Committee: Special Conference on Global Reform and Ethics

Issue: Ethics in the field of medicine and genetics

Student Officer: Sweder Steensma

Position: Deputy President

INTRODUCTION

We live in a world where we are capable of a lot due to the amazing scientific developments of the last centuries. Nowadays, we are able to prevent hereditary diseases, manipulate genes, terminate unwanted pregnancies and intentionally end someone's life in order to relieve pain and suffering. There is no wonder, however, that ethical issues in medical genetics have accompanied these developments.

The Human Genome Project (HGP), the international collaborative research program whose goal is the complete mapping and understanding of all the genes of human beings, has made genetic information accessible. The HGP is therefore the main driver of advances in genomics, a large-scale approach of DNA sequencing and analysis that continues to have an enormous impact on biomedical research nowadays. According to the HGP, all adults have the right to know their genetic makeup as it can determine the health of their offspring.

The HGP has undoubtedly improved human health standards, but its achievements have also raised public concerns on the issue of genetics. At the moment, the debate focuses on questions such as, 'Who controls the available genetic information?', 'How is the privacy of genetic information in possession of institutional third parties guaranteed?', 'What health risks, if any, are associated with genetic modification?', 'Should restrictions be placed on genetic techniques?', and 'Will these interventions redefine what it means to be "normal"?'

It is time, therefore, to discuss, through international cooperation, the issues in medical genetics by setting up generally accepted guidelines on complex ethical issues regarding genetic services, in order to diminish the concerns and protect people with genetic disabilities as well as their families. The issues in the field of medicine and genetics can be identified within four large fields: (1) research and its application to all forms of life; (2) allocation and delivery of health care resources; (3) ethical problems that arise in clinical

encounters between health care professionals and patients; (4) ethical problems around the preventive use of medicines (WHO, 2003).

Within the next decade, carrier screening and screening for common disorders are likely to further increase the role of genetics within primary health care. It is becoming ever more likely that we will be able to genetically modify human beings. In April this year, Chinese scientists successfully edited for the first time the DNA of non-viable human embryos. This practice is banned in Europe, because scientists and religious groups have expressed fierce criticism regarding the practice of genetic engineering on human beings.

Ethics in the field of medicine and genetics is important because health care professionals enjoy certain rights and privileges that others do not. For instance, they are the ones to decide on whether or not a patient should be operated on, or whether survival should no longer be sustained in cases of chronic, incurable conditions. Moreover, they are entitled to prescribe powerful drugs and chemicals that might be harmful if improperly administered. They are the ones who decide about the use of high sums of money as well as of available resources and about whether the information given to them by patients will be kept private, and, if not, how and with whom it will be shared. These questions are really important because they deal with human health, life and death. The goal of medical ethics is to develop universal ethical norms for the practice of medicine. Therefore, the concerns of medical ethics are among the most important ones in human life.

Note: The following study guide will primarily focus on the issue of genetic engineering and questions that arise from gene manipulation regarding ethics in medicine practice, as it is a major topic in the field and most attention should be drawn to this. Nonetheless, there are numerous other phenomena that can be related to the issue, for example cloning, birth control, abortion and euthanasia, which raise serious ethical dilemmas and have severe implications on the society, individuals and medicine. The Committee is free to decide to what extent it will focus its attention on those aspects.

DEFINITION OF KEY TERMS

Ethics

Ethics refers to well-founded standards of right and wrong that describe what humans ought to do, usually in terms of rights, obligations, and benefits to society, fairness, or specific virtues. It's a system of moral principles that has a great influence on how people make decisions and lead their lives. Ethical standards include standards relating to rights, such as the right to life, the right to freedom from injury, and the right to privacy. Biomedical ethics (or bioethics) is an interdisciplinary field for the systematic study of ethical issues that arise in research, medicine and society (WHO 1992a; UNESCO, 1993).

Genes

A gene is the basic physical and functional unit of heredity. Genes, which are made up of DNA, act as instructions to make molecules such as proteins. Proteins are the workhorses of the cells in the human body. Therefore, genes contribute to each person's unique physical features (WHO, 2005). Let us take the following example to illustrate the importance of proteins and thus of genes. The protein haemoglobin (HB), which may sound familiar if you are a blood donor, is located in the red blood cells and allows for the transportation of oxygen through our body. If we are poor in 'HB' we speak of anaemia and we often feel fatigued due to the lack of oxygen.

Genetic Engineering

Genetic engineering is the process of adding new DNA to an organism using biotechnology in order to add distinguished qualities or characteristics that are yet not found in the organism and eliminate the chances of any inherited diseases (UNL's AgBiosafety for Educators, Web). Genetic engineering could be used to change physical appearance, metabolism, and even improve physical capabilities and mental faculties such as memory and intelligence.

Medical Genetics

Medical Genetics is the specialty of medicine that involves the diagnosis and management of hereditary disorders. Medical genetics differs from human genetics in that human genetics is a field of scientific research that may or may not apply to medicine, but medical genetics refers to the application of genetics to medical care (Epstein, 2006).

Eugenics

Eugenics is a set of beliefs and practices that aims at improving the genetic quality of the human population by controlled breeding to increase the occurrence of wanted heritable characteristics (WHO, 2003). Sir Francis Galton largely developed eugenics as a method of improving the human race.

Cloning

The biotechnological processes of producing copies of a DNA fragment (molecular cloning), cells (cell cloning) and or complete organisms. While cloning can be used for various reasons, an important implication in the field of medicine is the cloning of sole organs or stem cells, used for therapeutic purposes (the so-called 'therapeutic cloning').

Birth Control and Abortion

Birth control (or contraception) refers to the methods of preventing pregnancy, while abortion refers to methods of terminating pregnancy. Whether contraception and/or abortion are considered ethical, or even legal, varies from country to country and depends on social, religious and moral norms.

Euthanasia

The term refers to the act of deliberately terminating a patient's life, if they are in extreme pain and/or very serious health condition. Again its morality and legality vary in different countries of world.

BACKGROUND INFORMATION

Importance of Genetics

Genetic research will help us reduce the number of hereditary conditions that are affecting millions of families worldwide. Genetic research is important because it generates knowledge to improve the health of the individual and the community. In addition, it reveals information about an individual's susceptibility to hereditary diseases and hence plays a role in the determination of the individual's future health. Such information may be of interest and benefit to research participants, especially if preventive strategies exist.

The importance of genetic research for a complex disease like Alzheimer becomes more apparent when you look at a complex problem experienced in everyday life, such as the problem of traffic congestion. Genetic research only examines the genes in our body,

which are the blueprints of our proteins. The traffic problem can be analysed by looking at blueprints in two areas. One area that has many congestions and another that has none. In Alzheimer's genetic research, exactly the same happens: the genes of both people with the disease and people without the disease are analysed.

If one notices that the blueprints for asphalt and/or traffic signs in the congestion area differ from those in the area without congestions then one can conclude that the quality of asphalt and/or traffic signs is the cause – or one of the causes – of the high amount of traffic jams. Once the cause is identified, the asphalt and/or the traffic signs will be improved in order to stop the traffic congestions. Scientists do the same when they examine the blueprints of people with and without Alzheimer. First they analyse their DNA and afterwards they search for differences in their blueprints (genes). When a blueprint from people with Alzheimer repeatedly deviates, it is very probable that this abnormality is somehow involved in the disease. Due to genetic research, genes that cause these abnormalities can be detected, and genetic engineering makes it possible to manipulate the genes involved in the disease. In this way, Alzheimer's disease and other hereditary disorders can be prevented because of genetic research and engineering.

Hereditary disorders harm millions of people throughout the world. About 5% of all pregnancies result in the birth of a child with a significant genetic disorder, congenital malformation or disability (WHO, 2003). Scientists believe that your genes and chromosomes cause 43% cases of severe intellectual disability (IQ<50). In More Economically Developed Countries (MEDCs), hereditary conditions account for about 36% to 53% of perinatal and infant hospital admissions (Institute of Medicine, 1994). In developing nations, hereditary conditions account for about 15% to 25% of perinatal and infant mortality (Verma and Singh, 1989). Most non-infectious diseases, which are the major cause of death in developed nations, are highly likely to have a genetic component (Holtzman, 1989).

Although many individuals affected by hereditary conditions live happy lives and do not experience any form of pain or suffering, many families are profoundly affected by genetic conditions, despite improved treatment, education and support services.

There is also substantial cost to society for non-institutional, outpatient, educational, medical and social services, as well as lost economic output from family members who care for persons with genetic disorders (WHO 2003), since having children with a hereditary disorder has a particularly high cost because parents can rarely rely upon

subsidized health care or insurance to pay for often expensive therapies. Therefore, continued efforts to develop effective treatments and make them available worldwide are important to the public health.

Ethical Principles in Medical Genetics

A common framework used in the analysis of medical ethics is the "four principles" approach proposed by Tom Beauchamp and James Childress in their textbook *Principles of biomedical ethics* (2001). The book recognizes four basic ethical principles, which are to be judged and weighed against each other, with attention given to the scope of their application (Table 1).

Table 1. General principles of medical ethics
Autonomy
Beneficence
Non-maleficence
Justice

The principle of autonomy ensures that a patient is able to make an autonomous choice after genetic information is given and that the confidentiality and privacy of the information is in compliance with the patient's wishes, as well as in accordance with national and international laws. Patients have the right to refuse or choose their treatment (*voluntas aegroti suprema lex*). This principle states that there has to be freedom of choice in all matters relevant to genetics and, furthermore, that compulsion by government, society or health professionals has to be prevented. According to this principle, people who are not able to make an independent decision, for example, young children, people with mental impairments and people in a coma, who therefore have a diminished autonomy, should be protected.

The principle of beneficence states that gathering genetic information should always, directly or indirectly, have the aim to provide a benefit to an individual or the community as a whole (*salus aegroti suprema lex*). This may vary from families, to individual patients, to humankind. Improving the public or individual health with cooperation of people from the society involved is a key medical goal. However, uncertainty surrounds the precise definition of which practices do in fact help patients and which practices do not.

The principle of non-maleficence is embodied by the fundamental principle of medical practice: “first, do no harm!” (*primum non nocere*). This means that, being a physician, it is more important not to harm your patient, than to do him/her good. Humans have the duty to avoid harm, or, if it cannot be prevented, to minimize harm to individuals, families and society. It is also important that physicians know how likely it is that their treatment will harm their patient.

According to the principle of justice, the use of genetic and medical data, and the conduct of genetic and medical investigation must be guided by the conviction that people should be treated equally (*iustitia*). Furthermore, the benefits (e.g. treatment) and the burdens (e.g. costs of expensive care and research) of health care should be distributed in society as fairly as possible.

It is highly possible that a conflict arises between autonomy and beneficence when patients disagree with the opinions of healthcare professionals. In other societies, physicians react differently when the patient’s interests conflict with his/her beneficence. In the West, the autonomous choice of a mentally competent patient is generally the most important, even in cases where the medical team believes that the patient does not act in his / her own interest. By contrast, many other cultures prioritize beneficence over autonomy. Examples include when a patient does not want a treatment because of religious or cultural views.

Furthermore, all physicians are bound by the oath of Hippocrates. The major promises relevant to genetics that a doctor makes, when he/she is sworn in modern version of the oath (written in 1964 by Louis Lasagna, Academic Dean of the School of Medicine at Tufts University, and used in many medical schools today), are the following: “I will apply, for the benefit of the sick, all measures which are required”, “I will respect the privacy of my patients, for their problems are not disclosed to me that the world may know”, “I will prevent disease whenever I can, for prevention is preferable to cure” and “I will remember that I do not treat a fever chart, a cancerous growth, but a sick human being, whose illness may affect the person's family and economic stability”. The Hippocratic Oath also states that confidentiality has to be applied to conversations between physicians and patients. This concept is also known as the patient-physician privilege. Legal protections prevent physicians from revealing their discussions with patients, even under oath in court. Traditionally, medical ethics has viewed the duty of confidentiality as non-negotiable. In recent times, multiple critics have argued for a more nuanced approach to the duty that acknowledges the need for flexibility in some cases. The intentional crash of the Airbus A320 in the French Alps in March this year, which was committed by co-pilot Andreas Lubiz en

route from Dusseldorf to Barcelona, has further fired up the debate about the patient-physician privilege.

Currently, there is no direct penalty for breaking the Hippocratic Oath, however, judging from incidents in the past, it can be argued that the malpractice carries a wide range of penalties from legal action to civil penalties.

Genetic engineering on humans

Ethical principles regarding genetic engineering focus on the following beliefs: every foetus has a right to remain genetically unmodified, parents hold those rights, and every child has the right to be born without a preventable disease. For adults, genetic engineering could be seen as a technique to add one or more distinguished qualities or characteristics. There are theorists who claim that moral considerations limit genetic engineering, but they do not ban it entirely.

There are various views on genetic engineering on humans. Some argue for a complete ban, others for provision for everybody, whereas others for professional self-regulation. The American Medical Association's Council on Ethical and Judicial Affairs stated that "genetic interventions to enhance traits should be considered permissible only in severely restricted situations: (1) clear and meaningful benefits to the foetus or child; (2) no trade-off with other characteristics or traits; and (3) equal access to the genetic technology, irrespective of income or other socioeconomic characteristics" (AMA Council, 1994).

Since 1990 the science of biotechnology has been against attempts to change people with new instruments that came available because of the continuous development of technology. Within the last decades concerns have been raised in the public about the possible use of genetic information especially by insurance companies and employers, in a manner perceived as discriminatory or exploitive and harmful to less fortunate members of society who may be at a higher risk for certain diseases. With the advent of new techniques like CRISPR, in March 2015, scientists urged a worldwide ban on clinical use of gene editing technology. That is why the Western world was shocked when Chinese scientists edited the DNA of non-viable human embryos using CRISPR in April 2015, a fact that has led to sparking controversy.

MAJOR COUNTRIES AND ORGANIZATIONS INVOLVED

China

China actively supports and encourages biotechnology and genomics-related industries. In 1998 the Ministry of Science & Technology established both Chinese National Human Genome Centres (CNHGC) in Shanghai and Beijing as the national-level genome research centres to specialize in genome sequencing and analysis. Therefore, China has played a significant role in the sequencing by characterizing 1% of the human genome.

In addition, China has developed advanced ways to collect and analyse complex genetic codes to support further genome-sequencing research.

China supports collaboration with foreign researchers, but recognizes the need to protect Chinese genetic resources from exploitation and bio piracy (WHO, 2005). China is keen to ensure that some of the benefits of international genetic research, based on Chinese genetic samples, flow back to the Chinese society. The director of the Chinese Division of Health Technology has stated that all cooperative international projects based in China and working with Chinese genetic resources should follow the principles of equality, mutual benefit and joint participation.

Multi-denominational Arab Societies

In states where Islam is predominant, bioethics is practiced in a context different from that of the West. These states have not experienced the process of secularization that had a great impact on the West for centuries. Many of the Arab states have a homogeneous view with regard to their beliefs and are less inclined to legislate in a profile with which they are unfamiliar and where universal values conflict with the values of their different religious communities. Despite this, in 2005, almost all Arab states approved the universal values of bioethics and human rights proclaimed in the UNESCO Universal Declaration on Bioethics and Human Rights. The majority of the Arab population is not comfortable with the bioethics in the West and want bioethical principles to conform to Islamic convictions. Muslim authors underline often that ethics needs to be compatible with religion. According to these authors raising the question of Islamic anthropology, which is entirely defined by man's relationship with God, it is necessary to present the fundamental principles of ethics in Arab societies.

It is important to bear in mind that this conviction is shared by the three "religions of the book" (Islam, Judaism and Christianity) in the region, although each may interpreted the human's autonomy and the basis of his/her dignity in its own way.

Hence, in the region, bioethical thought is often expressed at the level of religious dignitaries. Indeed, the First International Conference of Medicine (held in Kuwait in 1981) ended with the publication of the "Islamic Code of Medical Ethics". Furthermore, the first Congress of Islamic Sciences (held in Cairo in 1985) and the positions upheld afterwards at the annual sessions of the Councils of the Fiqh Academy, as well as numerous fatwas (a ruling on a point of Islamic law given by a recognized authority) issues by religions Islamic authorities (UNESCO, 2011), fully support the above.

World Health Organisation (WHO)

The World Health Organisation believes that genetic engineering can ensure that the health of individuals, families and entire communities can greatly improve. Therefore, governments should encourage research in the field of genetics. In addition, it is very important that there is an international collaboration, allowing data to be shared and the technique is still to develop.

Although genetics can provide an enormous improvement of human health, it is extremely important that ethical issues are properly analysed. Genetic engineering must fit within the four fundamental ethical values (autonomy, beneficence, non-maleficence and justice) and strict control is necessary in order to achieve that. Furthermore, it is of great importance that genetics never results in the detriment of the privacy of people.

TIMELINE OF EVENTS

Date	Description of Event
July 1990	*"Genetics, Ethics, and Human Values: Human Genome Mapping, Genetic Screening, and Therapy"*, organized by the Council for International Organizations of Medical Sciences (CIOMS) in Tokyo and in Inuyama City, Japan.
October 1990	Start of The Human Genome Project
September 2001	UNESCO-organized debate about "*The New Aspects of Racism in the Era of Globalization and the Gene Revolution"*, at the World Conference Against Racism and Xenophobia in Durban, South Africa.
April 2003	Completion of The Human Genome Project.

October 2003	UNESCO's International Declaration on Human Genetic Data. This Declaration covers various practical issues, such as but not limited to privacy (Article 7) and circulation and international cooperation (Article 19)
October 2005	UNESCO's Universal Declaration on Bioethics and Human Rights. This Declaration addresses ethical issues related to medicine, life sciences, and associated technologies as applied to human beings, taking into account their social, legal, and environmental dimensions.

UN INVOLVEMENT: RELEVANT RESOLUTIONS, TREATIES AND EVENTS

Concerning treaties, resolutions, and other UN documents, there is rather little pertaining to the issue of ethics in the field of medicine and genetics. The following international documents, though, are the most relevant:

- Declaration on the Human Genome and Human Rights, 11 November 1997, **27 C/5.1**
- The human genome and human rights, 10 March 1999, **A/RES/53/152**
- Genetic privacy and non-discrimination, 21 July 2004, **ECOSOC Resolution 2004/9**

PREVIOUS ATTEMPTS TO SOLVE THE ISSUE

The Council of Europe emphasizes the importance of the rule of law and the observance of human rights in Europe. The Council of Europe adopted the European Convention on Human Rights and Biomedicine (1997) to setup a uniform code for its 47 member-states. The Convention brings international human rights law and medical ethics together. It provides special protection of physical integrity for those who are unable to consent, which includes children (Yim, 2013). The Convention states the following. "Predictive genetic tests may be performed only for health purposes or for scientific research linked to health purposes and are subject to appropriate genetic counselling". "Interventions on the human genome may only be undertaken for preventive, diagnostic, or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants".

Several UNESCO declarations underline the content of the European Convention on Human Rights and Biomedicine.

The Universal Declaration on Bioethics and Human Rights (October 2005, UNESCO) was the first time in the history of bioethics that member states, as part of the international community, had to respect and apply the fundamental principles of bioethics set forth within a single text consisting of 28 articles. The following articles are the most relevant to genetics and genomics (Yim and Yeung, 2013). Article 17 encourages to improve biological and genetic research and to make it easily accessible in order to protect the biosphere, environment and biodiversity in the world. Article 21 states that appropriate measures, both on national and international levels, should be taken to combat illegal trade in bioterrorism and illicit traffic in genetic resources and other genetic-related materials.

POSSIBLE SOLUTIONS

Ethics Committees

The setup of ethics committees is important for ethics in the field of medicine and genetics. Simple communication is not enough to resolve an ethical conflict. Therefore, a hospital must convene the ethics committee to come up with a solution for the issue. These bodies are primarily made up of health professionals, but also include philosophers, laity and clergy. Indeed, in many parts of the world, their presence is required to provide the balance considered. There is much discussion about the best structure of an ethics committee. Questions that arise are: 'what should the balance between health professionals and lawyers or philosophers be?' and 'should there be clergies in the committee?'

Education

Education about genetics for the public, medical and other health professionals, teachers, clergy and other people ordained for religious duties, is important for the beneficence of individuals, families and communities. The goals of medical genetics can only be achieved in the context of an educated public. It is important that individuals and families are active participants of genetic services and therefore it is necessary that they be educated in the basic principles of genetics. Genetics education for the public can be achieved through education in schools, for example. It is of great importance that health professionals pay special attention to the four general principles of health care ethics (autonomy, beneficence,

non-maleficence and justice) in parts of the world where they are unfamiliar or infrequently used.

Universal ethical principles

In establishing universal ethical principles, a discussion between stakeholders, health care providers, health-insurance companies, health care companies, ethicists, philosophers, the government, and non-governmental organisations, such as the World Health Organisation or UNESCO, is necessary. They are jointly responsible for reaching consensus on what uses of medical data will lead to individual and societal benefits, and what uses will have a negative impact on the public health. Such consensus will define best practice principles, result in high ethical standards and will help to take away the concerns about possible misuse of genetic data.

BIBLIOGRAPHY

AMA Council on Ethical and Judicial Affairs, Report on Ethical Issues Related to Prenatal Genetic Tests[dead link], 3 Archives Fam. Med. 633, 637–39 (1994).

Epstein, Charles J. "Medical Genetics in the Genomic Medicine of the 21st Century." American Journal of Human Genetics. The American Society of Human Genetics, n.d. Web. 13 July 2015. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1559539/.>

Holtzman NA. 1989. Proceed with Caution: Genetic Testing in the Recombinant DNA Era. Baltimore, Johns Hopkins University Press.

Institute of Medicine, 1994. Committee on Assessing Genetic Risks. Assessing Genetic Risks: Implications for Health and Social Policy. Edited by Andrews LB, Fullarton JE, Holtzman NA, and Motulsky AG. Washington, DC, National Academy Press.

UNESCO, 1993. Report by N. Lenoir to the Director-General of UNESCO on the Human Genome. SHS-93/Conf.015/3, Paris, 2 August 1993.

UNESCO, 1994. Report of Mapping Bioethics Regulations in 17 States in the Arab Region. Ethics and Law in Biomedicine and Genetics: An Overview of National Regulations in the Arab States. Cairo: United Nations Educational, Scientific, and Cultural Organization, Cairo Office, pp. 3-8.

UNL's AgBiosafety for Educators. What Is Genetic Engineering and How Does It Work? University of Nebraska-Lincoln, n.d. Web. 1 July 2015. <http://agbiosafety.unl.edu/basic_genetics.shtml.>

Verma IC and Singh B. 1989. Ethics and Medical Genetics in India. In: Wertz DC and Fletcher JC (eds) Ethics and Human Genetics: A Cross-Cultural Perspective. Berlin, Springer-Verlag, pp. 250-270.

WHO, 2003. Review of Ethics in Medical Genetics. Consulted by Professors Wertz, D. C., J. C. Fletcher, and K. Berg. Review of Ethics in Medical Genetics. Rep. Geneva: WHO.

WHO, 2005. Genetics, Genomics and the Patenting of DNA. Human Genetics Programme Chronic Diseases and Health Promotion World Health Organization. Geneva: WHO.

Yim, Seon-Hee, and Yeun-Jun Chung. Genomics & Informatics. Publication. US National Library of Medicine National Institutes of Health, n.d. Web. 13 July 2015. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3897849/. >