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## Human Dignity and Quality of Life Assessments

### Introduction

In July this year the Deutsche Bundestag passed a law which legalizes Pre-implantation Genetic Diagnostics (PGD in the following) for the first time. The ban of PGD which was the result of the last big quarrel concerning PGD has been replaced therewith by a qualified and in several respects limited acceptance of this medical option. But although this result of the political process on the one hand hints to a change, the public discussion before, during and after the law passed the Deutschen Bundestag was, on the other hand, characterized by stagnation. There were heard the same principled objections and the same invocations of threatening cultural disasters from those who still want to criminalize PGD. And we heard the same arguments which can be offered in favour of this option from the other side as we had heard during the last decade. I think this is evidence for the claim that in this context very deep and maybe even hidden ethical intuitions manifest themselves and crash undamped.

As I see it, scientific and medical progress in the context of reproductive medicine forces us to think about the ethical acceptability of quality of life assessments in the context of medical action. Many attempts to demonstrate the ethical wrongness of PGD based on the principle of human dignity start from the premise that assessing the quality of human life and basing decision of selection on them is incompatible with human dignity in principle. For example those members of the Deutscher Ethikrat, who voted for criminalizing PGD, argue that

“the human embryo procreated in vitro is subject of special responsibility due to the fact of his artificial procreation and that this responsibility forbids

to procreate such an embryo with the intention not to implant him in case he shows some unwanted features”.<sup>1</sup>

This group has demanded to criminalize PGD because this option would

“reintroduce the embryo-pathic indication, i.e. the licence to reject human life because of unwanted features, which has been banished from the law of abortion explicitly”.<sup>2</sup>

This ethical intuition is widespread in the German bioethical debate. Today I want to focus on this crucial premise which is operative in many contexts of biomedical ethics. This premise, I will call it the “incompatibility-assumption”, claims that human dignity and quality of life assessments are incompatible without exception. As I have said this incompatibility-assumption is operative in the quarrel about Pre-implantation Genetic Diagnosis, too.

But on this occasion, I do not want to discuss the questions related to PGD in detail. Instead I will discuss the incompatibility-assumption and I will try to show that this ethical premise cannot stand a critical examination. If this can be established some very influential arguments against PGD which are based on the incompatibility-assumption are seriously flawed.

## I. From “human nature” to “human dignity”

The topic I have chosen is urgent in our days because of the progress science has made — both with respect to knowledge and with respect to new technological options for our actions. These developments prompt us to rethink some of our deepest ethical intuitions, which have guided our ethical thinking but may no longer stand the test of time since our societies are changing dramatically. Although my main topic is the relation between “human dignity” and

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<sup>1</sup> My translation; the German original is: „der in vitro gezeugte Embryo aufgrund seiner künstlichen Erzeugung einer besonderen Verantwortung unterliegt, die es verbietet, ihn zu erzeugen, um ihn im Falle unerwünschter Eigenschaften zu verwerfen“ (Deutscher Ethikrat: *Präimplantationsdiagnostik*. Berlin 2011, S. 113).

<sup>2</sup> My translation; the German original is: „eine embryopathische Indikation wieder eingeführt würde, also die Erlaubnis, menschliches Leben aufgrund unerwünschter Eigenschaften zu verwerfen, die aus der Schwangerschaftskonfliktregelung ausdrücklich ausgeschlossen wurde“ (ebd.).

quality-of-life-assessments I will start with some short comments about the notion of “human nature” since there is a close relation between the notion of human dignity and the notion of human nature, in at least one sense of the latter. Let me explain.

There are several meanings of “nature” which also affect the notion “human nature”. In our everyday concept of “nature” and “human being” these different meanings are run together. For our purposes it is important to distinguish two of them.

(i) In one sense “nature” can mean everything the natural sciences deal with. As a consequence “human nature” then stands for the biological constitution of human beings. This biological nature itself cannot carry moral status *directly* since it is a purely descriptive entity. For sure this biological nature (its structure, properties and functions) can be studied and can be modified — at least to some degree — by new biotechnology. Both, new discoveries and new options for intervention, can lead to an irritation of our common sense notion of a “human being” and this can provoke moral trouble. For sure, our biological nature can be morally relevant *indirectly*. This can be the case in several ways of which I want to mention only two which are the most important in my mind. On the one hand, aspects of our biological nature can simply be causal enabling conditions for features which are taken for being morally relevant (e. g. having a well functioning nervous system for being able to experience pleasure and pain). On the other hand it may be the case that aspects of our biological nature have been evaluated implicitly by us but this hasn’t come to our mind explicitly. If we can change these features now by use of biotechnology this might cause a feeling of moral loss or a feeling of disorientation. In this case it isn’t the biological feature which has moral relevance but this effect. Therefore expressing this feeling cannot be a moral argument not to change that feature but has to be taken as a demand to think about these possible losses in moral terms (maybe technological developments concerning biological reproduction is an evident example for this constellation).

(ii) In another sense “nature” can mean the essence of a thing that is those features that make it the kind of entity it is. “Human nature” then stands for those special properties and abilities which make human beings unique *as human beings* (not as individuals) and give them special moral status qua species-membership. Let us ignore the further complication whether it is possible in principle to separate the essentialist claim and the ethical claim. Probably the

essence of being a prime number doesn't carry any ethical weight, but normally in the case of human beings the essentialist and the ethical claims come as a package deal.

It is the essentialist/ethical sense of „nature” which I address in this paper. And this special nature of human beings is referred to normally by using the notion of “human dignity”. This comes in two steps. In the first step “human dignity” is a marker of the special ethical status of human beings — here the ethical dimension of “human nature” comes into play. In the second step the essential features of human beings are determined which substantiate this special ethical status — and so the ontological aspect of „human nature” enters the scene.

By taking “human nature” in this second sense, the connection to human dignity and to the topic of my paper should be clear. In the third part I will distinguish several ways of giving content to the very idea of “human nature” in this essentialist/ethical meaning. But before I come to this I would like to give a very brief example which shows that the incompatibility-assumption is operative at least in German bioethical debates.

## II. The incompatibility-assumption: the case of PGD

In July this year PGD was a hot topic in Germany, having been legalized for the first time in principle. In this debate the incompatibility-assumption can be seen to be still at work as the quotes of the vote of those members of the Deutscher Ethikrat who want to criminalize PGD show. This idea that human dignity and quality of life assessments are incompatible can already be found in the vote of those members of the Nationaler Ethikrat, who have defended the position that PGD should be prohibited by law in 2003.<sup>3</sup> This position was formulated by Regine Kollek in 1999 in the following way:

“A process in which potentially human beings are intentionally produced on a trial basis and are judged to be worthy of existence and further development by the future parents only after a genetic diagnosis is not compatible with the dignity of human life” (my translation).<sup>4</sup>

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<sup>3</sup> Cf. Nationaler Ethikrat: *Genetische Diagnostik vor und während der Schwangerschaft*. Berlin 2003, S. 83 ff.

<sup>4</sup> R. Kollek: „Vom Schwangerschaftsabbruch zur Embryonenselektion? Expansionstendenzen reproduktionsmedizinischer und gentechnischer Leistungsangebote“. In: *Ethik in der Medizin* 11 (Suppl 1) 1999, S. S121-S124 (deutscher Wortlaut des Zitats: “Ein Verfahren, in dessen Zusammenhang potentielle menschliche Wesen bewußt auf Probe erzeugt und von den zukünftigen Eltern erst nach einer genetischen

As it is common, in both statements this position is combined with slippery-slope arguments based on the presumed arbitrariness of those value assessments included in the procedure of PGD. But at the heart of the position we find a principle objection. And the kernel of this objection is the incompatibility-assumption.

### III. Different meanings of “human dignity”

The idea that human life is of absolute value and admits no value assessments is a strong ethical claim which needs justification. Some writers try to evade this by saying that our behaviour simply shows that we ascribe such an absolute value to human life. Against this strategy I want to object firstly that it is a matter of philosophical interpretation whether our behaviour shows this (or not). And secondly if it comes e.g. to the very early beginnings of human life or to some said varieties of the end of human life it seems evident to me that not all of us show this behaviour.

Against the objection I have just made the following reply can be made: O.k., but we *should* act only in such ways that express this attitude (of ascribing absolute value to human life) or is at least compatible with it.

Now it is evident that a moral claim is made which needs to be justified. Traditionally this absolute value of human life which is the foundation of or manifests itself in human dignity can be given different justifications. I will now distinguish two such justifications which are the most prominent in our culture (at least to my mind). In a third step I will give different interpretations of the meaning of “absolute”. This will show that there might be even more concepts of “human dignity” at stake in our present debates.

#### 1. “Human dignity” as “Sanctity of human life”

In one tradition “human dignity” is interpreted in the doctrine of “sanctity of human life”. The special moral status of human life is justified by the ‘fact’ that God has given human life

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Untersuchung für existenz- und entwicklungswürdig befunden werden, ist mit der Würde menschlichen Lebens nicht vereinbar”).

this special ethical value. The theological impact of this is made obvious by the term “sanctity”. Since in a pluralistic and secular society a theological justification of moral claims and even more of legal rights is problematic, many authors have tried to give an analysis of “sanctity” in non-theological terms. And the main candidate is the notion of “absolute value”.

As should be clear I just took the opposite route using the concept of “sanctity of human life” to make clear one of the prominent conceptions of “human dignity”. As we will see there are two different interpretations of “absolute” (at least there are two I want to distinguish) and to make clear the difference we have to go back to the roots, i.e. the theological background of one concept of “human being”.

## 2. “Human dignity” as personal autonomy

In another tradition the special ethical status of human beings marked by “human dignity” is justified by special capacities of normal human beings. Most prominent here is the following feature: Human beings are able to lead their life autonomously in the sense that they can decide and judge in the light of self-given moral rules. As I understand it this interpretation of human dignity can be freed from theological assumptions (although it might not be able to free it from all metaphysical assumptions). The basic idea is that human beings can lead their lives as persons. Included therein is the idea that human beings have a sense of meaning and worth of their own existence. As I have defended elsewhere it is an irreducible aspect of being an autonomous person to identify with one’s own character. This “identification with” is an evaluative self-relation meaning that human persons do have a kind of self-image including values of different kind. Human persons have a sense who they are and they have an idea of who they want to be or become to be.

It is this basic capacity to lead an autonomous life as a person which demands and justifies that we owe each other respect. And it is this respect which is the central aspect of the absolute value of human life which is expressed by “human dignity”.

To sum up: There are three crucial differences between both conceptions of “human dignity”.

- Theological versus philosophical justification (none is self-evident, none is purely empirical, none is value-free)

- The source of the one is external (God), the internal structure of human beings' minds is not important; the source of the other is internal, i.e. a special capacity of human beings which I have named personal autonomy
- The theological one doesn't take the perspective of individual human beings into account ("human dignity" doesn't reflect the internal structure of personal autonomy), while the autonomy-based conception is based constitutively on the self-relation human beings enter into qua leading a life as a person ("human dignity" thereby reflects the internal structure of personal autonomy).

### 3. The strength of human dignity

We can distinguish now between different interpretations of the intended strength of the value of human life indicated by "human dignity". I want to discuss only two of them: the absolute-reading and the intrinsic-reading.

According to the *absolute-reading* there are two crucial features of human dignity and the value of human life: It is (i) not derived from something else e.g. human interests (except God's will), and (ii) it is not allowed to be weight up against other ethical values.

According to the *intrinsic-reading* the special value of human life (i) is not derived from something else e.g. human interests (except God's will), but (ii) it is allowed to be weight up against other ethical values.

As should be clear the official understanding of "human dignity" in the German Grundgesetz is of the absolute kind. Although the right to life may be weight up against other very important ethical values human dignity may not. The intrinsic-reading would be a serious revision of our meaning of "human dignity". Such a revision might be necessary and ethically justified if our notion of human dignity causes ethical problems in the new contexts created by new technical developments like PGD. But first we should try to make coherent our ethical intuitions in these contexts and the absolute-reading of human dignity. As I will show now it is possible to find such a reflective equilibrium if we combine the absolute-reading of human dignity with the conception of human dignity based on personal autonomy. But before I can do this I have to distinguish different models of quality-of-life assessments.

#### IV. Different models of quality-of-life assessments

There are four models of quality-of-life assessments I want to distinguish for the purpose of my argument. We can distinguish them by looking at the standards these models use for the assessment. The four models use

- the naturalistic standard
- the social-objective standard
- the standard of rationality and intersubjectivity
- the personal standard

The model using a *naturalistic standard* claims to be free from ethical norms and values and pretends to assess the quality of life only on the basis of biological, psychological or medical facts. Since the quality of life cannot be naturalised such a model is pointless, although it is defended sometimes.

The model using the *social-objective standard* claims that factually accepted and dominant values and norms in a given society have to be taken as the measure of quality of life.

Both, the naturalistic standard and the social-objective standard, are normally not defended by those who think that quality-of-life assessments should be used in biomedical ethics. But they are often referred to by those who hold the incompatibility-assumption and ascribed — wrongly or even demagogically — to their opponents. They allege that quality-of-life assessments are versions of reducing ethics to biology or even versions of racism. Or they suspect that quality of life assessments are led by socially accepted norms and values. Therefore these two standards are alive in the discussion not because defenders of quality of life assessments do defend them but because their critics foist these standards on them.

Thus it is very important to make clear that there are two more standards which can and should be used instead in quality-of-life assessments.

The *standard of rationality and intersubjectivity* is an explicitly normative one. It includes those elements rational human beings would choose rationally because of their nature as human beings (including features as embodiment, ability to sensations, social needs, and capacity to

personal autonomy). Such a standard — this is the idea — can be applied to all human beings (unless they autonomously argue — on the basis of ‘personal’ values — against elements included in it).

The *personal standard* should not be misunderstood as a version of subjective relativism. It is not meant that only private sensations which cannot be understood by other subjects constitute the quality of an individual’s life. The subjective standard wants to take into account that human persons take an evaluative stance towards their own existence. Human persons who lead their lives autonomously identify with their own future (or do not) in the light of their own values and plans. This capacity which is constitutive for the autonomy-based conception of human dignity is constitutive for the personal standard of quality-of-life assessment. This standard takes the value of a human’s life as the value this human being ascribes to her own existence taken as the biography of a person. Such a biography can be understood by other subjects (understanding x has to be distinguished from accepting x in this context). Therefore this standard of quality-of-life assessments is not a version of subjective relativism. And since persons are rational beings life-plans and decisions based on personal autonomy can be criticised by others. At least we can ask for explanations and justifications if there are plausible reasons to be sceptical.

Thus the personal standard and the standard of rationality and intersubjectivity go hand in hand.

## V. The wrongness of the incompatibility-assumption

So let me put the different pieces of my argument together now. Those who defend the incompatibility-assumption face a dilemma.

*Either* they have to rely on the sanctity-of-life reading of human dignity which makes human dignity an absolute value such that even the single human individual is not allowed to evaluate its own existence. But this position has two serious flaws. On the one hand it seems to be incompatible with personal autonomy and therefore to be in serious conflict with core values widely held in our society. On the other hand it is in need of justification which seems to be unreachable within a secularised society, which restricts itself to the standards of the public use of reason.

Or they rely on the conception of human dignity based on personal autonomy. But in this case the incompatibility-assumption cannot be defended as a general claim. For sure, there are models of quality-of-life assessment which clearly are incompatible with human dignity. The naturalistic standard ignores ethical values and norms. So it has to ignore personal autonomy, too, since this autonomy is essentially evaluative. This makes this standard incompatible with human dignity. The same is true of the social-objective standard since therein the right of a human being of leading a life as a person and exercising her autonomy by evaluating her own existence is ignored, too.

But the standard of rationality and intersubjectivity and the personal standard clearly are compatible with the conception of human dignity based on personal autonomy since this standard explicitly recognises that human persons evaluate their own existence by leading their lives as persons developing their own personal framework of values and their own personality. In the case of autonomous persons — think of the problem of active voluntary euthanasia — we should respect autonomous judgements in which a person wants to die since she cannot identify with her own existence any more. If such a decision is understandable, respecting it is respecting the human dignity of this person and respecting the capacity of human beings to evaluate their own existence in the light of autonomously chosen values.

In other cases, think of PGD now, we have to rely on the standard of rationality and intersubjectivity to judge whether a rational subject would want to live a life under certain circumstances and in certain conditions. As I see it such a judgement can be made although we have to be very careful here.

On the one hand an individual's negative identification with a feature may be an internalization of a social standard, an internalization of stigmatization and therewith a case of alienation. On the other hand a negative evaluation of the condition of living oneself doesn't share (e. g. of a 'normal' individual judging the live of a disabled individual) may be the result of lacking or insufficient empathy. In both cases we cannot take our intuitions or non-reflective judgements at face value but have to critically reflect and examine them carefully.

Nevertheless we cannot evade these judgements since modern technologies have forced these situations and decisions on us. Hinting towards these difficulties is correct so far, but it cannot

come down to the conclusion that quality of life assessments should be banned. If I am right these assessments are compatible with human dignity as long as we try to take over the perspective of the human being whose life we assess.

For sure there are a lot of epistemological, ethical and methodological problems lurking here. But we have to develop tools for quality-of-life assessment which will make our judgements more adequate. Since human dignity is no argument to block quality of life assessments generally we have the duty to develop and refine our tools here.

## **VI. Concluding remarks**

The recent decision of the Deutscher Bundestag has created a situation which is an important improvement compared with PGD having been criminalized in Germany during the last decade. Having said this I want to add that this new situation still isn't optimal from an ethical point of view. PGD will be offered by a limited number of medical centres only. And there are a lot of very good arguments in favour of this solution. But the solution found now shies away from establishing a public list of indications which will make PGD acceptable and give access to it. Instead, there will be ethics committees in each centre that will prove in each single case whether a couple should be allowed to use PGD.

This is problematic not only because of the fact that thereby persons who already find themselves in a situation which is ethically and psychologically very complex are made object of an ethical "Stresstest". It is problematic also for the following reason: Each ethics committee will have to create such a list of acceptable indications for it since this is important to develop a rational procedure which can be justified in principle. And it is very likely that these local lists will differ to some degree from centre to centre, since the attitude towards PGD depends to some degree e. g. on religious belief or even confessional differences. Therefore we will end up with a twofold disadvantage: There will be more than one list of indication being operative to rule PGD in Germany. Since potential parents for whom PGD is an option at all are subject to grave psychological strain it is very likely that we will face a kind of PGD-tourism due to the diverging standards in Germany. Secondly the lists of indications which will be developed anyway will remain implicit so that they will not become the subject of a public debate and will not become the result of such a public debate at all.

Since we cannot avoid having a list of indications this way I think this is also a very serious disadvantage.

If one asks oneself which reasons have been effective in producing the situation now reality in Germany one suspicion comes to one's mind immediately: The members of the Deutscher Bundestag who voted in favour of legalizing PGD wanted to block such a public debate. Probably their main motive was that such a debate will have discriminating effects on disabled or ill persons living in our society (or persons who live with those genetic defects which have been put on the lists). Such discrimination, so the intuition might run, will be incompatible with their human dignity. Therefore I assume that even the new law in Germany concerning PGD still is impressed by the assumption that human dignity and quality of life assessments aren't compatible in principle. The arguments presented in this paper are intended to put this assumption on the table and to show that it can be criticized and rejected with very good reasons. Only in doing this can we see that there is no such principled incompatibility and that we cannot and should not stop where we are now.

I am sure that in some years we will have such a public debate how an ethical acceptable list of indications for PGD might look like. And I am quite optimistic that — if we discuss the standards of quality of life assessments publicly and rationally — our list will be much more restrictive than those lists we actually do find in other European countries.

Let me add one final comment: For a well justified all-things-considered judgement concerning the ethical acceptability and the ethical limits of PGD the question whether living with the genetic defects, the disabilities or the illnesses in question can be a life worth living (from the perspective of the human individual whose life it is), cannot be the only relevant question. This question has been in the focus of my talk since it is the crucial element if we want to evaluate the claim that human dignity and quality of life assessments are incompatible in principle.

If — as I have tried to achieve with this lecture — we can establish that both are compatible in principle if certain conditions are met the further question must be whether potential parents or even society as such can pose ethically acceptable claims which have to taken into account, too. In a society in which solidarity is a vivid principle shaping our social institutions and the way we treat each other in daily contexts this all-things-considered judgement will speak in favour of human life especially if parents of disabled children on the one hand and

chronically ill or disabled persons on the other hand will be helped by social institutions and will be integrated in our social life. In societies which are not able or are not willing to create such a social climate PGD shouldn't be legalized. Therefore arguing for legalizing PGD commits oneself to the claim that disabled and chronically ill human beings deserve our respect and our solidarity as do those who take care of them.