Human Gene Editing and Human Dignity

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Webinar "Do you want to be genetically engineered?"

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What's all this about dignity?

- Universal Declaration on the Human Genome and Human Rights (UNESCO 1997) (Endorsed by UN General Assembly 1998)
- (a) Everyone has a right to respect for their dignity and for their rights regardless of their genetic characteristics.
- (b) That dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity. (Article 2)
- (See Universal Declaration of Human Rights, 1948: "Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,..."

UNESCO Declaration (continued)

- No research or research applications concerning the human genome... should prevail over respect for the human rights, fundamental freedoms and human dignity of individuals or, where applicable, of groups of people. (Art. 10)
- The International Bioethics Committee of UNESCO should ... give advice concerning the follow-up of this Declaration, in particular regarding the identification of practices that could be contrary to human dignity, such as germ-line interventions. (Art. 24)

UN Declaration on Human Cloning (2005)

- (b) Member States are called upon to prohibit all forms of human cloning inasmuch as they are incompatible with human dignity and the protection of human life;
- (c) Member States are further called upon to adopt the measures necessary to prohibit the application of genetic engineering techniques that may be contrary to human dignity.

Vatican "Instruction on Respect for Human Life in its Origin and on the Dignity of Procreation" (Donum Vitae), 1987

Certain attempts to influence chromosomic or genetic inheritance are not therapeutic but are aimed at producing human beings selected according to sex or other predetermined qualities. These manipulations are contrary to the personal dignity of the human being and his or her integrity and identity.... Every person must be respected for himself: in this consists the dignity and right of every human being from his or her beginning.

Pope John Paul II, to the World Medical Association (1983)

- How, in fact, can [genetic] manipulation be reconciled with a concept that credits man with an innate dignity and an untouchable autonomy? A strictly therapeutic intervention whose explicit objective is the healing of various maladies such as those stemming from deficiencies of chromosomes will, in principle, be considered desirable...
- (On interventions *not* strictly therapeutic): Genetic manipulation becomes arbitrary and unjust when it reduces life to an object, when it forgets that it is dealing with a human subject, capable of intelligence and freedom, worthy of respect whatever may be their limitations; or when it treats this person in terms of criteria not founded on the integral reality of the human person, at the risk of infringing upon his dignity.

One meaning of dignity

- ▶ The dignity of achievement, of excellence
- Centered on autonomy, self-definition (see Steven Pinker, "The Stupidity of Dignity")
- Worldview of "expressive individualism"
- (Robert Bellah, Charles Taylor)
- Transcending one's given characteristics, potentially one's nature

Freedom from one's nature?

- Endorsing creation of a superior new breed that will not mix with inferior *Homo sapiens*
- See ethicist John Harris, Clones, Genes, and Immortality)
- Taking this a step further: the self-divinization of the post-human being
- (see Yale microbiologist Lee Silver, in *Remaking Eden*)

Paradoxes of absolute freedom

- Autonomous control of human evolution may involve control of one's experimental subjects and all future generations (C.S. Lewis)
- It easily becomes freedom over and against others: Power of the strong over the weak (hard coercion)
- The subtle power of accumulated free choices and societal expectations (soft coercion)

On "soft coercion"

- Parental expectations for an "engineered" child: Conditional love?
- Dr. Robert Edwards, 1999: "Soon it will be a sin of parents to have a child that carries the heavy burden of genetic disease." (Cf. Iceland)
- Athletics and Title IX
- Gattaca and the "invalids"

A richer meaning of dignity?

- Not reducible to particular rights or freedoms
- ▶ Equal in all humans, grounding equal rights
- Innate due to the unique composite nature of human beings: Body and soul, the given and the transcendent ("neither beast nor god")
- Not perfection, but a call to recognize one's imperfections and address them through bonds with others who complement us

Pope John Paul II, 1983

Each human person, in his absolutely unique singularity, is constituted not only by his spirit, but by his body as well. ... To respect the dignity of man consequently amounts to safeguarding this identity of the man "corpore et anima unus"... It is on the basis of this anthropological vision that one should find the fundamental criteria for decision-making in the case of not strictly therapeutic interventions, for example those aimed at the amelioration of the human biological condition....

Pope John Paul II, 1983 (cont.)

- To tell the truth, the expression "genetic manipulation" remains ambiguous and should constitute an object of true moral discernment, for it covers on the one hand adventuresome endeavours aimed at promoting I know not what kind of superman and, on the other hand, desirable and salutary interventions aimed at the correction of anomalies such as certain hereditary illnesses....,
- For these last cases, some are beginning to speak of "genetic surgery", so as to show more clearly that medicine intervenes not in order to modify nature but to favour its development *according to its own essence*, that of the creation, that intended by God. (also quoted by Pope Francis in *Laudato Si'*)

Samaritanus Bonus (2020)

The need for medical care is born in the vulnerability of the human condition in its finitude and limitations. Each person's vulnerability is encoded in our nature as a unity of body and soul: we are materially and temporally finite, and yet we have a longing for the infinite and a destiny that is eternal. ...Our vulnerability forms the basis for an *ethics of care*, especially in the medical field...

Implications of human dignity

- Does not demand quietism or opposition in the face of gene therapy or other medical advances
- A check on unlimited redefining and refashioning of oneself and others
- A sense of humility before the givenness (to a believer, the gift) of our humanity, which we do not invent but discover

"Essential sources of concern"

- From *Beyond Therapy*, a report by the President's Council on Bioethics (2003)
- In wanting to become more than we are, and in sometimes acting as if we were already superhuman or divine, we risk despising what we are and neglecting what we have.

In wanting to improve our bodies and our minds using new tools to enhance their performance, we risk making our bodies and minds little different from our tools, in the process also compromising the distinctly human character of our agency and activity. In seeking brighter outlooks, reliable contentment, and dependable feelings of self-esteem in ways that by-pass their usual natural sources, we risk flattening our souls, lowering our aspirations, and weakening our loves and attachments.

A final thought

What does it mean to be human? To have human dignity? What is *good* about being human?

If we can't answer, how do we know what a "better" human would be?

These questions go beyond the realm of science, and scientists alone cannot answer them. They are directed to all of us, and our answers may help determine the human future.