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Bioethics reading of the principle of non-discrimination and non-stigmatization

Leitura bioética do princípio de não discriminação e não estigmatização

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Abstract

This paper aims at an analytical reading of Article II of the Universal Declaration on Bioethics and Human Rights (UDBHR), from UNESCO, which states: "No individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms". Taking universal human rights as a reference, the following key concepts are discussed to better understand the processes of producing stigma and discrimination: identity, otherness, difference and tolerance. The text seeks to demonstrate the centrality of the principle of non discrimination and non stigmatization in the contemporary bioethics agenda, extending the discussion beyond questions related only to the bio-techno-science and health fields. In this sense, this paper reflects on social aspects, indispensable to providing a better understanding of moral conflicts in this field in the current international context, besides issues in the biomedical field itself.

Keywords: Bioethics; Discrimination; Stigmatization; Biomedical Aspects; Social Aspects.

Resumo

O presente estudo objetiva realizar, na perspectiva da bioética, uma leitura analítica do artigo 11 da Declaração Universal sobre Bioética e Direitos Humanos (DUBDH) da UNESCO, segundo o qual: "Nenhum indivíduo ou grupo deve ser discriminado ou estigmatizado por qualquer razão, o que constitui violação à dignidade humana, aos direitos humanos e às liberdades fundamentais". Tendo como referência os direitos humanos universais, são discutidos os seguintes conceitos indispensáveis à compreensão dos processos de produção do estigma e da discriminação: identidade, alteridade, diferença e tolerância. O texto procura demonstrar a centralidade do princípio da não discriminação e não estigmatização na agenda bioética contemporânea, ampliando a discussão para além das questões afetas unicamente aos campos da biotecnociência e da saúde, individual ou coletiva. Nesse sentido, traz para reflexão, além de questões do campo biomédico propriamente dito, aspectos de natureza social, indispensáveis no atual contexto internacional para uma melhor compreensão dos conflitos morais verificados nesse domínio.

Palavras-chave: Bioética; Discriminação; Estigmatização; Aspectos biomédicos; Aspectos sociais.

Introduction

The Universal Declaration on Bioethics and Human Rights (UDBHR) (UNESCO, 2006), unanimously approved by the 191 Member-States of the United Nations Educational, Scientific and Cultural Organization (UNESCO) in 2005, recognized human rights as the universal minimum reference for bioethics. The structural axes of the Declaration are justice, recognizing human dignity and respecting human rights and fundamental freedoms. Including social and environmental issues broadened the scope of bioethics and recovered the original meaning conferred in 1970 by Potter to this new area of knowledge, when the term was used to refer to the need for a field of knowledge dealing with human survival, based on an alliance between biological knowledge and ethical values.

In this article, we embrace the concept of bioethics as a field of knowledge constituted by the convergence of diverse forms of knowledge in a multi-, inter- and trans-disciplinary way (Garrafa, 2006), to find concrete answers to ethical and moral conflicts in issues related to health care and to life in general.

This perception is strongly felt in the UDBHR. Its first articles outline a broad concept of health care, relating right and responsibilities to justice and equity. The Declaration starts by recognizing that health care is the result of a myriad of aspects, covering not only scientific and technological progress, but also social and cultural factors.

Changes in the global economy due to the recent process of globalization have provoked profound changes in behavior, reducing the time/space relationship. This situation means individuals and social groups are in closer contact and displacement and seasonal and permanent migration have increased, imposing new forms of co-existence between different individuals and cultures. In this context, phenomena such as ethno-centrism, racism, xenophobia and homophobia have become more widespread and more visible as a consequence of intolerance of differences, leading to violations of the human rights of individuals and groups who are not integrated into the society around them.

The field of health care is not exempt from this phenomenon. Quite the opposite, it has been

the scene of ethical conflicts concerning different ethnicities, sexualities and genders. In the specific area of clinical bioethics, for example, which deals with issues concerning direct relationships between health care professionals and patients and their families, these ethical conflict are intensified due to differences, when unfamiliar moral codes are confronted with different values, concepts, beliefs and behavior, they are urged to establish some form of communication to make ethically based, shared decision making possible.

Thus, the area of public policies, especially concerning defining health care priorities, has often had to struggle with decision making processes permeated with ethical conflicts involving the differences present in society. Although important advances have been made in recognizing social rights – including the right to health care – as human rights, in some countries these rights are yet to be tangibly felt, especially for minority or socially excluded groups, a problem which must be tackled not only in the legal sphere, but also in social and ethics spheres. It can be observed in contexts in which some groups are severely disadvantage with regard to issues concerning access to health care, to health care services and to new medical technology. In clinical case studies, differences between individuals and groups come to constitute essential elements to be considered in relation to protecting research subjects, as well as issues concerning the distribution of any benefits therefrom resulting.

When considering differences, bioethics is becoming increasingly more involved as one of the reference benchmarks in decision making, which is expressed in article II of the UDBHR, which deals with the Principle of Non discrimination and Non stigmatization ("No individual or groups should be discriminated against for any reason whatsoever, this constituting a violation of human rights and fundamental freedoms"). From this perspective the bioethical agenda increases significantly, beyond the purely bio-techno-scientific dimension to which it was restricted. The social field itself came to be incorporated as an object of analysis and the behavior of bioethics in the debate of moral conflicts became a reference for decisions to be made in the field of health care public policies and research.

Based on the new situation verified in the international context of moral conflicts described above, the aim of this study was to encourage a bioethical reading of the process of producing stigmatizing and discriminatory practices in the area of health care and of the effects such practices have on individuals and on society, thus aiming to contribute to better understanding.

Stigma, discrimination, identity, tolerance... The social context of bioethics

Article II of the UDBHR explains that discrimination and stigmatization are violations of human dignity, giving the idea that stigma and human dignity are intrinsically associated; one can only exist when the other is absent. Stigma is produced and manifests itself as dignity is taken away, when the other is belittled, made to feel inferior and considered to be below other human beings.

Human dignity is difficult to define, producing theoretical and practical controversy concerning its meaning and content. A possible consensus on the concept deals with the fact that dignity is an intrinsic human quality and, therefore, is indispensable and inalienable, being a characteristics which cannot be created, conceded or taken away – although it can be violated – as it is inherent to the human condition, and it should be respected, encouraged and protected (Sarlet, 2009).

This interpretation stems from Kantian philosophy, according to which respecting the dignity of others is not making it just a means. According to Kant, "all rational beings are subject to the law that each of them should treat him/herself, and treat everyone else, never as a mere means, but always at the same time as an end in itself" (Kant, 1967, p. 98). For Kant, this is an end in itself "not just a relative value or a price, but rather an internal value, that is *dignity*" (Kant, 1967, p. 100). Although intended to be a universal value, human dignity ends up being defined by historical and social factors. This leads to diversity in understanding and in treatment, including within the legal system, relativizing the scope of the concept.

Human dignity, as well as ontologically constituting a human attribute and, therefore a value belonging to each individual, also has an inter-subjective dimension, expressed in recognizing and being recognized by the other. It is only in the context of communication and of relationships with the other that dignity can take on its full meaning. From the perspective of inter-subjectivity, human dignity presupposes respect for the other, for plurality and for human diversity. This recalls the thinking of Hannah Arendt, "plurality is the condition of human action by the fact that we are all same, that is, humans, but with no one being exactly the same as any other person that has ever existed or will ever exist" (Arendt, 2002, p. 16).

The process of constructing identity, be it personal or group identity, is a social construct which depends on inter-subjectivity i.e. that which happens in relationships established with the other. It is through "contrasting" and differentiating with this other that the process of individualization occurs, through which the "I" is configured. The "I" can only exist in relation to another, as noted by Lévinas (1997), the other precedes the "I", despite the fact that otherness can only be created from a subject. It is from this experience of otherness, of looking at the other and being looked at, that we can look at and perceive ourselves. This self-knowledge which the relationship with otherness permits is the same as that concerning the culture or identity of the group.

Recognizing identity is a condition for it being effectively constructed. Individualization of subjectivity requires the gaze of the other; to refuse to recognize someone is denying their development as a whole human. There are authors who defend the centrality of recognition in constituting identity, suggesting that being deprived of recognition is a factor in constituting a damaged identity, distorted and reduced, giving rise to negative feelings towards oneself. For Taylor (1994, p. 25), "due recognition is not merely a courtesy, but a vital human need". Honneth affirms

[...] the integrity of the human being is due to the underground nature of patterns of assent or recognition [...] (Honneth, 2003, p. 213).

[...] achieving a successful self-relationship depends on inter-subjective recognition of one's own ca-

pacities and achievements; if such a form of social assent does not occur at some stage of development, the personality suffers from a psychological gap, through which negative emotional reactions enter [...] (Honneth, 2003, p. 220).

Evidence of this can be found in the relationships of individuals with what is considered deviant behavior such as homosexuality and working in the sex trade or in prostitution. The social invisibility which these individuals seek to maintain in society, such as trying to hide their identities – and, consequently, their lack of recognition – is the source of enormous suffering and negative impact on their self-esteem (Guimarães et al., 2003).

Organizing themselves into a group is one way for individuals to deal with the social isolation they experience due to fear of prejudice and discrimination, and in search of social recognition. This process enables them to form a "group identity", according to the concept formulated by Castell (2001), through which they manage to restore self-respect to the individual members of the group.

The concept of identity evokes the idea of diversity, which translates into differences in class, race, ethnicity, gender, sexual orientation, etc. Postmodern thinking gives an unparalleled opening for differences, for social heterogeneity in the day-to--day life of individuals and of institutions. Human existence has multiple and diverse forms, and this plurality implies freedom and equal right for all human beings, the right to think and to live according to their values, beliefs and options. We are the same, but different. The same due to the human condition, which makes us merit the same consideration and respect, having the same rights but, at the same time, singular, which perforce makes us different. Differences should be recognized and must not be the cause of inequalities (Digilio, 2008).

Recognizing the plurality or diversity of human existence requires exercising the virtue of tolerance. According to Walzer, "tolerance makes difference possible – it is based on recognizing the essential equality between men and intrinsic human dignity, that is, in the value belonging to each human being, making them worthy of absolute respect. Tolerance is an "essential virtue for democracy and is inextricably linked to Human Rights" (Valenzuela, 2008, p. 118).

However, the term *tolerance* can take on negative meanings when it is understood only as accepting something while still seeing it as an error or a vice, "an evil to be tolerated". In this case, tolerance comes to have the meaning of condemnation, and not that of respect for the other, with their differences and their dignity.

Tolerance can be identified on a *continuum* which ranges from "accepted resignation of differences in order to keep the peace" to more substantial acceptance of difference. The essence of tolerance is respect of differences, but, at the same time, it is intrinsically based on the equality of all human beings, which consists of recognizing the other, in their difference, their singularity, as an equal. This is the concept of otherness, which brings with it recognition of the other as the same and, simultaneously, different.

Tolerance, as a virtue, involves political and social arrangements capable of providing peaceful coexistence between groups and individuals within the framework of respecting basic human rights.

Stigma and discrimination represent the opposite of recognizing otherness, they are the denial of tolerance, in the sense of respecting difference. Goffman (1980) defines stigma as a deeply derogatory characteristic or attribute, which occurs when a difference or deviation provokes negative reactions towards the individual who is different. Stigma belittles the individual, making them less than others, undermining their human dignity and decreasing their chances in life. Reduced individuality resulting from stigmatization can even dehumanize the stigmatized, their identity becomes defined by the stigma itself, or confused with it when, for example, the person comes to be known by the attribute: a schizophrenic, a leper, a gay etc.

Although stigma is conceptualized as a personal mark or attribute, it is essential to recognize that it is a social product, the fruit of structural conditions and power relationships established in societies (Link and Phelan, 2001; Parker and Aggleton, 2001; Parker, 2010). From a social point of view, not all human differences are relevant and constitute a stigma. Link and Phelan (2001) prefer to use the term "label", to make the idea of something placed on a person more explicit, something that was externally determined, in order to avoid falling into the trap of assigning a meaning to the stigma giving the attribute a possible personal or natural character.

The role of stigma in producing and reproducing relationships of power and control was stressed by Parker and Aggleton (2001) in their early work developing a new conceptual framework for thinking about stigma linked to HIV and AIDS and its repercussions. For them, in addition to the individual dimension, we should also consider that stigma is a social product which reproduces social inequalities. It may be reproducing hierarchical and dominating systems, when related to social class, gender, race, ethnicity and sexual orientation, serving to create, maintain and reinforce social inequalities.

Stigma leads to loss of status and to discrimination. Discrimination is an inherent part of stigma, there would be no stigma without discrimination. When an individual is labelled and that label is associated with negative characteristics, there is a rational construct which disqualifies, rejects and excludes. Stigma means that the stigmatized individual experiences situations of being socially disadvantaged, as it creates structural discrimination which negatively affects the environment around them. In the literature, the following are highlighted as possible negative consequences of stigma: tense and uncomfortable social interactions, limited social networks, compromised quality of life, low self-esteem, symptoms of depression, unemployment and loss of income (Arboleda-Flórez, 2008).

The stigmatized individual is deprived of self--respect, of autonomy and the capacity of self-determination in their own life. Their chances decrease still further because of the feeling of not belonging and having no rights. The stigma increases, as vulnerability on the part of individuals and groups directly affects state of health.

On the other hand, although discrimination is an individual experience which occurs in inter-personal relationships, it is the social structures and the way society is organized which creates conditions for economically dominant groups to impose their worldview, their values and norms, to the detriment of minority groups or the socially disadvantaged.

Stigma and discrimination, therefore, have a dual character: on the one hand, they constitute individual experience, suffered in micro-social spaces

of inter-subjectivity and, on the other, they represent a social process determined by macro-social structures which involve relationships of power and domination (Monteiro et al., 2012). Regardless of the dimension considered, it always involves social interactions. The eminently social character of stigma and discrimination has implications for the field of bioethics, as it calls for incorporation of a wider analysis of social structures so that the processes which produce stigma, and its implications for health, can be better understood.

Discrimination and stigma in the context of biomedical bioethics

The reflections above, when traced in the actual biomedical bioethics sphere – understood as ethical practice aimed at issues which affect life and health which, in an inter- and trans-disciplinary and pluralist way, discuss the ethical conflicts which permeate health care research, especially biomedical research, and the diverse aspects related to health care – show that stigma and discrimination compromise exactly what health care seeks to guarantee, in terms of protecting the individual or collective subject.

Historically, abuses committed in the field of bioethics against groups that had been socially rejected based on differences defined as negative, were a driving force behind the appearance of bioethics aimed at controlling clinical research on human beings. Iconic examples of the negative implications of stigma in conducting scientific research, such as those practiced on the Jews by the Nazis, when atrocities were committed, show that the prevalence of the principle of non stigmatization and non discrimination with regards bioethics aimed at protecting research subjects. Another classic example of racism was a piece of research conducted in Tuskegee (Thomas and Quinn, 1991), in the United States between 1932 and 1972, when, in order to study the natural evolution of syphilis, a group of black men, the majority of whom were illiterate, were denied treatment, even after medical treatment for the disease became available in the 1940s. These cases show to what extent stigma and discrimination cause humans to be devalued, to lose their dignity and cause human rights to be violated.

In the field of biomedical research abuses are still committed, albeit of less visibility and less dramatically than in the above mentioned cases, against groups who are less socially valued, or socially disadvantaged, be that due to socio-economic bias or ethnic, gender or sexual orientation bias.

Ethical problems in conducting research in poor countries, such as many African countries, have been roundly denounced, such as the adoption of the so called double standard, when different research criteria are adopted for research conducted in central and peripheral countries, with more vulnerable populations lacking protection (Garrafa and Lorenzo, 2008). In social contexts involving severe scarcity of resources and difficulties accessing health care services and resources, the situation created by the double standard, which is serious discrimination against poor populations, becomes even more aggravated by these research subjects having little autonomy and reduced capacity to make decisions in the face of their adversities.

Regarding gender, beyond not considering the often greater vulnerability of women, biomedical research has adopted the male physiology as the model for therapeutic care, transposing these results on to women, without considering the particularities of the female body, which determines a different response to the medicine in women. It is only when the studies focus on questions regarding reproductive health that women are prioritized (Cook, 1999). Inequalities in male and female participation in clinical trials constitute a gender inequality, as well as being an object of bioethics.

New biomedical technologies represent new possibilities of incursions of proceedings loaded with prejudice and discrimination, to which bioethics should be alert. The possibilities arising from genetic manipulation and the use of genetic information bring with them a potential for harm which should be considered and they also constitute new domains within the field of bioethical reflection. To what point is it ethically acceptable to control genetic information for reproductive ends I order to decide sex or some other characteristic of the future child, to guarantee the production of a child possessing socially approved genetic characteristics and free from those disqualified by society?

Genetic selection may be performed for motives which, ethically speaking, are more or less acceptable, and, at their limit, may approach eugenics. New scientific knowledge allow the individual's genome to be mapped, which may help in preventing future diseases. However, how can it be guaranteed that this information will not be used against the individual's own interests, to discriminate against them in the interests of employers or health insurance companies? Bioethics is able to encourage the necessary discussion in terms of preventing scientific and technological advances being at the service of stigmatizing and discriminatory practices, reinforcing the dominant social groups to the detriment of other groups less valued within society.

References to human dignity and to non stigmatization and non discrimination are hallmarks of decisions on better health care policies and practices, contributing to making difficult decisions involving questions such as: the use of surgery in gender reassignment, in the cases of transsexual individuals; the right of homosexual individuals to maternity/paternity; the right of individuals living with HIV/AIDS to exercise their sexuality and have children; critical situations involving cultures very distant from western culture, such as infanticide and female genital mutilation. In these cases, external intervention, even when undertaken in defense of human rights, are not based on the concept of respecting difference and may backfire as an authoritarian act of moral imperialism.

Concerning caring for the health of the individual, when there is direct contact between health care professionals and service users, ethical conflicts appear resulting from different cultural concepts concerning life and health, differences also become more relevant when formulating and implementing public health care policies. The Brazilian public health care system, to the extent that it aims to be universal and, therefore, seeks to cover all social groups in its territory, increasingly has to consider inter-cultural differences in the area of health care policies and in the care provided. Lorenzo calls attention to the need to "reflect on the construction of clinical bioethics capable of acting within the inter-ethnic relationships encouraged by public policies, which aim to guarantee the provision of goods and services of Western health care to traditional communities which, historically, have been excluded" (Lorenzo, 2011, p. 338).

Health care should consider the stigma borne by those with certain diseases, which reduce their chances of treatment. Many patients, as in the case of mental illness, for example, who would benefit from treatment, do not turn to health care services for fear of being identified as having such a disease and suffering the consequences resulting from being labelled in this way (Arboleda-Flórez, 2008). Refusals to seek medical attention or poor adherence to treatment are phenomena associated with stigma, and are also seen in other types of illness, such as leprosy and AIDS (UNAIDS, 2005).

The stigma associated with certain diseases is an additional source of suffering for those who, already struggling with the threat the disease represents to their body, have to also deal with the impact the disease provokes on their whole way of living and relating to others. The stigma associated with the disease cancels out or decreases the value of that body, as it now finds itself in a situation of extreme vulnerability. The word "disease" has negative connotations. Canguilhem emphasizes that the condition of being ill implies "being harmful or undesirable or socially devalued" (Canguilhem, 1982, p. 93).

The stereotyping process defined by Goffman, in which the disease is associated with negative attributes or negative stereotypes, can be identified in Sontag's description of how society deals with disease and death, and how she transforms disease into a metaphor:

> There is nothing more punitive than attributing meaning to a disease when this meaning is invariably moralist. Any significant health problems, the cause of which is unclear and the treatment ineffective tends to be overloaded with meaning. First, the objects of the deepest fears (corruption, decadence, pollution, anomie, weakness) are identified with the disease. The disease itself becomes a metaphor. [...] Feelings related to evil are projected in a disease. And the disease (thus enriched with meaning) is projected in the world (Sontag, 2002, p. 76).

Whether based on disease, ethnicity. Gender or sexual orientation, stigma results in inequalities, imbalances in power and in social injustice. Differences for which an absolute lack of recognition is noted – in the meaning conferred by Honneth (2003), regarding the conscious act of positive valuing the Other – constitute significant causes of discrimination and social exclusion. Whatever the source of the stigma, the consequences are the same: violating human dignity, isolation and social exclusion, less access to health care services, compromised chances in life, deterioration in quality of life and increased risk of death.

Final considerations

Recurring violations of human rights based on discrimination and ethnic, gender, sexual orientation or any other type of prejudice affect the dignity of life and should be on the list of concerns in the bioethical debate. This does not mean merely incorporating the points of intersection between society and health care, but rather in that which society itself represents as an object of bioethical, at least from a bioethical perspective committed to equity and justice. In this case, the social body itself becomes the object of bioethical concern and interventions.

An individual's dignity is the central principle of human rights. It is imperative that it be defended, and this requires struggling against processes of discrimination and stigmatization, which contribute to increasing the vulnerability of certain social groups. Differences and different moralities should not be motives for discrimination.

This is a fundamental aspect of bioethics, giving it its eminently social character. Socially committed bioethics defends diversity, not allowing it to be suffocated by the hegemonic perspective (Gonçalves, 2011), but, on the contrary, maintains that individuals should live according to their values, beliefs, sexual orientation, culture even when this system of values and beliefs deviates from the dominant moral standards.

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