

PGD as a Tool of Letting Die

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Summary

Pre-Implantation genetic diagnosis (PGD) have been criticized mostly for its ability to select embryos and to make choosing desired embryos possible because that opportunity would probably be used for negative eugenic aims. In Foucault (1976)'s argumentation, 'biopower' could include both 'making live' and 'letting die' concepts. By regarding Nazi Germany as one of the best biopower examples which this world was experienced, the close relationship between PGD and 'letting die' concepts is examined in this paper. As one of the social results of these human-made selection processes removing 'disabled' genes and people from the life discussed through a focus group discussion and observations.

Keywords: *Biopower, Disability, Eugenics, Letting die, Pre-implantation genetic diagnosis (PGD).*

Introduction

Pre-Implantation genetic diagnosis (PGD) has an ability to select desired embryos and it is possible through other biotechnological techniques to implant those desired embryos in the prospective mother's womb. This reproductive application is controversial in many respects because that opportunity would probably be used for negative eugenic aims. According to Foucault (1976), 'biopower' includes both 'making live' and 'letting die' argumentations. In their ages Nazi movement used mass killing technique in order to make negative eugenics possible. However today modern individual has the opportunity to remove undesired masses before birth. To show these relationships, paper will remind Nazi eugenics, and then will show its close relations to PGD and biopower concepts in a critical way.

Theoretical Discussion

Nazi movement wanted to remove undesired people from the society (negative eugenics) and to encourage the desired ones' reproduction and thus to achieve the 'Arian race' (positive eugenics). To make these applications real, they did not even hesitate to make 'slaughters' and moreover, to use science and technology, and specifically biology and anthropology and genetic sciences and scientists. Physicians and psychiatrists, mostly professors, hospital directors, and bureaucrats, directed the T4 killings and also served as medical experts¹ to select the victims whom, however, they never saw (Friedlander, 2002: 59). It is embarrassing that many technological developments in especially genetics and medicine today owe many things to the political directions in technology in Nazi Germany and to the wars happened before and after that time. The worse thing is it is still possible and accessible to use science and technology and their experts for political and eugenically aims.

The use of PGD as a Tool of Biopower

The most important and famous development in reproductive biotechnology is shifted from 'infertility treatment' to the 'diagnosis of genetic disorders / diseases' through genetic testing and even to the 'embryo selection without genetic disorders /diseases' through Pre-Implantation Genetic Diagnosis (PGD) and to inseminate these selected embryos to the womb through In Vitro Fertilization (IVF). The former of these new missions, 'diagnosis,' would lead the prospective mother to the termination of that pregnancy if the result seems like as 'abnormal,' and also if professionals or gynecologists and the social environment of the woman canalizes in that way. This process reminds us negative eugenics because there is again a destruction of undesired individuals, the only difference is, this time they are unborn. The latter one chooses the 'normal' individual before the insemination and inseminates it to the womb and gives that embryo the right to live. So it reminds positive eugenics. No one can know if this new eugenics would be succeed by the personal preferences of mother and father candidates or not; but one can know that here is an emergent necessity of reexamination of nearly all humanistic values and concepts on behalf of technology, society and ethical values.

¹ Almost every SS physician at Auschwitz did experiments: many were young and inexperienced physicians who wanted to learn. They took instruction from renowned inmate physicians, had them write their papers, and did experiments to get degrees or for publications (Friedlander, 2002: 70).

The conceptualization of ‘bio-power’ is remarkable here in order to see and give a meaning to the recent and partially different eugenic applications through reproductive biotechnology. ‘The body’ was transformed into a focus of the clinical gaze as Foucault wrote and it is mentioned before. Rose (2007: 4) underlines the transformation of ‘medicine’ as: ‘it became techno medicine, intensely capitalized, highly dependent on sophisticated diagnostic and therapeutic equipment’ and ‘Patients’ as they ‘...became ‘consumers’ actively choosing, and using medicine, biosciences, pharmaceuticals and ‘alternative medicine’ in order maximize and enhance their own vitality, demanding information from their doctors, expecting successful therapies, and liable to complain or even go to law if they are disappointed’ (Rose, 2007: 11). As Illich (1995: 1653) wrote:

‘...Medicalization led people to see themselves as two legged bundles of diagnoses. It did not, however, disembody self perception; today, systems’ thinking does. People now watch the curve of their vital parameters. As they approach the end of their “lives”; they have been under professional management – some since well before birth.’

As ideal consumers, people took this technology which was developed and transformed over these consumers bodies and put it in the centre of their lives, namely reproduction. The concept of ‘reproduction’ is the most related subject to life and death, in other words, the most natural functions of humanity.

In the eighteenth century, at least in Europe, Foucault argued, political power was no longer exercised solely through the stark choice of allowing life or giving death (Rose, 2007: 52). The ‘letting die (*laissez mourir*), making live (*faire vivre*),’ namely ‘biopower’ conceptualization is mainly based on Foucault’s bipolar diagram of biopower (in volume 1 of *The History of Sexuality*). While the one pole of biopower focuses on an anatomopolitics of the human body, seeking to maximize its forces and integrate it into efficient systems; second pole is one of regulatory controls, a biopolitics of the population, focusing on the species body, the body imbued with the mechanisms of life: birth, morbidity, mortality, longevity (Foucault, 1976: 139: quoted from Rabinow and Rose, 2003: 2).

Giorgio Agamben (quoted from Rabinow and Rose, 2003: 8) identifies the Holocaust as the ultimate exemplar of biopower; and biopower as the hidden meaning of all forms of power from the ancient world to the present. While Agamben was attributing the

concentration camps, labor camps and death camps of the Nazi's as the "nomos" of modernity; Rabinow and Rose (2003: 8, 9) considered that Holocaust was not an exceptional moment of throwback to a singular barbarianism, but an enduring possibility intrinsic to the very project of civilization and the law and was undoubtedly one configuration that modern biopower could take.

Then biopower or biopolitics is something which may occur both as visible as Holocaust and as invisible as molecular level. Here, this conceptual framework will go on with explanations over some biotechnological diagnoses and treatment methods which were discussed in the *Genomic medicine* (Rabinow and Rose, 2006: 212) or *Molecular biopolitics* (Rose, 2007a: 6) topics of these writers by sharing their argumentation over the issue: '...For its advocates, the genomic identification of functional pathology must inevitably open a path towards molecular intervention; but to the degree that this logic proves impossible to release, genomics will remain only one dimension of health care and biological understanding, one that gains its intelligibility within a wider field of knowledge on the aetiology, prognosis and treatment of disease (Rabinow and Rose, 2006: 16).

Reproductive biotechnology has a different place in this sphere because of its ability of shaping the generations' features and so the future. PGD and IVF are possibly the most important parts of the developments in reproductive technology. Hence, neither health nor beauty is inseparable part of the 'natural' anymore. The worst thing is that the 'making live' and 'letting die' functions of bio-power are not visible as it is seen in the Holocaust, and conversely, they are invisible and stands behind the rationalities, namely, so-called individualistic choices of the parents. Individualism in which there is neither an autonomous decision of woman nor having an informed consent of her.

Another transformation in the pregnancy examinations and experiences of women is discussed anymore. The responsible thing for this is especially pregnancy screening and many other reproductive choices. The natural structure of pregnancy is transformed into a problematic situation. Pregnancy becomes a case of risk (Beck-Gernsheim, 1990); Silja Samerski (2002) speaks about a shift from "good hope" to "bad expectations;" Barbara Duden (2000) describes this change from a haptic experience to a medically defined reproductive process; Barbara Katz Rothman (1989) argues that prenatal testing has led to pregnancy on a trial basis: the tentative pregnancy (quoted from Wieser and Karner, 2006: 31). All these approaches need the critical explanation of Rose's (2007: 11) conceptualization of 'molecular biopolitics,' which means a sort of reduction of the bodies to mere limbs, organs, tissues, flows of blood, hormones [socio-biology may be criticized in this point], and so forth; in other

words ‘molar level.’ According to Rose (2007a: 15), molecularization is not sufficient on its own; as we shall see, many other factors must be added – notably standardization, regulation and even ethics – to make up circuits of vitality. At this molecular level, that is to say, life itself has become open to politics.

Family experiences with Down syndrome

There is another group of people who have a very special situation in this respect. That is families of children who born with Down syndrome.

It is widely known that quite a few women who were obtained as very risky in having a baby with Down syndrome and who rejected to undergo abortion had very healthy babies; and in parallel with this many women who were obtained as non-risky in having such a defected baby and continued pregnancy had babies with Down syndrome. Some people think that this result takes its source from the chance or religious factor, while others think about the unreliability of screening tests. It is obvious that, no matter this technology is used or not, there will possibly be disabled people in our closer social environment.

Four in-depth interviews with the people who have children with Down syndrome are conducted as a focus group research. In addition to a mother who was the president of the Ana Kucağı Association of Protecting Children with Down syndrome, Ankara, Turkey; there were three more people, two mothers and one father, who have a child with Down syndrome in the group.

Two of mothers who have a child with Down syndrome were from the special group of which health conditions of their unborn babies could not be estimated via pregnancy screenings. They were under 30 years when they are pregnant, their husbands were not their relatives, they have no relative with Down in their wide-families, their gynecological visits and ultrasound findings were also normal. They were in an expectation of having a healthy baby during their pregnancies however they got their babies with Down on the birthday.

Third mother could not have a chance even to undergo pregnancy screening because of the timing; her child with Down syndrome was born 20 years ago. 20 years ago there were neither screening applications nor ultrasound technologies in Turkey. However she was extremely happy because her daughter with Down syndrome was one of the lucky children with Down syndrome, she would work as an office holder from now on. She was lucky three times because in addition to get a job her syndrome was not developed dramatically as many

others and her other family members were helpful and patient for her special education, so that her little sister would like to be a social worker in order to help her sister in her education.

All of three female interviewees were unemployed and housewives. Male interviewee was of course employed because he had to get money for his twin babies one of which was born with Down syndrome, and wife. In addition to the efforts of mothers, there are generally other women (generally mother in law) who help the women of the house in the general baby care and special child care. It is seen that it is the life of the family and particularly woman which is affected from that exceptional situation. Woman who has a baby with Down syndrome cannot be employed easily because there is neither a person nor an institution where her special child could be looked after and educated, similar with her.

It was supposed before the in-depth interviews with parents of children with Down syndrome that there should be an intentional reason of being a mother or father of a child with Down. However, there was nobody who had a chance to choose to have a baby with Down syndrome or not: they were all people who were made a mother or father of a baby with Down by the technology or destiny as ‘exceptions.’ However the father of twin babies explained that he would not have wanted his wife to undergo an abortion even if he could have learnt the syndrome of his son because of his religious beliefs. The statement of the president of the Ana Kucağı Association of Protecting Children with Down syndrome, Ankara is considerable here:

‘..in our Association, there are many people who did not choose to undergo the termination of the fetuses with Down only because of their religious beliefs’.

Male participant was a new father of a twin babies. He and his wife were informed that triple test could not be applied on twins or other multiple pregnancies by their doctor. Their ultrasound findings were normal. However, while their daughter was born very healthy, their son was born with Down syndrome. He explained that he asked for another hospital if they could perform these tests for their twins there but they were answered negatively again. After these interviews, the possibility of applying these tests on multiple pregnancies is asked to some fertility clinics and hospitals and it is learnt that of course these tests could also be performed on multiple pregnancies. They were evaluating the results for each of the babies separately. As noted above, the result would not differ according to the test results; he would choose, or he would also affect his wife’s decision in favor of the birth of the baby with Down syndrome. One of his share was remarkable,

‘...especially our older male relatives, fathers or brothers, do not believe in the syndrome of our baby. We show the physical differences of his hands, foot fingers, eyes from his twin sister, but they still insist on believing in his normality..’

Below you can find some statements about abortion:

‘...If the syndrome of my baby had been predicted during the pregnancy.. yes I would have undergone an abortion’ says a mother of a child with Down. However she adds, *‘...but now it is impossible to think this.. I love my daughter.’* They are in general, fond of their children with Down. Hence, a mother of a boy with Down says surprisingly, *‘...yes, it is so difficult. But I got used to my boy. So sometimes I imagine if something happened to my son – god bless him- I would look after another child with Down from Child Welfare Agency..’*

To me, this is a sort of response to the people who is afraid of having a baby with Down syndrome because of an anxiety if they die before the baby. For this woman, the death of her son would be a disaster for her because her life gained another meaning after the birth of her son with Down syndrome: she is ‘making live’ him ‘with her hands’..

The president of the Association and a mother of a daughter with Down explains

‘...of course there are people who undergo an abortion as a result of a pregnancy screening. I know a couple like that. But they regretted doing it after the application..’

The reliability of doctors and screening tests were juddered for all of the people who were interviewed. Because of the fear of having another baby with Down syndrome or of being unable to spare time to that baby, two mothers that were interviewed explained sincerely that they underwent abortions after the birth of their child with Down. One of these mothers added,

‘..it [having a child with Down] takes all the time of especially the woman.. I would not spare time for another baby..’

When they were asked if more money was needed for the care of their special children or not they answer, ‘no’ at first moment. However they remember that their child was caught diseases because of their weak immune system and generally problematic respiratory and cardio-vascular systems. They have health problems also with their eyes and so they have to

use eye-glasses and see a doctor regularly. All these health care applications need money after a while because there are various difficulties in the health care system of Turkey. The president of the Association gives an example and makes it easier to understand:

“...one day, she became sick after she came home from her school. When I questioned I understood that she sit under the sun for a long time and became sick because of disinterestedness. She is unable to understand and say something related to her situation even if it is too bad.. If I had more money I could keep a tutor for her education.’ They have everything to ‘make live,’ however they need money for ‘making life better’ for their children as everybody else.

One of the mother says, *‘.. in spite of everything I am happy. Really.. because I see that my efforts to my daughter are not bootless. However my efforts to my (healthy) son are completely bootless. My daughter answers me too late [because of her special health situation] while my son does not answer intentionally.’*

Through an Observation

There is a Cafe in Kızılay, Ankara, Turkey where young people with Down syndrome works as waiters and waitresses. I find people who goes there as customers very kind, tolerant and gentle in general. For example waitress came and asked in a rude way: ‘What will you drink?’ Customer answered kindly: ‘..fruit juice, please honey.’ Waitress asked again: ‘What do you want?’ Customer answered in a gentle way again: ‘Fruit juice, please.’ Waitress understood the order, however wanted to ask the sort of fruit juice. Waitress asked again: ‘Madam, which fruit juice?’ Customer answered her in a happy mood for her understanding: ‘Oh, sorry. I would like to drink peach juice.’ After this relatively long conversation, waitress girl with Down syndrome brought orange juice. And customer smiled and drank it even if she disliked orange juice.

This little conversation is very important with respect to the humanity side. It is not difficult to estimate the intolerance of customers if this conversation is occurred in a ‘normal’ café. This customer knows waitress’ special health and mental problem and goes there intentionally, in order to have a contribution to the employment of these young people. Waitress uses an order paper for the notes of orders but of course she notes as she understood. However these misunderstandings are not transforming into big problems there because customers behave in extremely gentle way there.

On behalf of Result

As it is remembered from the little conversation above, modern individual became very intolerant to other, even to the ‘undesired unborn other.’ Rationality and the lack of social state in many developing and underdeveloped countries led people, especially women to give their decisions in this way. The main point that forgotten is all type of disabilities belong natural human existence. If one disability could not be overcome with through social precautions, it would create social disasters and even negative eugenics to remove them from the world through genetic attempts. Finally, it is the point of this paper and humanlike behavior that to learn how to overcome with or reduce the problems of the ‘unequals’ in the life rather than removing them.

References

- Friedlander, H. 2002. Physicians as killers in Nazi Germany: Hadamar, Treblinka, and Auschwitz. *Medicine and Medical Ethics in Nazi Germany*. Nicosia, F. R. & Huener, J. (Eds.). pp. 59 - 76. New York. Oxford: Berghahn Books.
- Illich, I. 1995. Death undefeated: from medicine to medicalization to systematisation. *BMJ*, 311, 1652-1653.
- Rose, N. 2007. *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century*. Princeton University Press.
- Rose, N. 2007a. Molecular biopolitics, somatic ethics and the spirit of biocapital. *Social Theory & Health*. 5, 3-29.
- Rabinow, P. and Rose, N. 2003. Thoughts on the Concept of Biopower Today. <http://www.lse.ac.uk/collections/sociology/pdf/RabinowandRose-BiopowerToday03.pdf> . Accessed Oct 2011.
- Rabinow, P. and Rose, N. 2006. Biopower Today. *Biosocieties*, 1, London School of Economics and Political Science, 195-217.
- Wieser, B. and Karner, S. 2006. *Prenatal testing: Individual decision or distributed action?* (Wieser, Karner and Berger, Eds.) Wien: Profil.