mentioned as contrary to human dignity.

Moreover, there is an important responsibility with regard to use of human tissue of fetuses for therapeutic purposes. Here, the intrinsic value of human life is at stake and we have to acknowledge that there are some things a society, due to respect for human dignity, simply will not do.

iii) Integrity accounts for the inviolability of human beings⁸. Although originally a virtue of uncorrupt character, expressing uprightness, honesty and good intentions, it has, like dignity, been universalized as a quality of the person as such. Thus it refers to the coherence of life that should not be touched and destroyed. It is coherence of life that is remembered from experiences and therefore can be told in a narrative. Moreover, respect for integrity is respect for privacy and in particular for the patient's understanding of his or her life and illness. Integrity is the most important principle for the creation of trust between physician and patient, because it demands that the physician listens to the patient telling the story of his or her life and illness.

With regard to integrity it is clear that personal privacy should be respected in the use of human material in biobanks. This involves respect for the individual identity of the person when using biomaterial. There is a close connection between the personal understanding of bodily harmony and the use of body tissue that would be permitted by the individual. The reference to the individual's integrity means that tissue must not be used in a way that violates the connection between personal identity and integrity.

iv) Vulnerability concerns integrity as a basic principle for respect for and protection of human and non-human life⁹. It expresses the condition of all life as prone to be hurt, wounded and killed. Vulnerability concerns animals and all self-organizing life in the world, and for mankind it must be considered a universal expression of the human condition. The idea of the protection of vulnerability can therefore create a bridge between moral strangers in a pluralistic society, and respect for vulnerability should be essential to policy-making in the modern welfare state. Respect for vulnerability is not a demand for perfect and immortal life, but recognition of the finitude of life and in particular the suffering presence of human beings.

The idea of vulnerability, being of a different nature from the other principles, challenges the rationality of the developments of biobanks. The question is whether the distribution and storage of human tissue is a legitimate medical use of resources. To use vulnerability as an ethical idea means fighting both mortality and disease, but it also includes an awareness of the additional human vulnerability that might be created in the biobanks project.

Ownership of human bodies

Contemporary biotechnological developments are accompanied by the fear that commodification of human tissue and DNA will lead to exploitation of dignity and integrity of innocent individuals. Ethical principles and historical traditions can constitute powerful arguments against direct commodification of the human body. The main problem is if we can understand ownership in terms of rights to disposal over the human body, that is rights to make the decisions over the use of the body.

Historically, it is the liberal philosopher John Locke to whom the view of the body as property is ascribed. He argues that the principle of autonomy provides a basis for ownership of the body¹⁰. The foundation for the social contract is that individuals own their own bodies and products of the body because the latter come from their labor or other activities. The basis of a free society is the individual's right of ownership. This liberal position has many adherents today. It is often combined with utilitarian arguments to the effect that ownership is the most efficient way of ensuring individual disposal over the body. Utilitarians think that ownership based on autonomy gives individuals the most extended rights over their bodies. This theory does not state that ownership is in conflict with ethical principles of dignity and integrity. According to the liberal position, these ideas are based on autonomy and respect for these principles will automatically include respect for these other ideas because they can be reduced to autonomy.

The Lockean and utilitarian view is, however, criticized. With Immanuel Kant we can argue that commodification of human beings as moral agents is a violation of human dignity. If the body is the person the result of commodification there is a reduction of human beings to mere objects. The connection between person and body means that bodies cannot be considered as a commodity. However, the difficulty with this position is that some parts of the body, even those in a special sphere between person and thing (e.g. compensation for blood or sperm donation), are sold without this seeming to be a violation of human dignity. The answer to this objection is to suggest that body parts but not the whole body might be regarded as "special commodities" situated in a special sphere of social exchange. We would of course never permit a market of whole persons, but within strict rules of compensation it might be possible to establish a room for exchange of particular body products.

This kind of argument may be supported by the phenomenological tradition in Western philosophy. Edmund Husserl distinguishes between "Leib" and "Körper", between the lived body, the body from the perspective of the person and the body seen from the outside as an object in time and space¹¹. Maurice Merleau-Ponty points to the lived experience of human individuality, to the close connection between person and body, and he refuses to reduce the body to an object.¹² In a somewhat different manner, Jean-Paul Sartre insists on the fact that the body is an ambiguous foundation of the lived human existence¹³. The body is the basis for sensation, life, freedom and desire to exist. But human beings transcend their bodies and relate to themselves as mere things. The experience of the body is simultaneously a perception of subjectivity and objectivity. This ambiguity is also a tension. From this perspective we can understand why commodification of the human body always runs the risk of violating the lived experience of humanity, considering the human person as a mere object in a world among other things.

Moreover, taking into account the tension between person and thing in the experience of the body, a widely used alternative to commercialization of the human body is to conceive the notion of biobank in the perspective of an economy of the gift¹⁴. This third logic of the gift is an alternative to a pragmatic utilitarian logic on the one hand, and on the other hand the economic logic of the gift implies principles separating the body from the intimacy of the person. The logic of the gift is based on the idea of the body as something between person and thing. Basic principles in such an economy of the gift in order to organize a system of distributions of tissue and body parts are the ideas of informed consent, anonymity, generosity, solidarity, respect for dignity and acknowledgement of dependence on community. This organization of distribution of body parts is based on the fundamental ethical principles of autonomy, dignity, integrity and vulnerability.

Another major challenge to the concept of ownership in biobanks is the right to decide over the body in public or private storage of bio-information. There is a difference between administrative storage of information in medical treatment and storage of information in order to use it for scientific research. Scientific use of bio-information is very different from

administrative use of information, because it has no immediate impact on medical treatment¹⁵. However, storage of information for medical purposes involves major ethical issues. It is possible for outsiders to acquire new knowledge about the issue, and this might involve a major violation of individuals' right of privacy.

In this context the researcher might claim the right to dispose over the body, and this is very close to ownership: There will be no change in the ownership of the tissue, but the researcher in the private or public sector will use the tissue for different purposes. The traditional concept of ownership is difficult to apply, because the information can so easily be used in different treatment or scientific contexts. One could argue that some information cannot be subject to ownership, for example anonymous information used in different scientific investigations as a basis for medical treatment.

However, the researcher might still insist that his intellectual property rights should be protected. The researcher can state that rights of the inventor of a cell line or a genetic structure prevail over the rights of the donor. The argument is that researchers have made a significant effort in order to construct a new product and this effort should be rewarded. Researchers should be allowed an award for their labor. In Lockean terms it might be said that they are entitled to the products of their own work.

The argument is valid, but does not mean that the whole human body can be subject to patents. The primacy of human embodiment represents an important argument against patenting. In the perspective of general principles of rejection of ownership of the human body, the human body as such, as raw material delivered from the individual, in whatever form, cell, organ, gene etc. cannot be patented. But when there has been an intervention in the human body, using technical devices made by the researchers, and this has transformed the body parts into another product, a different situation applies. As long as the original removal of the body parts has taken place by agreement with the donor -with his informed consent – and as long as the removal does not violate basic ethical principles, the scientific process can be patented because it is no longer identical to the human body but has been subjected to scientific innovation and transformation. It is now a technology, a scientific intervention that can be a subject of intellectual property rights.

Conclusion

Summing up, the status of the human body between person and thing makes us reject total commodification, ownership and commercialization of the human body and body parts. Instead, we propose alternative logics of exchange; including establishing distribution of body parts inside a system based on donation, informed consent and extended rights of disposal by individual donors. This logic of exchange does not exclude patenting of scientific inventions or incomplete commodification of certain body parts within strict rules of basic ethical principles within a particular sphere of distribution.

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