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Introduction

Justice and equality are two founding principles of universal human rights. Any attempt to infringe these principles is considered as an infringement of human dignity.

The equality principle implies the duty of equal treatment of any individual or group irrespectively of their particular characteristics. Based on the uniqueness of every human being and the duty of respect for human diversity, the nondiscrimination principle aims to ensure that no criteria or situation produce effects, which systematically disadvantage persons or groups possessing those characteristics or living under those situations. Historically speaking, slavery and all kinds of racism and xenophobia demonstrated dramatically the possible harms of discrimination.

Thus, the principle of nondiscrimination has been introduced from the very beginning of international attempts to institutionalize the human rights philosophy at a universal scale.

Obviously, as bioethics is an extension of human rights philosophy to the field of medicine, life sciences, and associated technologies, the nondiscrimination and nonstigmatization principles have been affirmed and considered as guiding principles in all discussions, documents, and legislations.

UNESCO has called on the nondiscrimination and nonstigmatization principle in almost all documents related to bioethics including the Universal Declaration on Bioethics and Human Rights (UDBHR) adopted in 2005.

Article 11 of the UDBHR states: “No individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms.”

This article addresses two issues: discrimination and stigmatization. Both deal with infringement of the equality principle and are considered as violations of human dignity, human rights, and fundamental freedom.

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The application of this article either in research or healthcare practice will have to deal with a major difficulty related to the fundamental problem of identifying precisely what is to be considered as discrimination. Some practices can be perceived differently from one context and culture to another. Thus, this article in the UDBHR is closely related to Article 12 on respect for cultural diversity, and the main concern is to identify ethical limits so that this article could not be invoked to justify any discrimination and stigmatization of persons or groups.

Finally, in each of these contexts, it is important to identify the relationship between Article 11 and others in the declaration.

Some Definitions

Discrimination

The word “discrimination” comes from the Latin “discriminare” which means to “distinguish between.”

To discriminate socially is to make a distinction between people on the basis of class or category or individual character without regard to individual merit, which is an infringement of the ethical theory of egalitarianism based on social equality.

Distinction between people based on individual merit (such as personal achievement, skill, or ability) is generally not considered socially discriminatory.

In contrary, distinctions between people based on race, social class or caste, nationality, ethnicity, religion, sex, sexual orientation, height, age, social conditions, physical or mental disability, diseases or genetic characteristics, or any other ground are generally considered in the whole corpus of human rights law as discriminatory and as a violation of human dignity, human rights, and fundamental freedoms.

Nondiscrimination

The concept of nondiscrimination is a social as well as a legal concept of long standing within human rights law. It requires the equal treatment of an individual or group irrespective of their particular characteristics. It is used to define and legally prohibit any criteria that may produce effects which systematically disadvantage persons possessing those characteristics.

The general aim of this principle is that in any decision or practice, no one shall be subjected to discrimination based on any grounds, including physical, mental, or social conditions, diseases or genetic characteristics, nor shall such conditions or characteristics be invoked or used to stigmatize an individual, a family, or a group.

Positive or Reverse Discrimination

There are several examples of discriminatory policies or acts that benefit a historically and sociopolitically nondominant group (typically women and minorities but sometimes majorities), at the expense of a historically and sociopolitically dominant group (typically men and majority races). Originally called “positive or reverse discrimination,” international bodies are now used to call it “affirmative action policies.” Such actions can be in any field to facilitate the access of vulnerable people to their rights including those related to health.

However, whether a given example of discrimination is positive or negative is often a subjective judgment.

Stigmatization

The word “stigmatization” is related to the word “stigma.” Among other definitions (Rivard, 2009), stigmatization is defined by the Oxford English Dictionary Online as a “distinguishing mark or characteristic (of bad or objectionable kind).” The verb “to stigmatize” is defined as to “call by a disgraceful or a reproachful name; to characterize by a term implying severe censure or condemnation.”

The concept of “stigmatization” is a social rather than a legal concept.

According to the *Encyclopedia Britannica*, “stigmatization” is a discrediting process which strikes an individual who is considered as “abnormal” or “deviant.” He or she is reduced to this single characteristic in other people’s eyes or opinions for whom this “label” justifies a range of social discriminations and even exclusion. The social impact of stigmatization shows a number of negative behaviors toward stigmatized people that can end in real discrimination as regards, for example, access to social services such as healthcare and education, employment and professional advancement, income level, and domestic life.

In the field of health, the concept of stigmatization has been frequently used in the work of WHO, especially in relation to HIV and AIDS, but also in contexts like mental health, genetic characteristics, diseases, or any other situation where a single physical or biological or a health character may be looked at as “bad” with a range of social and even legal negative impacts.

In the field of bioethics, UNESCO recognizes stigmatization as a distinguished kind of discrimination that may have a serious impact on the right to health and benefit of scientific research. It refers to any characteristics that may interfere negatively with a person or a group and infringe his/her/their right to access and benefit from the progress of “medicine, life sciences and associated technologies.” In this perspective, stigmatization is a violation of human dignity, human rights, and fundamental freedom.

For some authors, the concept of stigmatization amounts to limited or indirect kind of discrimination but not as understood in international law (Rivard, 2009).

International Human Rights Instruments on Discrimination and Stigmatization

The *Universal Declaration of Human Rights* (1948) clearly stated the equality among humans by proclaiming in Article 1 that “All human beings are born free and equal in dignity and rights.” Equality is therefore the basic fundamental principle of human rights philosophy. The same declaration stated in Article 2 that “Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind,” thus starting the concept of nondiscrimination among humans in any issue.

Article 7 specifically addresses the issue of discrimination “All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to discrimination.”

The recognition of this principle was historically extended to all kind of domains and rights including socioeconomic and political rights. It is stated in many national constitution laws as well as in several regional and international instruments approved via intergovernmental organizations.

Many other conventions have further addressed discrimination in socioeconomic, political, and cultural rights, and others addressed issues of discrimination based on specific grounds: racial, sex and age. The *International Convention on the Elimination of All Forms of Racial Discrimination* of 21 December 1965 and the *Convention on the Elimination of All Forms of Discrimination against Women* of 18 December 1979 are the two major examples.

Without any attempt to create new human rights with new grounds of discrimination, or to duplicate the entirety of established international law, every specific instrument of bioethics has been embedded within this larger body of international human rights law.

Discrimination and Stigmatization in International Instruments on Bioethics

The twentieth century is sadly full of examples of harmful practices in the field of health and medical and scientific research based on several grounds of discrimination. The most famous drama occurred during the Holocaust and gave birth to the Nuremberg Code (1948) followed by several other professional, national, regional, or international instruments.

Within its mandate as defined by its constitution, UNESCO has been engaged in the ongoing global debates under the broad rubric of bioethics, beside a number of other international and regional organizations such as the World Health Organization, the World Intellectual Property Organization, the World Medical Association, and the Council of Europe. UNESCO aims mainly to provide guidance to member states for the elaboration of their laws and regulations.

UNESCO's work in the field of bioethics called on the established standard-setting corpus and other international human rights instruments adopted by the United Nations and specialized agencies of the United Nations system as well as the other international and regional instruments, international and national legislation, regulations, codes of conduct, guidelines, and other ethical texts in the field of science and technology.

The concept of stigmatization could appear as a label of the UNESCO input. It was added as a principle to the general body of international human rights law as UNESCO declarations in the field of bioethics were the first international instruments related to human rights to use this concept.

Nevertheless, UNESCO consider that "questions of bioethics, which necessarily have an international dimension, should be treated as a whole, drawing on the principles already stated in the Universal Declaration on the Human Genome and Human Rights and the International Declaration on Human Genetic Data and taking account not only of the current scientific context but also of future developments" (10th paragraph of the preamble of the UDBHR).

Nondiscrimination and Stigmatization in UNESCO Declarations

To date, UNESCO produced three declarations that dealt with bioethical issues:

1. The *Universal Declaration on the Human Genome and Human Rights* (UDHGHR) adopted by the General Conference of UNESCO in November 1997
2. The *International Declaration on Human Genetic Data* (IDHGD) adopted by the General Conference of UNESCO in October 2003
3. The *Universal Declaration on Bioethics and Human Rights* (UDBHR) adopted by the General Conference of UNESCO in October 2005

The preambles of the three declarations endorse the main related international, regional, and professional instruments of bioethics and human rights.

- *The UDHGHR* dealt with discrimination in Article 6: "No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity."

Article 2 makes a direct link between genetic data and the risks of discrimination by proclaiming that

"(a) Everyone has a right to respect for their dignity and for their rights regardless of their genetic characteristics.

(b) That dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity."

However, the UDHGHR did not call on the concept of stigmatization.

- *The IDHGD* dealt with the two concepts of discrimination and stigmatization in paragraph (a) of Article 7: "Every effort should be made to ensure that human genetic data and human proteomic data should not be used for purposes that discriminate in a way that is intended to infringe, or has the effect of infringing

human rights, fundamental freedoms or human dignity of an individual or for purposes that lead to the stigmatization of an individual, a family, a group or communities.”

The paragraph 6 of the preamble recognizes that genetic characters may clearly expose an individual or a group to discriminatory actions both in their general life and in the issues of health and life sciences. They also may be cause of stigmatization: “Human genetic data have a special status on account of their sensitive nature since they can be predictive of genetic predispositions concerning individuals and that the power of predictability can be stronger than assessed at the time of deriving the data; they may have a significant impact on the family, including offspring, extending over generations, and in some instances on the whole group; they may contain information the significance of which is not necessarily known at the time of the collection of biological samples; and they may have cultural significance for persons or groups.”

Thus, Article 3 on “person’s identity” states: “Each individual has a characteristic genetic make-up. Nevertheless, a person’s identity should not be reduced to genetic characteristics, since it involves complex educational, environmental and personal factors and emotional, social, spiritual and cultural bonds with others and implies a dimension of freedom.”

- *The UDBHR* went further to proclaim nondiscrimination and nonstigmatization as universal principles of bioethics and human rights in Article 11.
- *Additional UNESCO documents* dealt with nondiscrimination and nonstigmatization. Further to the adoption of the UDBHR, the UNESCO Division of Ethics of Science and Technology has published a Bioethics Core Curriculum set out to introduce the bioethical principles of the Universal Declaration on Bioethics and Human Rights to university students. The primary target group of the core curriculum is medical students. Available on the UNESCO website, the core curriculum consists of two sections.

Section 1 provides the core contents with objectives, syllabus, and teacher manual for each unit of the curriculum.

Section 2 contains the proposed study materials for each unit of the curriculum.

The core curriculum is organized in units. Unit 11 is dedicated to the nondiscrimination and nonstigmatization principle.

Grounds of Discrimination and Stigmatization in Bioethics

In the field of healthcare and bioethics, some groups need more protection such as infants and elderly people, AIDS patients, psychiatric patients, and depressed patients.

The list of grounds of discrimination differs markedly from an international human rights instrument to another, starting from the UDHR. Arguably, the drafters of the UDBHR declined the proposal of identifying major grounds that are pertinent to the field of bioethics, in favor of a wording that makes it clearly embedded within

the established international law of human rights. This is why the enumeration of specific grounds has been dropped from the fourth draft of the declaration. This was based on the fact that any list would either be incomplete or even be seen as a way of creating new grounds of discrimination (Rivard, 2009).

This implies that the identification of the most pertinent grounds to the field of bioethics will be up to the implementation step and according to specific contexts of UNESCO member states.

1. Poor and vulnerable individuals and groups may be discriminated in the sense of suffering of deep inequalities in their right to access to healthcare services. A common argument in favor of positive actions toward those vulnerable persons is that it can correct some of these inequalities, while some opponents claim that it can create dependence and a sense of entitlement. Nevertheless, it can create a sense of discrimination for those who are excluded from the programs.

Case Study: Positive Discrimination for Poor Minorities

In a poor multiethnic country with limited health and economic resources, the government decided to give priority for primary healthcare to poor nomads of the desert minorities. For instance, specific funds will be allocated for the prevention, diagnosis, and care of trachoma and infantile diarrheal diseases.

(From Nouzha Guessous experience)

2. Advances in medical technology have the potential to create disproportionate disadvantages for some social groups, either by being applied in ways that harm members of these groups directly or by encouraging the adoption of social policies that discriminate unfairly against them with significant individual, social, and legal consequences.

For instance, reproductive medicine has developed techniques that enable parents to choose the sex of their child which raises the concern of discrimination against girls and women in societies where male children are valued more highly than female children. Similar concerns have been raised about the increasing use of abortion as a method of birth control in overpopulated countries where there is considerable social and legal pressure to limit family size. On the basis of cultural and/or socioeconomic background, in several parts of the world, there is a strong preference for male children. Prenatal diagnosis (PD) through chorionic villus sampling and direct fetal sexing or early ultrasonography are means to determine the fetal sex allowing couples to abort a fetus of a nondesired gender. PGD technology is used for this purpose as well, although only by a small elite that can financially afford it. According to the European Society of Human Reproduction and Embryology (ESHRE) 2002 Report, 70 % of the participating centers oppose the idea of embryo sexing and authoritative clinical geneticists have made a plea to limit PGD to medical indications.

In the 2003 report on preimplantation genetic diagnosis (PIGD), the UNESCO-IBC concluded as follows: “It is recommended that PGD be limited to medical indications. Therefore sex gender selection for non-medical reasons is considered to be unethical” (IBC-UNESCO, 2003).

Sex Selection in India

Prenatal testing and termination is the main problem in India, where its use has led to the ratio of girls to boys declining to 927 girls to 1,000 boys in 2001. In some regions, the ratio is as low as 800 per 1,000.

Sex selection is the exercise of sexism at the most profound level, choosing who gets born, and which types of lives are acceptable. In traditional patriarchal societies, such as in India and China, the preference for boys has led to huge imbalances in the sex ratio in the population. Worldwide, there are estimated to be 100 million missing women as the result of sex selection. Indian communities in the USA and the UK are now being targeted by clinics which have no scruples about exploiting these traditional prejudices for profit. In Western countries, there seems to currently be a preference among the majority white communities for girls, but the choices that are being made are still based on rigid, sexist, gender roles. Even in the case of “family balancing” (where a family has one or more child of one sex and wants a child of the opposite sex), which the HFEA views as relatively acceptable, rigid gender expectations are clearly operating. In how many cases where parents are “desperate for a girl” will they be hoping for a loud tomboy that grows up to be an engineer? Society must continue to fight sexist gender, not allow them to dictate who is born.

(From <http://www.hgalert.org/sexselection.PDF>)

3. Gender discrimination extends to many other areas both in the access to healthcare and to benefit from research. As women live longer in many parts of the world, elderly women might find themselves abandoned by their families, subject to inadequate healthcare, and disregarded by society. The prevalence of some diseases among mid-aged women may induce national positive actions to the exposed population.

Case Study: Positive Discrimination of Low-Income and Uninsured Women to Prevent Breast and Cervical Cancer

The national program for early detection of breast and cervical cancer in country A was designed to reduce disparities in mortality due to cancer by targeting primarily low-income and uninsured women.

The program has delivered notable improvements in access to screening for low-income women minority groups that could not benefit from the diagnosis campaigns in the 2000s with an emphasis on overrepresentation of women originating from rural areas.

This result was obtained at the expense of an underrepresentation of other women.

(From Nouzha Guessous experience)

4. Dominant moral and cultural habits and even legal dispositions may deprive adult women their personal authority to make important life and healthcare decisions.

Case Study: Discrimination and Stigmatization on Cultural-Based Grounds

MZ, aged 20, has come to Dr. NG for testing of her status for pregnancy and for sexually transmitted infections. She explains that her brother's friend has been sexually abusing her 1 week before. She further explains that, when she complained to her parents, they angrily denied the possibility and accused her of flirting and being sexually provocative. MZ lives with her family in a small village where the community is religiously devout, so any sexual scandal involving police or other authorities would be very stigmatizing. MZ asked for a prescription of an emergency postcoital contraception. She was very scared and asked that her parents not be informed of her visit because this would confirm their suspicions of her immorality.

(From Nouzha Guessous experience)

It may also deprive women from their right to equal access to healthcare services.

Case Study: Discrimination on Moral Grounds

In community A, any sex outside marriage is very strongly condemned, particularly for women. Furthermore, this community lives in a village with very limited health resources and is both poorly staffed and equipped in hospitals and delivery facilities. One evening, two women, Ms. KW and Mrs. MZ, came for delivery, with Ms. KW arriving shortly before. Ms. KW was known in the village as a sex worker and that she was pregnant as a single mother meaning that the father of her child was unknown.

Given the lack of resources, the administrators of the delivery hospital decided to give priority to Mrs. MZ as she was legally married and to refer Ms. KW to another maternity ward, approximately 2 h drive on non-asphalted road from village A.

(From Nouzha Guessous experience)

5. Migration and situations of war or civil conflicts also affect women especially. They are often vulnerable to abuse and to be deprived from their right to be part of the process for conflict resolution and reconciliation. The report of IBC on the principle of respect for human vulnerability and

personal integrity (IBC-UNESCO, 2011) provides an account of the principle of respect for personal integrity (Article 8 of the UDHR) and the need to protect those who are especially vulnerable. As one of the most important examples of special vulnerabilities, IBC more specifically deals with the position of women, in particular migrant women and women affected by war who are especially vulnerable to the risk of being unwanted, uncared for, abused, and rejected (IBC-UNESCO).

6. In the field of genetics, the use of relatively simple tests for determining a patient's susceptibility to certain genetically transmitted diseases has led to concerns that the results of such tests, if not properly safeguarded, could be used in unfair ways by health insurance companies, employers, and government agencies. In addition, through genetic counseling, prospective parents can be informed about the chances that their offspring will inherit a certain genetic disease or disorder; this will enable them to make more informed decisions about reproduction. This is viewed by some bioethicists and some NGOs as contributing to a social atmosphere considerably less tolerant of disability than it ought to be. The same criticism has been leveled against the practice of diagnosing, and in some cases treating, congenital defects in unborn children.

Genetics Privacy and US Legislation

In 2008, the "Genetic Information Nondiscrimination Act" (GINA) passed by the US Senate prohibits US insurance companies and employers from discriminating on the basis of information derived from genetic tests. GINA protects Americans from discrimination based on information derived from genetic tests. It forbids insurance companies from discriminating through reduced coverage or pricing and prohibits employers from making adverse employment decisions based on a person's genetic code. In addition, insurers and employers are not allowed under the law to request or demand a genetic test.

(From http://www.ornl.gov/sci/techresources/Human_Genome/elsi/legislat.shtml)

Special attention should be paid to the so-called research on the genetic bases of behavior. It is controversial though it is still in its infancy because of its potential to encourage the adoption of crude models of genetic determinism in the development of social policies, especially in the areas of education and crime prevention. Such policies, it is claimed, could result in unfair discrimination against large numbers of people judged to be genetically disposed to "undesirable" forms of behavior, such as aggression or violence.

7. Medical research in general is also a domain where groups of population or patients may be subject to discrimination. The Tuskegee experiment is one of the most famous cases.

Case Study: The Tuskegee Experiment

In 1932, the US federal government of Alabama launched into a medical study called “The Tuskegee Study” of untreated men with syphilis. At that time, penicillin was proved as an efficient treatment. The study selected 412 poor African Americans men infected with the disease and faked long-term treatment, while really only giving them placebos and liniments. The premise of the action was to determine if blacks reacted similar to whites to the overall effects of the disease. The experiment lasted 40 years and was only discontinued in 1972 when a Senate investigation was initiated. The survivors of the study did receive treatment and financial compensation after the Senate investigation.

(Based on the true story of the decades – long Tuskegee experiment, a movie, *Miss Evers’ Boys* (Director: Joseph Sargent), was adapted from the 1992 stage play written by David Feldshuh).

Limitations of the Principle of Nondiscrimination and Stigmatization

Article 26 of the UDBHR specifies the general framework of these limitations. “The Declaration is to be understood as a whole and the principles should be understood as complementary and interrelated.” This implies that if a bioethical issue or problem emerges, it is usually the case that several principles are relevant to the issue or problem and need to be balanced in order to reach a justified conclusion about what to do.

Article 27 specifies the limitations on the application of the principles. It mentions several conditions in which application may be limited by law:

- “in the interests of public safety,
- for the investigation, detection and prosecution of criminal offences,
- for the protection of public health,
- for the protection of the rights and freedoms of others.
- Any such law need to be consistent with international human rights law.”

Therefore, when public health is at risk, exceptions or restrictions to the nondiscrimination principle can be necessary either by “affirmative” actions in favor of some key persons or groups or by “negative” actions that may infringe upon individual rights. These exceptions must be publicly discussed and applied with transparency and according to the national law. They also must be subject to revision according to developments of the situation and scientific knowledge.

Interrelation of Article 11 with Other Articles in the Declaration

As with the entire Declaration on Bioethics and Human Rights, the understanding and the implementation of this article requires to be built in the context of the entire instrument, as stated in Article 26 above mentioned.

The provisions of Article 1 pertaining to the scope of the declaration cover those of Article 11 on nondiscrimination and nonstigmatization.

The injunction against discrimination and stigmatization is in reference to the resolution of “ethical issues related to medicine, life sciences and associated technologies as applied to human beings” with consideration of “social, legal and environmental dimensions.” It applies to states, individuals, and organizations.

To be coherent with the declaration, Article 11 is to be read and implemented as a theoretical and practical continuation of Articles 3 (human dignity and human rights) and Article 10 (equality, justice, and equity). Whatever it may be built on, discrimination is against human dignity and human rights in general, and it infringes the principles of equality of all humans and of their right to justice and equity.

Article 12 (respect for cultural diversity and pluralism) is closely related to the issue and risks of discrimination and stigmatization based on cultural considerations, rules, and habits. Therefore, it clearly affirms that “such considerations should not be invoked to infringe upon human rights and fundamental freedoms.”

Stigmatization on cultural grounds: Circumcision of girls

In some communities, a girl who is not “circumcised” may be stigmatized.

Mothers usually maintain such tradition under the justification that if they do not circumcise their daughter, these later will be considered negatively by members of her wider family and by her young peers and that she will not be eligible for marriage. This is facilitated by the fact that there are usually no legal prohibitions in the jurisdiction that ban the practice in the communities where the circumcision is practiced.

Because of the risks of such intervention, some mothers bring their daughter to medical doctors. They argue that if the medical doctor does not agree to perform the circumcision, the grandmother or a traditional birth attendant will undertake the procedure herself by customary unsafe and risky means responsible of severe bleeding and infection.

Finally, the duties of nondiscrimination and nonstigmatization are necessary for the comprehension and implementation of the principles of solidarity and cooperation (Article 13), social responsibility (Article 14), and sharing benefits among humans (Article 15).

Conclusion

In bioethics like in human rights philosophy, the principle of nondiscrimination is based on the understanding that discrimination is socially constructed rather than “natural.” This recognizes the need and paves the way for concerted action against inequality and the institutional mechanisms which perpetuate it. It also aims to fight against any discrediting process which stigmatizes an individual or a group who is reduced to a single characteristic in other people’s eyes or opinions for whom this

“label” considered as “abnormal” or “deviant” justifies a range of social discriminations and even exclusion.

This is to be understood, implemented, protected, and promoted, at national and international level, in accordance with the whole set of principles in the UNESCO Universal Declaration on Bioethics and Human Rights.

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