

## HUMAN DIGNITY AS A REGULATIVE INSTRUMENT FOR HUMAN GENOME RESEARCH

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Yesterday we have discussed legal instruments to regulate the Human Genome Research and its results. And we have seen contrasting legal situations, for example the USA and Canada, or Spain, Germany and Argentina. That means countries with a high developed regulation, especially Spain on the one hand and Germany e.g. on the other with more or less intensive discussion on these subjects but without using many legal instruments until now.

The question is if we need at once an extensive regulation or not. Indeed, the human genome analysis program tends to create, in the public, the idea of unlimited capacity of genetics in the prediction of future life and health. The double-helical thread of DNA seems to encode all our tendencies and wishes, all our future reactions and decisions, all our human destiny and individuality. It strives to make us believe that, if we succeed in deciphering our genome, we can read our future in it, like in a magic glass. And men would become glaziers, with all the risks and chances.

This expectations and fears are a dangerous error. Even when the human genome becomes completely deciphered, human life and health remains not fully reducible to genes. Environmental factors, education, human experiences and habits have a decisive impact on gene expression. In addition, psychological motivations, cultural values and historical background also play an important role in human health. Public education and discourse should therefore demythologize the powers of genetics and establish its real limits in the prediction of future diseases and life.

And I fully agree with Salvador Bergel who yesterday emphasized on discussion as a long lasting democratic process. In this discussion scien-

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tific society gives proof of its understanding of not only scientific research and results but also of its own course.

Nevertheless legal instruments are necessary, and I want to describe *one* in the focus of Bioethics and Law, which is often cited as the leading ethical principle to judge innovations —the principle of *human dignity*—.

This can be understood in the sense that the human dignity is a basic principle with a wide field of appliance.

The basic importance of human dignity is revealed by the fact, that the notion “dignity” was more and more fixed in the national laws and constitutions and in European and international regulations or declarations especially in the 20th century as a reaction of despotism leading humans into a position without any dignity and making objects of them. The summit was reached with the violent activities in the national socialistic area in Europe. The first international document where the notion “dignity” was introduced, was the preamble of the “Charta of the United Nations” from the 26th of may in 1945 referring to the dignity of the human personality. In Germany human dignity is the highest principle, regulated in Art. 1 of the Constitution: (sect. 1) “The dignity of the human beings is untouchable. Their respect and protection is the obligation of all governmental authority”.

The double function is to constitute values as well as rights.<sup>2</sup> The strange phenomenon is that the concept of human dignity is increasingly treated as a legal term, also it is not that.

It is here that ethics and law touch each other and are overlapping in the notion of human dignity. While human dignity is undoubtedly a basic frame of reference in ethics, based upon a credal assertion, as such, concerning the status of a human being it has found entry into the preambles of constitutional texts without being designated as an originally ethical frame of reference.<sup>3</sup> It operates as a broad axiom from which at least certain prohibitions and negations can be deduced. Such deductions occur often in connection with the double reference of human dignity and human rights, whereby it is not clear from the outset whether the latter are grounded in the former or whether the two function independently as frames of reference. In the following, the principle of human dignity has to be examined if it really contributes to the problem and conflicts solution and

2 Hailer; Ritschl, 1996, S. 91 (101).

3 Hailer; Ritschl, 1996, S. 91 (99).

answer the title ‘regulative principle of bioethics’ in spite of being in the meantime inflationary used and that the notion as such is anything but distinct.

When the important European Convention on Human Rights and Bio-medicine was firstly presented to the public in July 1994 there were a lot of protests. The convention regulating a Europe-wide frame for the handling with the progresses of human biology and human medicine and following the convention for the protection of human rights and basic liberties from the Europe Council was criticized especially in Germany because of the lack of enough protection guarantees and so not corresponding to the demands of human dignity. There are no final protective regulations in this convention. But it should be made guidelines for a new legislation in the countries with no or only unsatisfying legal limits in the area of biotechnology. In the preamble of the convention is stressed that the human being should be respected as an individual as well as a member of the human species and his human dignity has to be respected. A corresponding prohibition was already confirmed by the German Federal Constitution Court in 1992.<sup>4</sup> Art. 13 of the convention prohibits manipulations of the human genome so to change the genetic characters of the following generations.

The importance of human dignity in the modern biotechnology should be shown with some examples of the area of human genetic and reproductive medicine.

The embryo research is one field where the human dignity plays an important role. This kind of research is very important so to get scientific knowledge and seeks to balance the respect for the nascent human life with the benefits that can be produced by advances in scientific knowledge. But the question is if the “use” of embryos for concrete research aims of high importance as to save human lives is not without problems. In the German law even the embryo is protected by the human dignity with the consequence that not any use is allowed because the embryos are sacrificed for human life. By this procedure human beings become an object and this is an offence to human dignity in Germany.

In this case the general emotional appeal to human dignity is used in the form of a knock-down argument in the medical-ethical field of problems indicating that rational analysis and argumentation discourse has

4 Bverfge, 1987, 209 (228).

not taken place or is avoided in favour of what seems to be a foregone conclusion and all dominating assertion.<sup>5</sup>

This is evidenced by the fact that roughly the same catalogue of basic human rights is part of a lot of constitutions in the world, whereas there is a complete lack of unanimity with reference to the moral status of the human embryo.

On this point both opinions diverge widely between and within national cultures. Where German Embryo Protection Act strictly prohibits any form of embryo research, embryo research is legal in Great Britain under the conditions that the research is clinically relevant, that the donor of the tissue contents and that the zygote is cultivated in vitro only up to the stage of development of the 14 days.<sup>6</sup> The mere extent and the intensity of the disagreement on this point should be a warning to all politicians eager to enforce a so far extended principle of human dignity by penal sanctions.

A further problem and a further principle of human dignity is given by the predictive diagnosis. The knowledge of the genetic predispositions of a human being has private and social consequences for the individual and his relatives who has a right of information in Germany, given by Art. 1 and 2 of the Constitution. But has he also a right of not being informed? It seems to be consequent that this right is given as well as a part of the human dignity and the right of personality.<sup>7</sup> But this reveals several problems, as for example the handling of results of the genetic testing. The right of self-determination including the right of maintain secrecy can be in collision with the interests of information with third people. There has to be a weighing up of interests.

A special case of passing on genetic results to third people is the pre-natal diagnosis. It seems to be a problem to make this diagnosis touching the interests of the later born human being because of the interest of the parents to know about probable diseases or handicaps of their children and perhaps followed by an abortion. The human dignity of the nascent will not be respected if human dignity means protection. Therefore sex selection by applying this diagnosis is principally not permitted in Germany because the unborn life can not be object of the parental disposition. But there is no possibility for the nascent to express his human dig-

5 Alexy, 1986, S. 21.

6 *Human Fertilisation and Embryology Act*, sect. 1, 3.

7 Münch, art. 20., rz, 1985, 22 a.

nity in the sense of self-determination. If he could express himself he would perhaps agree to this diagnosis. This point of view of human dignity can not be respected. This is the more or less ruling opinion in Germany but one gets the impression that the inherent emphasis and the inherent concept is exploited simply in order to exclude the difficulties of giving rational arguments for more and legal injunctions against not welcomed practices. The fact that practices like P.G.D. are rejected more or less emotionally is by itself not sufficient to justify either the moral judgement that they are inherently immoral or the penal sanctions imposed.

By functioning as a knock-down argument the human dignity argument offers an easy way out of this dilemma. Human cloning is the deliberate creation of a human being that is genetically identical to another human being or has the same nuclear gene set as another human being. Human being can be done by nuclear substitution either by replacing the nucleus of an embryo, or replacing the nucleus of an egg with the nucleus from an embryonic cell and since the birth of the sheep Dolly by somatic cell nuclear transfer, where the nucleus of an egg cell is replaced with a nucleus of a somatic cell taken from an adult. In general cloning by nuclear transfer is not acceptable considering human dignity. The protection of human dignity is also given for life produced by nuclear transfer even when there is no “fertilisation” in the common sense.<sup>8</sup> But fertilisation includes as well the nuclear substitution of an egg. Stressing the protection aspect of human dignity cloning human beings is not allowed because the cloned human being can not be asked if he agrees this procedure effecting his birth. He gets his genetic criterias because of a decision and a technique made by other people. The worst case will finally be the cloning of a lot of human beings for medical purposes only. There the technical aspect has got priority. The clone himself cannot be asked if he agrees and after his birth it is too late to ask him. The German Embryo Protection Act contains a regulation prohibiting human cloning, 6. Human dignity guarantees the individual and not uniform life. Human beings would be used to prove that they are able to produce genetically identical human beings without respect for their personality.<sup>9</sup> But there is once again the question if this regulation corresponds to the high Constitutional principle of human dignity. Under the aspect of liberty of self-determination and

8 Keller; Günther; Kaiser, 1992, 8.

9 Häberle, 1992, 20 rz. 92; Benda, NJW, 1985, S. 1730 (1733).

autonomy there is a lack of possibility for the clone to make his own decision being born by cloning procedure. There is a conflict between two aspects of human dignity.

It is possible that human cloning will become illegal in most of the EU countries because of the pressure for a global legal ban on the development and use of this technique on human beings. In fact many European countries have already signed the European Convention on Human Rights and Biomedicine and its additional protocol on the prohibition of cloning human beings. This protocol makes what was implicit in the Convention explicit by declaring that “any intervention seeking to create a human being genetically identical to another human being, whether living or dead”, is prohibited. Since “genetically identical” is defined as “sharing with another the same nuclear gene set”, somatic nuclear cell transfer is included within this prohibition. Furthermore there is a number of another international instruments banning human cloning. For example, in November 1997, UNESCO published the Universal Declaration on the Human Genome and Human Rights, which stated that, practices which are contrary to human dignity, such as reproductive cloning of human beings shall not be permitted. Also in 1998 the EU has passed a Directive on the Legal Protection of Biotechnological Inventions, which states that “processes for cloning human beings” are unpatentable. This is very likely to act as a disincentive for commercial research and investment into cloning.

Interesting in our context is the attempt made by Benda, the former President of our Federal Court of Constitution to derive prohibition of the technique of cloning people right from the “essence” of man. According to Benda it is an elementary right of anyone not to be genetically the exact copy of one of his parents. Characteristically this kind of natural law argument is presented without any further explanation.<sup>10</sup> No consideration is given to the fact that the existence of identical twins make it doubtful whether genetic individuality is really part of the “essence of man” in any not purely normative sense.

There are two consequences resulting from the different examples and problems concerning human dignity.

First of all human dignity in Germany is one word including two principles. It is not only an objective principle but contains as well an active

<sup>10</sup> Benda, *NJW*, 1985, S. 1730 (1733).

part realised by the right of personality.<sup>11</sup> In Germany the jurisdiction has developed this right with the task to guarantee the personal life sphere and to maintain of their basic conditions in the sense of highest principle of constitution which is not given by the traditional freedom guarantees. The right of personality includes the protection of the private, secret and intimate sphere with the right of self-determination and in the medical area the right of patients autonomy.

The ethical-legal principle of human dignity guarantees the basic rights of life and integrity as well as the right of self-determination with the necessity of human's consent for all interventions of third persons. In the medical area the self-determination of patients is intensively discussed as the problem of "informed consent" as prerequisite for all medical activities and influencing all decisions in medicine and research. These problems have already been described in the beginning for the area of gene analysis and human cloning. The right of not being informed if in one's family will be a disease or not and if when it will appear can be deliberating for the person using this right. But in the other hand if someone wishes information about diseases it cannot be avoided that the effected examinations give information as well of members who have not participated these examinations and perhaps do not wish these information. So for example because of a prenatal diagnosis a mother will know if she herself will be ill or not in the next time. This principle contains a great potential of problems.

The second fact is that every form of development of human life is the subject of human dignity creating a wide field of appliance and a special importance. By a leading opinion Human life exists since the 14th day of perception and independent of age and the ability of judgement. The German Federal Constitutional Court already decided that even the nascent has human dignity because the potential abilities of the earliest human being are enough to cause this dignity.<sup>12</sup> A variation or degradation of human dignity is not acceptable for the court. These two reasons are qualifying the human dignity as a regulative principle, but by the problems created "inside" this dignity because of the two principles there is a danger that human dignity becomes an unfounded formula. This is difficult to understand because the meaning of "dignity" is easy to des-

11 Enders, 1997, S. 311.

12 Bverfge 39, 1 (41).

cribe. The problems normally begin with the relation of dignity and human beings because there is a variety of what is meant by human leading finally to a lack of determination. In fact, human dignity is indeed an open and undetermined word making necessary a review to its historical developments and meanings.

Main aspects for the human dignity are the picture and the idea of the human being composed by two perspectives: the biological on the one side and the Christian and philosophical on the other side.

From the biological view the human being is a part of the living nature and follows the natural laws. He is the highest developed living being on earth and participates to the category of vertebrate animals and mammals. The picture of the natural science influences conscious or unconscious the reflection of the human being about his own nature and of what means being a human being. By the modern biotechnology the human being as biological being gets more and more transparency and the procedures of nature become more clear and more explicable and can be modified for the future.

In the old philosophy dignity had a double sense. Dignity was the expression of a social position in the society with the consequence of a more or less of dignity and dignity was the difference for every human being from the not human creature getting a special position. This position was explained in a Christian and a philosophical way.

To justify this special position after the Christian ideas the so called idea of "imago-dei" has been used calling the human being as the crown of the whole creation.

Another justification was given by the philosophical ideas. In the renaissance Pico de Mirandola explained the human being as the being with possibilities which could be chosen by him and that was the expression of its dignity.<sup>13</sup> The human being gives himself his aims. He is able to determine his willing because of his intelligence and his intellect. His freedom is his dignity.

In the enlightenment the basic for a moral picture of the human being was born. The modern sense of human dignity is related very intensively with the person of Immanuel Kant and his philosophy. By Kant the picture of the human being is made by the idea of moral autonomy and the quality of subject supporting the individuality of each human being and

13 Wassermann, art. 1 Rz. 3, 1989.



the fact of not being renewed. The human freedom is expressed by the ability of the human being willing to follow only the idea of mere intellect. The autonomy of the willing as the reason of human dignity is determined by the quality of the willing to give oneself the law —independent of empirical reasons—. Kant transfers the objective right into the formal lack of contradiction of a subjective willing able to being generalised. Because of his nature the human being is a person and of an absolute worth being in the same time the difference to all other beings without intelligence and having only a small worth as a thing.

The Christian and the philosophical idea form the picture of the human being for the German Constitution and the intellectual basis developing the guarantee of the human dignity. This picture has been modified by the years.

### *Conclusions*

We can say: When the idea of human dignity was born and later when the German Constitution began to exist, the developments of biotechnology were completely unknown. In our days these developments provoke the fundamental principle of human dignity and in a certain sense are a danger for it. Critics reproach that human dignity has only the character of a general clause allowing each opinion and being defended with the argument of human dignity. But instead of resignation this could be the beginning of a new orientation. The initial anthropozentric understanding of dignity, the base of the German and other Constitutions, does not lead to a fix picture closed for any interpretation and prohibiting a correction or modification of the picture of the human being. The understanding of the Constitution has to be adapted to the developments of human beings including their activities in research and science. It is not only the duty of a Constitution and its values to describe the original “status quo” but to be formulated to give solutions for many problems and situations without being a general or an unfounded formula. Human dignity is a good example for this: It is not a static notion but follows the dynamic of the development of the picture of the human being so that the sense of human dignity has been modified over years.<sup>14</sup> The openness of main values to which belongs the human dignity as well, makes the Constitution permissible for social and cultural developments influencing the legal and ethical

14 Caspar, 1999, S. 347.

reality and order without leading each time to a concrete modification of the Constitution. These are the prerequisites for a good function of a Constitution and the only possibility to bear the developments and progresses in the area of biotechnology. There is for example the demand of the fighter for animal rights to recognise a dignity of animals beside the human dignity as an expression of a modified picture of humans, nature and the relation of both. The actual discussing about this problem shows how far the sense of human dignity has already been modified and would be able to be modified furthermore.

After all it can be said that the public needs a regulative principle for its own orientation and to judge ethically the modern developments especially in the area of biotechnology. A regulative principle is the base for the public acceptance of developments in biotechnology. Till now the value of human dignity represented a mostly consented standard of the ethics and was a good relation on the national and international level between the discussion of bioethics and the general ethical discussion. This seems to be a helpful analysis of the functions and capacities of the notions of human dignity also applicable to the medical ethical problem cases. "Most problems in medical cases have to be dealt with the context of the social matrix and also often with reference to the individual story of the patient" and only a few medical ethical problems can be settled in an absolute way.<sup>15</sup> So, trading with embryos for example or definition of death in relation to exploitation of organs.

However, even some of these and related problems cannot always be resulted for the protection of the patients in question, and the conception of human dignity inside the German Constitution has already been intensively discussed on the issue of abortion: "This concept was and is incapable of carrying the burden of proof in complex questions of medical ethics and legislation pertaining to it. But it has always needed a minimal frame of ethics and rights for understanding".<sup>16</sup> In so far it can also be called on the one hand a dialogical concept in the sense of Rawls or Habermas<sup>17</sup> and at the same time in some cases on the other hand a conversation stopper, setting an issue and tolerating no further discussion. If the problems inside the idea of human dignity as shown by the examples

15 Hailer; Ritschl, 1996, S. 91 (102).

16 Hailer; Ritschl, 1996, S. 91 (102).

17 Hailer; Ritschl, 1996, S. 91 (104).

will not be solved in future there is a great danger to destroy this consensus described above with the consequence that there will be a lack of a basic regulative principle in bioethics.

And so I can summarize with the impressive words of Salvador Bergel: What we especially need is a continuing and responsible public discussion —as we had it yesterday and have it today in this institute—. And in this discussion our view must be focused not only on legal instruments, but on their fundamental basis —Bioethics, and this as an dialogical concept, perhaps leading to a new understanding of human being—.

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