

Genetic Manipulation and the Individual Model of Quality of Life

Motomu SHIMODA

Osaka University Graduate School of Medicine

shimoda@eth.med.osaka-u.ac.jp

Abstract

This essay aims at the examination of some ethical issues following with the advance of biomedical science and genetic engineering, especially those of genetic manipulation (testing, diagnosis, therapy and enhancement), in which life is an object of selection, modification and designing. Genetic manipulation always raises questions concerning value or valuing of life, which indicate dichotomy of quality of life like “normal/abnormal”, “superior/inferior” and “abled/disabled.” The most important question is the relation between genetic manipulation and discrimination or eugenics. In connection with this question an interesting controversy has taken place in *Journal of Medical Ethics*. By inquiring into this controversy I discuss such problems as a difference between impairment and disability, dimensions of disability and a transformation of eugenics. And then the individual model of quality of life is investigated critically, which denies the connection of genetic manipulation and discrimination or eugenics. This model is very influential in contemporary discussions in bioethics or medical ethics, but has some fatal defects concerning the understanding of individual-society-relation and self-other-relation. So I propose the communication model as an alternative model of quality of life, in which quality or value of person's life is considered to be defined by diverse overlapping communication.

Keywords

genetic manipulation, quality of life, disability/impairment, eugenics, the medical model/the social model/the communication model

Introduction

The intervention technology to a life has progressed quickly on the level of a genome, DNA, and a gene, as the research result of life science (biomedical science) and genetic engineering permeates a medical field. Under these circumstances, a life is changing into the object which is performed manipulations, such as a selection, an alteration (repairment or improvement), designing, and production, from “what is given” and “a thing without a substitute.” The act of manipulation toward the other being brings to light the evaluation of the manipulator, eg. “superior/inferior” or “normal/abnormal”,

and at the same time it has also raised the social sides -- the regulation and the policy decision by law are demanded about each act, or a market is formed as business according to people's desires and needs. How should we consider the meaning of life or the "quality" of life in the face of such a situation?

Certainly, the QOL (quality of life) in question may seem to be completely different from the QOL of the patient which is aimed at improvement by ordinary medical treatment or terminal care. However, also in the manipulation, another way of relation to the other, there is something common in a relation with a patient as far as quality evaluation is concerned, that is, the measure is required of individual physical and mental conditions. Furthermore, in respect to living one's own life, relating to the other and making the framework on which people live with people, different phases of the living forms the meaning of life, so we cannot find essential difference between these two relations.

From above, under the framework of "genetic manipulation" I want to examine the ethical and social problems which are raised by the intervention in a life, and to try to consider "quality of life" from various angles in this paper.

1 Genetic manipulation and disability -- from a certain dispute

On *Journal of Medical Ethics* published in Britain, some articles focus on the ethical and social side of genetic medicine (diagnosis, testing, counseling, therapy or enhancement) appeared.¹⁾ Among laborious works, an exchange between John Harris and Solveig Magnus Reindal is especially interesting. I would raise some problems from this exchange which constitutes the axis of a series of disputes involving the manipulating intervention in genes (therapy/enhancement) and its relation to disability and eugenics.

1-1 "Is genetic manipulation discrimination against disabled people?" -- some questions raised by J. Harris

The beginning of the dispute was an article in *Bioethics* entitled "Is gene therapy a form of eugenics?" by J. Harris, a prominent bioethicist of the Manchester University.²⁾ At first, Harris refutes a view which criticizes gene therapy in connecting to the eugenics. If eugenics is understood as the knowledge and technology which "are adapted to the production of fine offspring", there is no problem that gene therapy is eugenics, and if it is understood as a policy by the condition of "discouraging genetically weak from reproducing", gene therapy is unrelated to such a thing. In any cases, it is unconvincing to the argument which ties both up. It should rather be asked in connection with this problem, ① whether or not there is a relevant moral distinction between attempts to remove or repair dysfunction on the one hand and measures

designed to enhance function on the other? , ②whether gene therapy as a technique involves something specially morally problematic? (Harris 1993:178-9)

According to Harris, it's natural that parents want a child who is "fine healthy". Moreover, even if there are those who are going to avoid or treat a child with disability in advance in a stage of fertilized egg or embryo, it should not be blamed at all. "Sane decent person" would accept the view "disability is somehow disabling and therefore undesirable." That perceptions of Harris is supported by the definition of disability that "disability is surely a physical or mental condition we have a strong rational preference not to be in, it is, more importantly, a condition which is in some sense a 'harmed condition' " (Harris 1993:179-80).

On this presumption, one can also make clear answer to the question①. Treatment of disorder of genes (=cure dysfunction) is a duty, but adding something and improvement (=enhance function) cannot be considered as a duty although it is permissible depending on the case. Harris refutes such an opinion by giving following examples which ask for different types of handling in these two intervention styles. For instance, when an introduction of genes which make the antibody of AIDS or hepatitis or the gene therapy for delaying the aging become possible technically, shouldn't we say these improvement are not only permissible, but a duty? And when disability can be avoided in advance or removed and repaired, not taking those measures means "knowingly harm" on the individual, the same thing is true of the case in which man doesn't carry out means that can prevent disease. (Harris 1993:181) 3)

It is the gene therapy to the germ line in the undifferentiated stage which can expect the effect to the whole individual rather than the gene therapy to the somatic cells in the stage where the cells and the organizations have already been specialized that such intervention is performed more efficiently. Objections to the former are strong because of the danger which cannot be predicted since it also affects offspring, or of cultivating a way to "human remodelling" by specific intentions, such as production of human being with certain traits. However, according to Harris, such objections are overridden by the affirmation theory which gives priority to the clear benefits for the parents (couple) of selecting child's quality.

Next, concerning the relation between genetic manipulation and discrimination against disabled people, Harris refuses clearly the argument which ties both up. Like the medical treatment-intervention which removes or repairs the disability which exists actually, when technically possible, it is a medical professionals' duty to prevent generating disability in advance. This is applied not only to selective abortion of the fetus and euthanasia of the newborn infant who is severely disabled but the genetic manipulation before implantation. As long as it depends on the voluntary intention of persons concerned, it's not appropriate to criticize that removing and repairing the disorder or defect in a gene level implies "looking down upon worth of character of disabled people", and that practice is unrelated to discrimination against disabled

people. First of all, Harris himself -- he insists -- defends the view “all persons share the same moral status whether disabled or not”, and doesn't have any intention of discrimination against disabled people. (Harris 1993:182)

Harris appeals from such a position, “it is not that the genetically weak should be discouraged from reproducing but that everyone should be discouraged from reproducing children who will be significantly harmed by their genetic constitution.” (Harris 1993:183) While the old eugenics performed in a rude manner like compulsory sterilization, the technique of genetic manipulation has made possible a eugenic idea by the more accurate means. It is the important part of an opinion of Harris that this morally justifiable eugenics 4) differs fundamentally from the old eugenics in that it is based on the voluntary intention of persons concerned, and that it cannot be connected to discrimination against disabled people.

1-2 “Disability is a social construction” -- criticism by S.M.Reindal

In his article “Disability, gene therapy and eugenics -- a challenge to John Harris” (Reindal 2000), Reindal turns the brunt of the criticism to the presupposition “disability equals undesirable QOL.” Reindal, as a researcher of education of physically and mentally disabled children, attempts to highlight the problematic of Harris's concept of disability by urging cautions to multiple dimensions of disability concept.

At first, Reindal specifically focuses on selecting disabled being, and the level of a phase that parents' hope and judgment of a doctor in concrete. Taking up three examples 5) in which embryos are sorted out by the preimplantation diagnosis, he raised a question of moral justification of selection/avoidance of the quality of impairment. According to Harris, bearing the child is morally unjustifiable, when parents expect beforehand genetic constitution of the child which damages seriously him/herself, even if parents hope so. Conversely, it is not wrong, when a doctor overrides parents' hope and implants a normal embryo. However, the core of Harris's disability concept consists in a phase of quality itself of a child, which is clear from its definition, “a condition we have a strong preference not to be in”, “to remove and repair as much as possible”, “it is undesirable” in any situations. That was also deeply concerned with the fundamental question, “what is disability?”, and it was necessary for Reindal to move a point of argument to the “disability” concept itself.

According to Reindal, Harris is completely wrong in considering that disability is an individual problem and a condition inside a subject. This is called *a medical model* or *an individual model* in Disability Studies, in which having an impairment and being disabled are equaled. And it is considered there that “disability is seen as a product of biological determinism or personal tragedy.” However, according to the latest research, about 40 percent of adult men and women hold the illness and disability over a long period of time, about 50 million people in whole Europe, and about 500 million people are in such conditions in the whole world. Considering this, it is difficult to limit

disability to the object of medical disposal (recovery and rehabilitation) and “disability is a sociopolitical construction, a product of organisation and culture rather than a personal limitation due to a person's impairment.” (Reindal 2000:92)

This viewpoint called *a social model* of disability shows that an individual physical and mental impairment is only one factor that forms quality of life of disability. The social phases in connection with disability, i.e. “social barriers, norms and values” are also indispensable factors. The way of thinking itself that a objective (=medical) definition of “disability is such and such” can be given forms discrimination against disabled people, and it has supported and now support eugenic policy. And aren't the voice, experiences and views of disabled people omitted easily there, either?

Such a suggestion by Reindal indicates that as long as the argument involving genetic manipulation is based on the medical model or the individual model, the circuit which turns its eyes to the various phases of disability is shut and it would be reduced to a simple causal relationship “impairment \Rightarrow disability.” We could find there the criticism to the opinion “blaming for genetic manipulation as eugenics and discrimination is irrelevant because it is based on the voluntary intention of persons concerned .”

1-3 Disability is “a harmed condition” physically and mentally -- counterargument of J. Harris

To criticism of Reindal in “Is there a coherent social conception of disability?” (Harris 2000), Harris adds a counterargument as his opinion being more radicalized. It makes the main point that “physical and mental conditions which harm the individual” and “social conditions which disadvantage the individual” must be distinguished clearly, therefore “the concept of disability based on social factors” by the social model is not accepted.

Although Reindal claims “once the social dimensions of disability have been resolved no seriously ‘disabling’ features remain”, a peculiar meaning of physical and mental dimensions of disability is overlooked there. And Harris retorts “if disability could be identified simply in terms of social conditions, for example social exclusion or discrimination, then all victims of racial and gender discrimination would count as disabled.” (Harris 2000:95) For Harris, the important part of the concept of disability” is a harmed condition physically and mentally how society would be, and it contains in itself the meaning of disability. Harris calls this “the harmed condition model of disability.” (Harris 2000:99).

About the purpose (intention) of the correction or dissolution, there is a serious difference between the discrimination by the biological and social attribute (race, sex, nation, religion) and by the physical and mental conditions. In the former curing the attribute is not intended, but eliminating social stigma and disadvantage by the discrimination and exclusion is chiefly called for. On the other hand in the latter, it is

intended to be eliminated disability itself, “which a rational person would wish to be without.” (Harris 2000:98)

Reindal does not distinguish disability which is a harmed condition physically and mentally from disadvantage which is the problem of a social dimension. While the former is direct harm for the individual or impairment, the latter is a social exclusion or discrimination and people's consciousness which are caused by it. Each of these two concepts has its own dimension respectively. Impairment itself is disability whatever the social conditions may be. It is because “important options and experiences” which would otherwise be possible are taken by that. Therefore, the act of the couple, Reindal mentions, who dares to bear the child of being known to be disabled in advance is not accepted. Although the reproductive freedom or autonomy should be supported, “deliberately to make a reproductive choice knowing that the resulting child will be significantly disabled is morally problematic, and often morally wrong.” Because such an act doesn't avoid disability in spite of being avoidable in advance nor cure in spite of being curable, in either way the act is “to harm a child.” (Harris 2000:96-8)

You should not mix up the problem of an individual level and of a social level. To the argument that the selective abortion by the prenatal diagnosis and selection of embryo by preimplantation genetic diagnosis are or connected with discrimination against disabled people, the counterargument is often raised that the prevention of generating disability in advance and the advocate or deterrence of discrimination against disabled people or the improvement in welfare to disabled people in present are compatible. From this position of a double standard theory, Harris also thinks that the problem to eliminate a social discrimination and exclusion by the reason of disability and the problem to prevent birth of a child with impairment in advance or to treat it are distinguishable. Harris insists “we must separate the question what constitutes disability and ethics of minimising its occurrence in the future.” (Harris 2000:98-9)

2 Arrangement of problems -- what should be asked?

There are some articles which relate to the dispute of Harris and Reindal, we have seen above. While referring to them I want to arrange the problems occurring from this dispute, and show which questions should be asked involving the relation between genetic manipulation and disability, eugenics or discrimination.⁶⁾

2-1 Genetic manipulation and disability

(a) the medical model and the social model These two models have become the central point at issue by the above-mentioned dispute. In response to the criticism from the social model to the medical model, two questions are raised by the latter to the former. Suppose that the social system in which social disadvantages for people with impairment are eliminated and social discriminations and prejudices are also deterred

severely. In spite of that, if the person him/herself in question wishes to escape from his/her physical-mental condition, isn't disability the individual's personal matter? When the parents desire the enforcement of technology which can remove or repair the disorder of genes causing impairment in advance, can society show the reasons which forbid that choice?

(b) Parents' choice and interests of a child The range and grade of the selection may pose a problem in connection with a child's own interests, even though selection of the quality of the child by genetic manipulation could be admitted as parents' reproductive autonomy. Is it morally wrong to bear a child who is known to be impaired according to a hope of parents since it is narrowing experience of a child for the sake of parents' convenience and contrary to a child's benefits? Or can we blame the parents who bear a child with superior quality, such as high intelligence or an outstanding athletic ability, saying it is designing a child as a means of satisfying desires of parents? First of all, as the selection of quality by parents may bring about serious influence in respect of a child's sense of identity or psychology, should such parents' selection be restricted?

2-2 Genetic manipulation and eugenics, discrimination

(a) idea and method of eugenics Eugenics has been defined as the control of reproduction by the state, concretely the compulsory measures against prospected parents (sterilization etc.) and management of the quality of the child-to-be (negative/positive intervention). So, it is irrelevant to blame the genetic manipulation by parents' voluntary selection as eugenics, and one cannot say that it is a mistake even if it is eugenics, -- in relation to such an opinion raising the following questions. If eugenics is eliminating inferior heredity traits and expanding superior heredity traits for the purpose of improving genetic characters of humankind, what's the matter? When the intervention in the quality by genetic manipulation is not as a policy by the condition but as individually performed with voluntary intention of persons concerned, can society prohibit or regulate it?

(b) discrimination We face two major problems, one is that whether or not the genetic manipulation especially preimplantation genetic diagnosis or genetic improvement on germ line are connected with discrimination against disabled people, and the other is that whether it can be said promoting genetic manipulation and supporting living disabled people are not contradictory or compatible. Specifically, the following questions would be raised. Is implanting embryo which has turned out to be normal as a result of preimplantation genetic diagnosis by a couple with severe hereditary disease an idea of disabled people discrimination because it prevents the birth of disabled people and implies the thought disabled people had better not exist in this world? Or rather is it merely a value selection from personal circumstances? When

disabled people insist that selecting embryo by genetic manipulation is never received because it denies being of disabled people, how does society respond that claim?

3 Critical examination of the individual model

Next, after reconstructing the position represented by Harris in which the questions above mentioned are resolved by the individual model of quality of life, I try to examine critically its view. It is considered as “the individual model” because the being concerned is not only the object of medical treatment (=patient), but the biological human individual which includes from a fertilized egg, an embryo, a fetus to a newborn infant, and the concept of “quality” implies disability and high intelligence or an outstanding athletic ability attempted by genetic manipulation.

3-1 Atomism and a status quo affirmative thinking

The most important index that determines quality of life of an individual in the individual model is the moral status. “Moral” can be understood in the meaning of the consideration according to evaluation measures, such as person, autonomy and interest or welfare of the being. At first, it becomes a big turning point that whether the being is person or not. According to Harris, “persons are beings capable of valuing their own lives.” And it is included in the respect for a person that two dimensions of “concern for its welfare” and “respect for its wish.” “Wish” in the latter is being able to select/avoid what is good/bad for one's life. (Harris 1985:192-3) Whether or not having an ability of valuing, that is a capability of judging the condition of one's own life and of evaluating what is good or bad, this serves as the first standard on which this bisects of the quality of life of the individual.

The autonomy that Harris mentions was “reproductive autonomy”, which consists in the freedom of selecting the quality of a child. Moreover, it was the conditions of autonomy that “one's decisions are one's own, unfettered by others” and the “ability of control”, “reasoning” of a desire or action, and the “information” for selection. (Harris 1985:196-200) The second level of quality evaluation is set up here. You may call it the boundary line between two modes of lives, the one is selected as valuable quality by a person's desire and reason, and the other is a life that is excluded or eliminated as quality without value. Therefore, as long as genetic intervention is performed based on the voluntary intention of persons concerned, intervention in somatic cells or germ line and negative way or positive way, it is approved as what depends on valuing of the persons.

For Harris, the quality of disability is evaluated by the condition which the person wants to slip out from by him/herself, or the condition we have a strong rational preference not to be in, so it is not only subjectively valued but is the quality which is undesirable for the whole society. And it is a strong moral obligation to remove in

advance the harm and the suffering which can be prevented, and its strength depends on seriousness of the harm which can be prevented, the cost taken to prevent it and possibility of generating. It is considered that the quality which brings about disability is the objective thing to be evaluated according to such measures. (Harris 1998:31)

On the other hand, when a being in question is regarded to have neither capability of valuing nor autonomy, it is the others with capability of valuing or autonomy that make the judgment of having not capability of valuing and autonomy to that being. The quality of life of an embryo or a patient with serious consciousness disorder is evaluated from the outside of these individual beings, such as not worth living, useful on medical treatment and contrary to the interests of the individual. Such evaluations can also gain the objective basis of medical evidences, as many people support it and it becomes to be recognized socially by obtaining institutional insurance (admission by law).

Thus, at first, the individual model underlines a boundary in the form of existence/non-existence of capability of valuing or autonomy. After that, on the one side, the quality is given by the individual that “superior/inferior”, “desirable/undesirable”, and “worth living or not” etc. On the other hand, the individual which lacks in the “capability of valuing” is chiefly positioned as an object of manipulation and evaluation. In each case, quality is evaluated inside the individual and the social and objective determination at the same time. This idea concludes in the understanding that the technology of the intervention in the quality itself is good as far as there are needs to it, and that the technology becomes good/bad practice according to the way of use (voluntary selection of the person/compulsion by the state). It can be said that the view of Harris is based on such an understanding, that the idea of eugenics itself is just if people consider it as desirable, there is only a good/bad method of performing it.

As Disability Studies based on the social model insist, it cannot be denied that the “normalization” by the medical model has a strong tendency to “validate and further impose the dominant social group's preferences and biases.” (Silvers 1998:74) It may be necessary to turn our eyes to mechanisms of strengthening the dichotomous value consciousness “abled/disabled” which has stretched the root widely in society. The idea itself that one can make a life with impairment the object of evaluation of “worth living/not worth living” supports “the power to define” (Reindal 2000:93), and constitutes a basis of the eugenics as a system and of discrimination -- you should never underestimate that situation. However, it is not that a power organization of the state and the government exerts coercion on an individual as a policy any longer. Rather, it takes the form which persons concerned select quality based on their own sense of values.

In the cases of discarding the individual if the disorder of its genes is discovered and removing an abnormal factor or repairing before implantation, and also of introducing

suitable genes into an embryo in order to produce a child with desirable quality, free choice of persons concerned is set on the starting point. In the case of the latter, the freedom of producing a child with the attributes that many people consider superior, e.g. high intelligence and an outstanding athletic ability, may be positively accepted as “laissez-faire eugenics” or “consumer eugenics”, in general “new eugenics.” (King 1999)

The individuals as subjects supporting a market mechanism are also those who accept the sense of values which is framed by the society in the diagram of “superior/abled/disabled.” In the individual model, it is only private matters of persons whether to live with disability or to select superior quality.

3-2 Dichotomy of an individual and society

According to Harris, living with the impairment forms the harm to the person and is undesirable condition for everyone what social conditions may be, therefore it is disability. And when social factors such as institutional discrimination and people's discriminating consciousness are added to it, it may bring the person (and the family) disadvantages. So, even if social conditions are improved and the cause of disadvantages is removed, the social dimension of disability has been solved but the person would still be a disabled.

You may say that there is a way of thinking of the dichotomy confronting an individual and society at the basis of such a view. As already mentioned, for this thinking that opposes the reproductive autonomy of an individual and the public regulation by the state, quality of disability is closed inside an individual being and separated from the social relations. Even if social conditions were improved, an individual physical and mental condition disables him/her. However, although impairment is often inconvenient for the person, it is based on certain social conditions that it becomes disadvantageous. The individual model could also recognize that disability has the side of a social, political and cultural structure as the social model claims. The question is whether such side forms the exterior of an individual and the quality inside an individual can be evaluated independently, or not.

As long as the quality of life of an individual is taken to be closed in the individual, one fails to seize that the sense of values -- “without disabilities it would be better”, “generating disability can be prevented in advance” -- effects as the power which strengthens the difficulty of living of disabled people. Improvement of the social conditions assumed from such a viewpoint cannot but remain external and superficial level, and omit dynamism with various phases of quality which contends and collides with each other. Living with disability is exactly living correlation with the power of norm or value which always works in a family, a local area and a community, or a state simultaneously.

It may be difficult to mention the positive basis which supports the concern “prevention of the generating impairment by the prenatal or preimplantation diagnosis

is discrimination to living disabled people and promotes it.” However, that difficulty is a theoretical one so to speak in dealing with the social sense of values which includes especially discriminating consciousness and the phenomenon of discrimination. Doesn't the sense of values “without disability it would be better” stab at people with disability as a cold look, and support their difficulty of living -- screening and exclusion in education or employment, people's discriminating consciousness and unconcern, which don't appear in statistics? We should not overlook such a doubt, even if there cannot be proved the causal relationship between “preventing the birth of people with impairments” and “disabled people's difficulty of living.”

Since Harris persists in the “disability” concept divided into the impairment which is confined in an individual and the disadvantages by social conditions, the “voices of sufferings” of those who live with disabilities do not reach him. He misses the reality of disability, that is living with disability consists of multiple or various phases of living activities. How do non-disabled people respond to some thoughts of disabled people which are intricately interwoven, such as “I want to cure my impairment if possible”, “I like to have the same experience as an abled person”, “even so, present my life is by no means unhappy”, “I would not yield to a public discriminatory look”? The individual model would turn these questions into mere personal matters, that is “each man's sense of values.”

When a very critical hereditary disease is found in preimplantation genetic diagnosis and the couple selects not to implant the embryo, the individual model considers that selection should be accepted as freedom of choice by persons concerned. According to this position, if society forbids such selection by the reason it is (or connected with) discrimination against disabled people, it's the infringement of individual freedom of choice. To be sure, as long as we accept the principle of freedom of individual choice, such selection itself cannot be totally forbidden with law. Even so, can you say that since it is personal choice of persons concerned, neither third persons nor society should not intervene? Though this “liberal” attitude seems to respect the freedom of choice of the others, it rather complements social discriminating structure since we find the viewpoint “it is unrelated to ourselves whether others will live with disabilities” behind that attitude.

When various types of manipulation are performed by the free choice of persons concerned, one should discern carefully how the choice effects as the power to people with disabilities, especially whether it is acting in the negative to those who are forced disadvantage in the society. For that purpose, it is necessary to continue questioning the individual freedom of choice. Even if under a certain condition it can be accepted, you should recognize that it is also the public issue which does not remain in the personal problem of a person concerned and presses constantly for reflection to social members. What conditions should be imposed or what process is required to decide the conditions, -- these questions would be important there. They must never be

understood as mere technical questions. For they're deeply connected with the question of the "ethics", that is how we are concerned with the other and build mutual relationship. I want to consider this problem finally.

4. Relating to the other or relationship with the other -- toward the communication model

According to the individual model, disability is estimated as the condition which is undesirable and he/she wants to slip out from if possible. The following relationship between self and the other is concluded from this model, that is relationship with the other is made on the basis that "I don't want to get others into trouble if possible" or "I don't want to be troubled by the other." And it connects the attitude to the other which regards the other as an object of manipulation, saying "I want the other to be satisfactory for me if possible, or I want to change him/her to my satisfaction." Conversely, the evaluation of the superior quality will push the way of looking that regards the other as an object of the designing vision, saying "I want to be so if possible."

The power of the desire is accelerated through the progress of life manipulation technology by which selecting and changing quality of life would be possible. On the one side, the power tends to cut the "unexpectedness" that existence of the other is what gives surprise, sense of incongruity and joy from the exterior. And according to the characteristics of human being ranked by "superior/abled/disabled" which the person him/herself has already held, he/she is going to enclose the other in a frame of a controllable object.⁷⁾ On the other side, the power also decreases the "humbleness" at the face to the other. Humbleness is the attitude in which one accepts the other's own possibility of self-realization. You can read that point from the following passage, "if the goal of enhanced intelligence and better health is something that we might strive to produce through education, including of course the more general health education of the community, why should we not produce these goals through genetic engineering?" (Harris 1992:142) In this way of thinking that catches education and genetic manipulation in analogy, the openness in the life and the power developing the life of the other would not be respected.⁸⁾

To this understanding of the other in the individual model which regards such quality as the candidate for manipulation, there is a criticism from the position which is based on substantial life value, especially on the "sanctity of life". To be sure, this position is consistent that denies the manipulation in not only the quality of life but its activity, from screening and research of embryo to abortion. However, this position shares the same premise as the individual model in that the intrinsic value proper to the individual itself is assumed. Moreover, in these two positions, the difficult problem which the individual and society face concerning quality of life, especially the question

how to decide the conditions to permit various interventions will be dismissed. We consist in the dichotomy of “the manipulation of the quality as the free choice of a person concerned” and “the absoluteness of life value”, so is it necessary to gain the perspective to transcend that dichotomy? I want to consider the possibility below from a viewpoint that separated from the practices of people's living in the relation of various phases, the quality of life is never determined.

The relation weaving quality of life consists of the accumulation of various levels of communication from the face-to-face intercourse of the individuals to social activities in the organizations and institutions. The quality of disability, or of a superior child is greatly influenced by the communication supporting practices of such ways of living. The important thing is a decision making process at the time of intervening in a fertilized egg and an embryo in connection with genetic manipulation. When manipulation (selection and design) is technically possible, a thought and a sense of values of persons concerned come to the surface compulsorily, related to what quality they desire or avoid, which measures of evaluation they intervene in quality and what social life of the manipulated beings is expected. However, as long as they will be reduced to the free will of a person concerned, they are not exposed to the question or appeal by the others, especially by the people with disabilities.⁹) It is required to face such a question and an appeal, to answer this and set up an opportunity to think together, in the place where the manipulation is performed.

Even if a final determination should be left to the choice of persons concerned, making such a communication process -- according to circumstances -- compulsorily may become the decisive factor which determines the reality of the relationship between self and the other. In other words, whether or not to strengthen further self-understanding of the subject which determines and controls such intervention by regarding the other as an object of the manipulation, or whether or not to cut off such a circuit and to respond to the question and appeal by the other and to be shaken and changed by the response, -- those differences of the relationship have great influences on quality of life of self and the other.

Such a direction could be called *the communication model* of quality of life as an approach in which quality of life is oriented in the concrete communication of each time, so it differs from the social model oriented in the general relation between an individual and society. In this model, the quality of life of each being is determined by the various levels of relationship consisting of the individual beings in question, -- a fertilized egg, an embryo to which the hand of manipulation is added, and a fetus and an infant which may be discovered disorder and cut off its life, people living with disabilities, and living a designed life, and a terminal patient who would be considered to be let die. And the relationship is created in the overlapping communication that is how to regard others or to be regarded, and what to appeal or respond, and how to deal with such beings in respect of a social policy or institution. I would like to discuss this

model at another opportunity in detail, so to limit for showing an outline here.

NOTES

1) *Journal of Medical Ethics*, Vol.25, No.2, 1999; Vol.26, No.2, 2000. About a table of contents and those summaries, you can see at the following website. <http://jme.bmjournals.com/contents-by-date.0.shtml>

2) In his article “genetic enhancement” as a functional improvement and strengthening of conditions is included in the word “gene therapy” as well as removal of disorder or defect of genes, or repairment of the disease by introducing genes, and preimplantation genetic diagnosis is also mentioned in connection with them. So I discuss here “genetic manipulation” indicating genetic intervention at large.

3) Harris considers that the “cosmetic” intervention such as “improving the intelligence” is also justifiable. (Harris 1993:185)

4) Such eugenics based on the voluntary choice of a person concerned is called “the new eugenics.” Further examination of this theme is yielded to another opportunity although it is mentioned later in this article. The references are as follows. Caplan 2000; King 1999; Paul 1998; Ichinokawa 1999; Matsubara 2000; Morioka 2001; Sato 1999; Tateiwa 1997; Yonemoto et al 2000

5) Three examples would be summarized as follows. (Reindal 2000:90)

Example A: It's the case in which the selected embryos by the preimplantation screening will be transplanted to the womb, in order that the couple diagnosed as achondroplasia may have children with genes of achondroplasia which suit their life styles remade according to the height (furniture, car, etc.).

Example B: It's the case in which a couple with congenital deafness consider having children and think that it would be better for the children to communicate through sign language, they are going to select embryos which have the gene for congenital deafness by the preimplantation screening, and to implant them.

Example C: It's the case in which a couple experienced the miscarriage on the first attempt at in vitro fertilization and have tried the second as the last opportunity of implantation despite the embryos show some sign of impairment by the preimplantation screening.

6) cf. Draper/Chadwick 1999; Gillam 1999; Holtug 1999; Newell 1999; Persson 1999; Wikler 1999. Although it is a point in dispute also about the techniques of genetic manipulation, such as somatic cells or germ line and negative intervention or positive intervention, it is only noted here.

7) Rather than existence of a child is “a gift from God”, it is “selected products, expressing, in part, their parents' aspirations, desires and whims.” (King 1999:180)

8) In relation to this point, the act of the couple who dares to choose select embryos which may be impaired which Reindal mentions (note 5) is described briefly. To be

sure, this problem cannot be separated from the important theme of Disability Studies, such as the way of understanding disability as “individuality” and “difference”, the evaluation of disability culture and disability community like “deaf culture”, and the positioning of the “peculiar nature of one's sense of body” independent of social relation. However, it cannot be denied that the selection is a way of relating to the other which deals it as an object of manipulating. About this you can refer to the following references. Ishikawa/Nagase 1999; Kuramoto/Nagase 2000; Nagase 1998; Tateiwa 1998.

9) I will quote from the document by Disabled Peoples International Europe expressing concern over the influence of genetic research. “How can we live as equal citizens in society which uses negative images of us to justify the raising of funds for charity and research? This amounts to using disabled people as evidence of the need for our own elimination. We are continually being disabled by such images. How can we live with dignity in societies that spend millions on genetic research to eradicate disease and impairment, but refuse to meet our needs to live dignified and independent lives?” “Disabled People Speak on the New Genetics”, <http://www.dpieurope.org/htm/bioethics/dpsngfullreport.htm>

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