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GENETIC MEDICINES IN INDIA: BLESSING OR CURSE?

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Genetics grows so rapidly. Every month we receive a new announcement about the scientific achievement from the genetical research in plants, animals and human beings. Compared to other medical technologies, genetics can radically change the nature of environment and the nature of human being. Today we have genetically engineered trees, plants, animals, food, insects, bacteria and viruses. Genetic medicines also proved the origin of genetic diseases and the functions of genes. Genetic testing and screening, genetics therapy, genetic design and enhancement are the few developments in genetic medicine. Genetic engineering is so common and we live in the midst of it. There are many merits as well as demerits in genetics. The problems in genetics are very complex and complicated and raise many ethical and moral theological issues. In this context this paper is about "Genetic Medicines in India: Blessing or Curse?" We make an ethical evaluation on genetic medicines. We divide this paper into three sessions. The first session discusses a short view on genetic medicines in India. The second part describes ethical issues in genetics and the third part is an ethical appraisal of genetic medicines.

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1. Genetic Medicines in India

Genetics is a vast subject and we have to understand the meaning of medical genetic. It is "the specialty of medicine that involves the diagnosis and management of hereditary disorders." There is a difference between medical genetics and human genetics. Human genetics involves the research in the scientific area that may or may not relate to medicine. Medical genetics cover many fields, which consist of "clinical practice of physicians, genetic counselors, and nutritionists, clinical diagnostic laboratory activities, and research into the causes and inheritance of genetic disorders."¹ The main medical genetic disorders include chromosomal disorders (down syndrome, Turner, Klinefelter syndrome), single gene disorders (AD Achondroplasia, AR Thalassemia, XLR Hemophilia), mitochondrial disorders, polygenic (Multifactorial) disorders (Hypertension, CAD, Diabetes), and somatic cell genetic disorders (Cancer, Autoimmunity).

There are different services offered for medical genetics disorders such as diagnosis (history, examination, genetic test), counseling, management, prevention (prenatal diagnosis), newborn screening and therapy, population screening for carriers and primary prevention, premorbid diagnosis and intervention, screening for genetic predisposition, gene therapy/stem cell therapy, and forensic applications.

Today we have an enhanced view regarding genetic disease because of the successful completion of Human Genome Project (HGP) in April 2003 that makes it very easy for the scientist to "prevent primary and secondary type of genetic diseases, carrier testing, genetic diagnosis, prenatal diagnosis and preimplantation genetic diagnosis."² More than 6000 genetic disorders occur due to the chromosomal or gene mutations. Genetic disorder is a common thing which is a serious matter in India. There are different types of genetic disorders in India such as "down syndrome, fragile X syndrome, idiopathic mental subnormality, haemolytic anemias, inborn errors of metabolism and recurrent spontaneous abortions."³

¹Cf. http://en.wikipedia.org/wiki/Medical_genetics (accessed 17-11-2013).

²"Genetic Research Center, Mumbai, Engaged in Research and Service on Genetic Disorder," ICMR Bulletin 41/8-9 (2011) 49.

³"Genetic Research Center, Mumbai, Engaged in Research and Service on Genetic Disorder," 49.

Neonatal and infant morbidity and mortality is taking place due to congenital malformation and inborn errors of metabolism. According to the report of the March of Dimes (MOD), 7.9 million births happen yearly with serious birth defects. Also the report of World Health Organization (WHO) states that 61 to 69.9/1000 of birth defects occurs in India. Congenital heart defects, neural tube defects (NTDs) and down syndrome, hemoglobinopathies and glucose-6-phosphate dehydrogenase deficiency are the main major birth defects.⁴ According MOD and WHO, 70% of the birth defects are avoidable if we properly use evidence-based community genetics services.⁵ Moreover, genetic disorder is the cause for degenerative disorder in adults.

Sanjeev D. Dholkute, Director in Charge of Genetic Research Centre Mumbai, explains that consanguineous marriage is so common in certain parts of India. This is the reason for many recessive genetic disorders. Thalassaemia, sickle cell disease and spinal muscular atrophy have already been reported in India. Additionally, inborn errors of metabolism are the causes for paediatric mortality and morbidity. Consequently, congenital hypothyroidism, congenital adrenal hyperplasia, galactosemia methyl malonic aciduria and maple syrup urine diseases can be seen in babies. Moreover, chromosomal abnormalities are general among the people. Down syndrome and Turner syndrome are the signs for this.⁶

The Indian government is doing its best in genetic research as well as providing many services to the people in the country.⁷ There are three types of genetic tests, namely, cytogenetics, biochemical genetics and molecular genetics. For this we need trained manpower in highly specialized instrumentation. Today, sequencing and microarray programs are normal at clinical genetics laboratory in India.⁸ This is taking place both in the public and in the private sectors.⁹ Besides, there are many community genetics services such as

⁴Sharma R, "Birth Defects in India: Hidden Truth, Need for Urgent Attention," *Indian Journal of Human Genetics* 19 (2013) 125.

⁵Sharma R, "Birth Defects in India: Hidden Truth, Need for Urgent Attention," 127.

⁶"Genetic Research Center, Mumbai, Engaged in Research and Service on Genetic Disorder," 52.

⁷We do not get at present accurate date of the research and service of genetic medicine in India. So our information regarding this is partial. We only make the report of Genetic Research center at Mumbai.

⁸Editorial, "Medical Genetics in India – What Needs to be Done?," *Indian Journal of Medical Research* 130 (2009) 354.

⁹Editorial, "Medical Genetics in India – What Needs to be Done?," 354.

“number of activities for the diagnosis, care and prevention of genetic diseases at the community level.” The aim of community genetics service is to get healthy babies.¹⁰

Medical genetics in India, from the scientific and professional point of view, can prevent the spread of thalassemias and haemoglobinopathies in the national level. There are also national programs for “periconceptional folic acid supplementation for the prevention of neural tube defects which have an occurrence of 5 in 1000 births.” Additionally, medical research in genetics is taking place in the fields of foetal medicine and cancer.¹¹

Genetic diseases such as hemoglobinopathies, congenital malformations, mental retardation, and muscular dystrophies make trouble not only to the patients but also to their families and the community. Treatments for these are complex and very expensive. In this context many are discussing about the shift from treatment to avoidance of such births. This can be gained by the awareness program, genetic counseling, and prenatal diagnostic tests.¹²

In this context it is noteworthy to remember the contribution of Genetic Research centre at Mumbai which was established in 1986 by the Indian Council of Medical Research. The centre has undertaken so many genetic research activities and is doing a wonderful service to the nation. The major trust of the centre reads as follows:

- 1) Service component- attending to individuals with genetic disorders, classifying them clinically in syndromes, diagnosing them using state-of-the-art laboratory methods, genetic counselling, out-patient based treatment and follow-up and prenatal diagnosis in at-risk pregnancies; 2) Areas of research include- chromosomal disorders and single gene diseases particularly inborn errors of metabolism, genodermatoses and skeletal dysplasias; 3) Creating a database of ‘Disease-ome’ in India for the various genetic diseases. This may help in rapid screening, diagnosis and prevention.¹³

Moreover, the centre has gained the following achievements for the last 25 years:

¹⁰Sharma R, “Birth Defects in India: Hidden Truth, Need for Urgent Attention,” 127.

¹¹Editorial, “Medical Genetics in India – What Needs to be Done?,” 354.

¹²Praveen K., Prashant V., “Public Health Genetics in India: An Unexplored Evolving Specialty,” *International Journal of Health & Allied Sciences* 2 (2013) 143-144: <http://www.ijhas.in/text.asp?2013/2/3/143/120581>(accessed 8-12-2013).

¹³Cf. <http://www.icmr.nic.in/icmrsql/insprofile.asp?insno1=000662> (accessed 8-12-2013).

Techniques like TFISH, MFISH, sperm FISH and use of whole chromosome paints to identify chromosomal rearrangements as a cause of recurrent spontaneous abortions; screening for 22q micro-deletion to ascertain its role in congenital heart diseases and to offer this test for prenatal diagnosis; ELISA for HbA2 for detection of beta thalassaemia in rural areas; unraveling the molecular basis of disorders of sexual differentiation; Immunocytochemical test for Fragile X syndrome.¹⁴

Indian scientists, both doctors and researchers, are contributing their best in medical research particularly in medical genetics. For instance, there were 242,222 papers published from 1999-2008. This means they contributed 2.6% of world scientific output. Their publications include: Microbiology (2.33%), immunology (1.35%), molecular biology and genetics (1.27%), and clinical medicine (1.26%).¹⁵ This too shows the growth and development in the genetic medicine in India.

Many people critically evaluate the present situation of genetic medics in India. For example, Lalji Singh, BHU vice-chancellor, said that "most of the diseases have genetic causes and there is a need to carry out extensive research in this area. A number of communities [have disability] from genetic diseases and disorders are present in India." Communities suffering from genetic diseases in India do not match communities that are suffering from genetic diseases in other countries.¹⁶ In the opinion of S.S. Agarwal, former Head of the Department of Medical Genetics Sanjay Gandhi Postgraduate Institute of Medical Sciences, "there is also a need for strong quality control of genetic tests, requiring accreditation and monitoring of test results."¹⁷ Moreover, Rima Dada, Anatomy department teacher of the All India Institute of Medical Sciences, said that medical genetics offers hope to millions of cancer patients that helps diagnosis, prevention and cure of cancer.¹⁸

¹⁴Cf. <http://www.icmr.nic.in/icmrsql/insprofile.asp?insno1=000662> (accessed 8-12-2013).

¹⁵Kalra S., Kalra B., Pathak V., "Indian Medical Research: Encouraging Trends," *Perspectives in Clinical Research* 4 (2013) 240-241: <http://www.picronline.org/text.asp?2013/4/4/240/120176> (20-11-2013).

¹⁶"Many Diseases have Genetic Causes," Cf. <http://timesofindia.indiatimes.com/city/varanasi/Many-diseases-have-genetic-causes-Expert/articleshow/23679777.cms> (accessed 17-11-2013).

¹⁷Editorial, "Medical Genetics in India – What Needs to be Done?," 354.

¹⁸B K Mishra, "Medical genetics holds promise for cancer patients," *Times of India* Apr 22, 2011 Cf. <http://articles.timesofindia.indiatimes.com/2011-04-22/patna/>

The Indian health care system offers different programs to overcome genetic disorders. However, government and the people are unresponsive to the potential of medical genetics for the public good. The reason for this may be "the high cost of genetic tests and lack of their accessibility. Equally important is the lack of exposure to medical genetics in medical education and trained manpower in the specialty."¹⁹ Through the integration of public health and genetics we can prevent and control many health related problems. There should be facilities at the private and governmental institutions. We need collaboration between the private and public health care system. It is also good to "allow private partners to participate in use of genetic tools for the wider use in the community."²⁰ Apart from these programs, we have to provide awareness programs to the public about genetic disorders and their prevention. We need genetic counseling and trained medical professionals and other staff in the area of genetic medicines.²¹

2. Ethical Issues in Genetics

There are many ethical questions that arise from the research of genetics in the area of human beings. The following are the main ethical questions related to genetic medicines.

1. Since genetic testing and gene therapy can be quite expensive, who should be given access, and who should cover the necessary costs?²²
2. Under what circumstances do couples planning to have a child have the responsibility to undergo carrier screening for genetic disorders, and how should this information be used for reproductive planning?
3. If there is no treatment available for certain types of diseases, is it necessary to know or not know genetic risk factors?

29462459_1_cancer-patients-medical-genetics-mahavir-cancer-sansthan (accessed on 7-12-2013).

¹⁹Editorial, "Medical Genetics in India – What Needs to be Done?," 354.

²⁰Praveen K., Prashant V., " Public Health Genetics in India: An Unexplored Evolving Specialty," *International Journal of Health & Allied Sciences* 2 (2013) 143-144: [http://www.ijhas.in/text.asp?2013/2/3/143/120581\(20-11-2013\)](http://www.ijhas.in/text.asp?2013/2/3/143/120581(20-11-2013)).

²¹Sharma R., "Birth Defects in India: Hidden Truth, Need for Urgent Attention," 128.

²²Audrey R. Chapman, "Genetic Engineering and Theology: Exploring the Interconnections," *Theology Today* 59/1 (2002) 71-89, 77-78.

4. Does genetic testing imply that a pregnancy is only tentative, dependent on a favorable genetic screen? If so, what are the implications for our sense of human dignity and our perceptions of the disabled living among us?

5. Tests show that a pregnant mother is carrying a child with an inherited disease and is highly likely to develop an associated deafness. Would you recommend termination? If you terminate, you have probably just aborted a Beethoven. If tests indicate that a human fetus probably has a certain genetic disorder, do you think that the woman or couple should talk with people who have this disorder? "By labeling certain conditions as unacceptable, are we narrowing the terms of what it means to be human in purely genetic terms? Or is this an acceptable act of compassion on those families who suffer under the burden of bringing up children with severe incurable problems?"²³ Do we permit to give birth only to the best possible child into the world?

6. Is there any difference between eugenic practices of the twentieth century and the current drive towards genetic screening?

7. Is genetic enhancement ethical?

8. What is the moral difference between somatic and germ line gene therapy?

9. Do Genes determine everything about us?²⁴

10. Should an insurance company be able to have access to a client or prospective client's genetic information? Should an employer be able to have access to a prospective employee's genetic information? Should they be able to make hiring or firing decisions based on such information? Do you propose genetic coding for marriage?

11. If you loved someone and otherwise wanted to marry him/her, but genetic tests indicated there was a 25% chance that your children would have a certain genetic disorder would you still marry him/her?

In short, there are many ethical questions with regard to genetic medicines.²⁵ We have to discuss in detail the ethical issues like right

²³Celia Deane-Drummond, "Fabricated Humans? Human Genetics, Ethics and the Christian Wisdom Tradition," *Dialog: A Journal of Theology* 44/4 (2005) 366.

²⁴Audrey R. Chapman, "Genetic Engineering and Theology: Exploring the Interconnections," 73.

to know (disclosure of the diagnosis of down syndrome at birth), privacy/confidentiality (disclosure of the carrier status of wife to the husband), stigmatization/discrimination (screening for thalassemia carrier status in the extended family / community at risk / college children), autonomy/ psychological distress/ human dignity (testing of a child or adult for Huntington disease in a family with Huntington disease), cost effectiveness, available interventions, (screening for BRCA1 / BRCA2 in general population), human rights, fundamental freedoms, discrimination (preinsurance/employment screening – denial of insurance/job), rights of the unborn, genetic burden (abortion of a foetus with achondroplasia, albinism, down syndrome, thalassemia; prenatal sex determination and female foeticide), eugenics (prevention of marriage / having children – say for thalassemia carriers, or a ‘carrier’ of huntington disease gene), and safety — induction of cancer (somatic cell gene therapy), etc.

3. Genetic Medicine: Ethical Appraisal

3.1. Justification of Genetics

The following section discusses how different ethical theories justify those ethical questions in genetic medicines.

3.1.1. Liberalism

Regarding human freedom of the person, Christian ethics points out that every human being is responsible and must act, but God accomplishes his/her will, either with or in spite of human being's actions. Ideally, human actions are harmoniously integrated with divine purposes in a perfect synergy of divine and human wills. We are committed to the exercise of self-determination and responsibility in conformity with both human reality and divine purpose. But liberalism states that the person is free from everything. It justifies any types of genetics. John Harris, a prominent ethicists, argues that “if it is possible to manipulate our hereditary material ‘safely’ then why not do it? He sees no ethical objection to not allowing such a development to take place.”²⁶

²⁵For a detailed study see Cf. S.S.Agarwal, “Ethical Issues in Practice and Research in Medical Genetics,” http://icmr.nic.in/bioethics/cc_bioethics/presentations/sym_che/Ethical%20Issues%20in%20Practice%20and%20Research%20of%20%20Medical%20Genetics.pdf (accessed 8-12-2013).

²⁶Cellia Deane-Drummond, “Fabricated Humans? Human Genetics, Ethics and the Christian Wisdom Tradition,” *Dialog: A Journal of Theology* 44/4 (2005) 371.

3.1.2. Utilitarian Approach

The utilitarian approach also justifies any research in genetics. It reduces all moral values to a material calculation with no consideration for spiritual values regarding the calculation of good.²⁷ It does not consider different kinds of relations among friends, children, parents or citizens; the only factor relevant here is utility.²⁸ This has given way to hedonistic and consumer behaviour, which makes life merely superficial.²⁹ Moreover, the utilitarian approach promotes a quality of life approach, which represents an evaluation by an onlooker of another's life situation based on the utility. It prevents us from recognizing the human dignity in genetics.

3.1.3. Relativism

There are different types of relativism.³⁰ We are concentrating only on moral relativism. It is the philosophical theory that morality is changing and it is relative. Different people have different moral truths. There are two types of moral relativism — ethical subjectivism and cultural relativism. Ethical subjectivism describes that morality is relative to people. Cultural relativism argues that morality is relative to culture. Both of them reject the existence of moral absolutes or objective morality.³¹ Today we face the disregard of objective truth, which is a danger to medical science, especially in the area of research in genetics. When there is no objective norm in medical genetics, we make any type of research.

3.1.4. Scientific Positivism

It suggests that science is the only basis of knowledge. We need scientific progress for the development of the people. So we should not limit our research. Religion always blocks research on the basis of the dignity of human person. Research in genetics is necessary in medicine. Peter Vardy, in his book, *Being Human: Fulfilling our Genetic*

²⁷R. Crisp, "Utilitarianism and Accomplishment Revisited," *Analysis* 61 (2001) 163.

²⁸R. Noggle, "On the Cross of Mere Utility: Utilitarianism, Sacrifices, and the Value of Persons," *Utilitas* 12 (2000) 9.

²⁹The General Secretariat of the Synod of Bishops, "The New Evangelization for the Transmission of the Christian Faith," *Instrumentum Laboris* of 2012 Synod of Bishops, Vatican City: 2012, II, 52.

³⁰Thomas Padiyath, "Church in Dialogue with the Contemporary World: Responding to Individualism and Relativism," Colloquium on Vatican II Documents *Gaudium et Spes* and *Nostra Aetate*, December 13, 2012, Pontifical Institute of Theology and Philosophy, Alwaye, 4.

³¹Cf. <http://www.moralrelativism.info> (accessed on 7-1-2013).

and Spiritual Potential, says that "it would seem entirely logical for human beings to continue to use their reason to help their species evolve."³²

3.1.5. Scientific Materialism

Scientific materialism proposes that we can separate body and soul from human persons. They are two material universes. Body is a pure matter and we can have any type of research on human being, which naturally supports research in genetic medicines.

3.2 Moral Evaluation

In this section, based on just laws, faith and virtues, we morally evaluate genetic medicine.

3.2.1. Goals of Health Care

Research in genetics should not be against the goals of health care. It should help: a) to promote health and prevent disease; b) to deepen our understanding of the causes of disease and to develop new forms of treatment; c) to save life, cure illness or slow the progress of disease; d) to relieve suffering and disability; and e) to cure people when they are sick, and disabled or elderly.

3.2.2 Good of the Humanity

Genetics is not only for theoretical knowledge but also for the good of the individual, community and for the common good.³³ All have access to genetic knowledge; it should not be restricted to the hands of a few. All should be beneficiary of it.

3.2.3 Body and Soul

J. Keenan makes an application of body and soul in genetic research. For him,

ethical approach to genetic research has to find a middle way between reductionism on the one hand, where the human spirit is dissolved into the human genome without remainder and is totally explained in genetic terms, and dualism on the other hand, where body and soul are viewed as two separate and distinct entities, and the soul can treat the body purely as an instrument to be manipulated and disposed of as it sees fit.³⁴

³²Peter Vardy, *Being Human: Fulfilling our Genetic and Spiritual Potential*, London: DLT, 2003, 71.

³³Kevin D. O'Rourke and Philip Boyle, *Medical Ethics: Sources of Catholic Teachings*, 128.

³⁴J. Keena, "Genetic Research and the Elusive Body," in L.S. Cahill and M.A. Farley, ed., *Embodiment, Morality, and Medicine, Theology and Medicine 6*, Boston: Kluwer

According to Pope John Paul II, when one makes the genetic test in the body, "one touches the person itself."³⁵

3.2.4. Human Dignity and Moral Norms

Basing on human dignity and moral norms, Pope John Paul II argues that "all scientific and technical progress whatever must therefore keep the greatest respect for moral values, which constitute a safeguard of the dignity of the human person."³⁶ Besides, Pope Pius XII points out that research in genetic medicines should go in line with moral law. He argues, "among the methods contrary to morality, there must be included racism... and eugenic sterilization. Our predecessor, Pius XI, and we ourselves were obliged to declare as contrary to the natural law..."³⁷ Genetic interventions must not infringe on the origin of human life. Genetic interventions must, consequently, respect the fundamental dignity of human being and the common biological nature which is at the base of liberty, avoiding manipulations that tend to modify genetic inheritance and to create groups of different men at the risk of causing new cases of marginalization in society. The fundamental attitudes that inspire the interventions should not flow from a racist and materialist mentality aimed at a human well-being that is, in reality, reductionist. The dignity of human being transcends his/her biological condition.³⁸ Besides, research in genetics does not jeopardize the personality and the identity of the person.

3.2.5. Genetic Testing and Screening

At present, genetic centres offer many tests for commonly inherited disorders such as cystic fibrosis, Huntington's diseases, Duchenne muscular dystrophy, susceptibility to some types of breast cancer, and various types of degeneration of the brainstem, spinal cord and peripheral nerves. Genetic tests can take place at different stages of the human being such as before birth, before the embryo is implanted, and after birth, including before a person get married or

Academic Publishers, 1995, esp. 59, 62-63, 68-69 as quoted in Jack Mahoney, "Christian Doctrines, Ethical Issues, and Human Genetics," *Theological Studies* 64 (2003) 735.

³⁵John Paul II, "The Ethics of Genetic Manipulation," in Kevin D. O'Rourke and Philip Boyle, *Medical Ethics: Sources of Catholic Teachings*, St. Louis, The Catholic Health Association of United States, 1989, 130.

³⁶John Paul II, "The Ethics of Genetic Manipulation," 131.

³⁷Kevin D. O'Rourke and Philip Boyle, *Medical Ethics: Sources of Catholic Teachings*, 129.

³⁸John Paul II, "Dangers of Genetic Manipulation," 131.

conceives a child.³⁹ The consequence of these genetic tests includes the termination of human zygote, embryo and human foetus. Since life is a gift of God, religions do not support abortion. The National Council of Churches of Christ in the U.S.A. made a policy in 1986 on genetics, which reads as follows: "We cannot agree with those who assert that scientific inquiry and research should acknowledge no limits. All that can be known need not be known if in advance it clearly appears that the process for gaining such knowledge violates the sanctity of human life."⁴⁰

3.2. 6. Genetic Therapy

Gene therapy uses the recombinant DNA technology to cure illness involving missing or defective genes. Gene therapy can be targeted at somatic (body) and germ (egg/sperm) cells. In somatic gene therapy the recipient's genome is changed, but the change is not passed along to the next generation. In germ line therapy, the goal is to pass the change on to the offspring. Many scientists are interested in the area of gene therapy.

Gene therapy directed at the correction or amelioration of a disorder is acceptable to the Catholic Church, provided it promotes the personal well being of the individual being treated. Somatic gene therapy is commonly accepted in principle for proportionate reason. Pope John Paul II describes that "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, provided it is directed to the true promotion of the personal well-being of man and does not infringe on his integrity or worsen his conditions of life. Such an intervention, indeed, would fall within the logic of the Christian moral tradition."⁴¹

Germ-line interventions are of dubious moral probity. To be morally acceptable germ-line intervention should include due respect for the psychological nature of each individual human being. In addition, no harm should be inflicted on the process of human generation, and its fundamental design should not be altered, nor

³⁹Paul Flaman, *Genetic Engineering*, New York: Paulist Press, 2002, 34.

⁴⁰National Council of Churches of Christ in the U.S.A., *Genetic Science for Human Benefit*, New York: Office of Research and Evaluation, adopted by the Governing Board, 22 May 1986, 15.

⁴¹John Paul II, "The Ethics of Genetic Manipulation," As quoted in Paul Flaman, *Genetic Engineering*, 62.

should any new species be created.⁴² Arguments against human germ-line therapy state that,

the risks involved concern not only the individual treated but also his/her offspring... the price to be paid for any mishaps would be high, since these would be hereditary and transmitted from one generation to the next. Furthermore, germ-line therapy means treating or subjecting future generation to today's techniques, techniques that may seem crude and simple by tomorrow's standards.⁴³

Moreover, the Vatican's Pontifical Academy for Life clarifies that "germ-line gene therapy... is ethically unacceptable because it involves a high-risk technique used on embryos, usually coupled with in vitro fertilization. It also poses a long term risk to future generations."⁴⁴

3.2. 7 Genetic Design and Enhancement

Genetic design points out "deliberately designing a human being by choosing the genetic material he or she would have in the attempt to modify or produce certain desired traits. This could involve choosing for certain traits such as sex, tallness, skin colour, music ability, [language capacity, intelligence] and so forth."⁴⁵ In other words enhancement improves the quality of the people genetically. This can through "better looking, more artistic or more intelligent or athletic."⁴⁶ Genetic enhancement poses many ethical questions, namely, "what are desirable or superior human traits? Who should decide? To whom should we entrust authority to decide what is good gene and what is bad gene? Should we entrust this authority to scientists, corporations, governments, other groups of individuals and/or consumers?"⁴⁷ In this context, Agenta Sutton argues, personality is made up of intelligence, emotive, affective and other mental and spiritual characteristics working together and we are not allowed to make the change in the person.⁴⁸ Similarly Thomas Shannon explains that "the genetic enhancement debate is

⁴²GS 14, CCC 2275; Felix Podimattom, "Human Genome Project and Gene Therapy," *Indian Journal of Family Studies* 2/2 (2004) 18-43; Kris Dierickx, "Genetic Privacy and the Family," *Indian Journal of Family Studies* 2/2 (2004) 68-80.

⁴³Paul Flaman, *Genetic Engineering*, 63.

⁴⁴As quoted in Paul Flaman, *Genetic Engineering*, 66.

⁴⁵Paul Flaman, *Genetic Engineering*, 67.

⁴⁶Paul Flaman, *Genetic Engineering*, 67.

⁴⁷Paul Flaman, *Genetic Engineering*, 71.

⁴⁸As quoted in Paul Flaman, *Genetic Engineering*, 70.

characterized by an unacknowledged genetic determination, which assumes that all behaviours, no matter how complex, are caused by genes. This neglects the role of environment in developing our characteristics."⁴⁹ Moreover, the Vatican's Congregation for the Doctrine of Faith observes,

certain attempts to influence chromosomal 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. Therefore, in no way can they be justified on the grounds of possible beneficial consequences for future humanity. Every person must be respected for himself: in this consists the dignity and right of every human being from his or her beginning.⁵⁰

Besides, U. Beck explains that,

gene technology pits humankind into an almost godlike position, in which it is able to create new materials and living creatures and revolutionises the biological and cultural foundations of the family. This generalization of the principle of design and constructability, which now encompasses even the subject whom it was once supposed to serve, exponentiates the risks and politicises the places, conditions, and means of their origin and interpretation.⁵¹

3.2.8. Genetic Code

Today it is possible to read the genetic code of every one so that we can read the nature and the characteristics of the human being. Many religious communities comment that there is the possibility of "potential misuses of genetic data to discriminate against persons with genetic predispositions."⁵² Research must never assume that a person is wholly reducible to or determined by his or her genes. According to Pope John Paul II, "genetic manipulation becomes arbitrary and unjust when it reduces life to an object."⁵³

⁴⁹As quoted in Paul Flaman, *Genetic Engineering*, 71.

⁵⁰Congregation for the Doctrine of Faith, *Donum Vitae*, Rome: 1987, I, 6.

⁵¹U. Beck, *Risk Society: Towards a New Modernity*, London: Sage, 1992, 200 as quoted in "Celia Deane-Drummond, Fabricated Humans? Human Genetics, Ethics and the Christian Wisdom Tradition," *Dialog: A Journal of Theology* 44/4 (2005) 368.

⁵²Audrey R. Chapman, "Genetic Engineering and Theology: Exploring the Interconnections," 74.

⁵³John Paul II, "The Ethics of Genetic Manipulation," in Kevin D. O'Rourke and Philip Boyle, ed., *Medical Ethics: Sources of Catholic Teachings*, 130.

3.2.9. Genetic Manipulation

There are many genetic manipulations namely, making embryos, hybrids, putting human genes into the nonhuman organism to make new forms of life, and eugenics, etc. As K. Rahner writes: "genetic manipulation does two things: it fundamentally separates the marital union from the procreation of a new person as this permanent embodiment of the unity of married love; and it transfers procreation, isolated and torn from its human matrix, to an area outside man's sphere of intimacy." Research in genetics must go inline with the nature of human being.⁵⁴ In addition, Bernard Häring comments that "any attempt to identify criteria for improving the human genetic inheritance can refer only to interventions that respect the dignity of the human person."⁵⁵ In the opinion of Pope John Paul II, "genetic manipulation treats the human subject in terms of criteria not founded on the integral reality of the human person."⁵⁶

Conclusion

It was our attempt to make an ethical appraisal of the research in genetic medicines. Everything in genetic medicine is justified by liberalism, utilitarianism, relativism, scientific positivism and scientific materialism, where the dignity of person is not considered in the research. If we do not have an ethical approach based on just laws, faith and virtues, genetic manipulations will continue and the consequence would be a specially designed group in the society. Consequently, medical genetics becomes a curse for the human being. In our opinion genetic medicine should treat a human being as a person from the moment of conception to natural death so that we can protect the dignity of the human being. Therefore, on this basis, genetic medicine is a blessing.

⁵⁴Cf. K. Rahner, "The Problem of Genetic Manipulation," in *Theological Investigations* 9, New York: Herder & Herder, 1972, 246 as quoted in Jack Mahoney, "Christian Doctrines, Ethical Issues, and Human Genetics," *Theological Studies* 64 (2003) 732.

⁵⁵Cf. Bernard Häring, *Ethics of Manipulation: Issues in Medicine, Behavior, and Genetics*, New York: Seabury, 1975, 187-88 as quoted in Jack Mahoney, "Christian Doctrines, Ethical Issues, and Human Genetics," *Theological Studies* 64 (2003) 732.

⁵⁶John Paul II, "The Ethics of Genetic Manipulation," 131.