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UPDATE

The principle of non-discrimination and non-stigmatization: reflections on leprosy

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Abstract

This article is based on Article 11 of the Universal Declaration on Bioethics and Human Rights, which addresses the principle of non-discrimination and non-stigmatization. The paper discusses the concepts of discrimination, stigma and structural violence, analyzing the specific case of leprosy from the viewpoint of bioethics and human rights. The research also considers the fact that Brazil is the second country most affected by the disease. The conclusion stresses the importance of this declaration as a theoretical and practical instrument to address the social exclusion of people in this situation.

Keywords: Bioethics. Human rights. Social stigma. Social discrimination. Leprosy.

Resumo

Princípio da não discriminação e não estigmatização: reflexões sobre hanseníase

Este artigo baseia-se no artigo 11 da *Declaração Universal sobre Bioética e Direitos Humanos*, que trata do princípio de não discriminação e não estigmatização. O texto discorre sobre os conceitos de discriminação, estigma e violência estrutural, pensando-os no caso específico da hanseníase, sob a perspectiva da bioética e dos direitos humanos. A pesquisa considera ainda o fato de que o Brasil é o segundo país mais afetado pela doença. Como conclusão, destaca-se a importância da referida declaração como instrumento teórico-prático para enfrentar a exclusão social de pessoas nessa situação.

Palavras-chave: Bioética. Direitos humanos. Estigma social. Discriminação social. Hanseníase.

Resumen

Principio de la no discriminación y de la no estigmatización: reflexiones sobre la lepra

Este artículo se basa en el artículo 11 de la *Declaración Universal sobre la Bioética y los Derechos Humanos*, que trata del principio de la no discriminación y no estigmatización. El texto analiza los conceptos de discriminación, estigma y violencia estructural, teniéndolos en cuenta por el caso específico de la lepra, bajo la perspectiva de la bioética y los derechos humanos. La investigación también considera el hecho de que Brasil es el segundo país más afectado por la enfermedad. Como conclusión, se destaca la importancia de esta declaración como instrumento teórico-práctico para abordar la exclusión social de las personas en esta situación.

Palabras clave: Bioética. Derechos humanos. Estigma social. Discriminación social. Lepra.

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In 2005, in the *Universal Declaration on Bioethics and Human Rights* (UDBHR), the principle of "non-discrimination and non-stigmatization" was recognized by the United Nations Educational, Scientific and Cultural Organization (Unesco)[1]. In Article 11, the document states that *no individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms*[1]. In other words, the text censures discriminatory and stigmatizing actions that discredit people on social, political, legal and environmental grounds[2].

Discriminatory attitudes strike at dignity and fundamental freedoms, violating two founding principles of human rights: justice and equality. Violation of equality in the treatment of individuals or groups, regardless of specific characteristics, is considered discrimination. Such behavior violates basic rules of respectful coexistence and may be related to differences of gender, skin color, religious belief, political conviction, sexual orientation, etc.[2].

This study reflects on the principle of non-discrimination and non-stigmatization in the specific case of leprosy, a disease associated with poverty and the aggravation of inequality, alongside Chagas' disease, dengue fever, schistosomiasis, leishmaniasis, malaria and tuberculosis, among others[3]. These conditions, known as "neglected diseases," affect more than a billion people (about one-sixth of the world population) according to data from the World Health Organization (WHO)[4]. Regarding leprosy, Brazil is the second country with the most cases worldwide[4].

This article was divided into three parts: the first reflects on the concepts of "discrimination," "stigma" and "structural violence," considered as social processes; the second addresses the principle of non-discrimination and non-stigmatization in relation to human rights and bioethics; and the third proposes the application of this principle to public policies to fight leprosy.

Stigma, discrimination and structural violence

This article draws on studies by Erving Goffman[5] and Michel Foucault[6] to conceptualize "stigma" and "discrimination." In the second half of the 20th century those authors studied groups of discriminated-against and stigmatized people considered as "different" and "deviant." The paper also draws on the most recent research by Parker and Aggleton[7] on the stigma of AIDS. The discussion on structural violence, in turn, is based on the ideas of Paul Farmer[8], an American physician and anthropologist who, together with the Norwegian sociologist Johan Galtung[9], produced in-depth studies on peace and conflict resolution.

Goffman[5] worked with people discriminated against due to physical disabilities, viewing stigma as a cultural value that establishes rules. The American sociologist claims that stigmatization is triggered by individual attributes deemed undesirable, socially interpreted as deviations. In extreme cases the person is considered "inferior," "bad," "dangerous," "weak," "faulty" or "diminished" and demoted socially and morally.

Foucault[6] sought to understand exclusion from the viewpoint of insanity, addressing topics such as mental illness, crime, punishment and social construction through extensive analyses. The author reflected on the relationships between knowledge and power, explaining how social production establishes and preserves order. Therefore, power is not something that is held, like property, but something that is exercised.

According to philosopher, power produces knowledge, and there is no power relation without the constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute power relations[10]. The latter act as a force that coerces, disciplines and controls individuals – which is not always negative, but entails dangers, as such relationships, according to the author, construct and preserve social differences[10].

Parker and Aggleton[7] also interpret stigma and discrimination as social processes. For them, stigma occurs at the intersection of culture, power and difference, playing an important role in the production and reproduction of power and control relations by devaluing certain groups and making others feel superior.

Stigma has negative consequences for rendering social interactions uncomfortable, limiting social networks, compromising quality of life and generating unemployment, perpetuating the cycle of social and economic exclusion, loss of individual status and discrimination. Thus, stigmatization increases the vulnerability of people and groups, directly harming the health and social representation of those it affects. Its implications are of direct interest to bioethics[11], considering the inequality that develops into exclusion and results from relationships between cultural processes and power structures. Therefore, analyzing stigma requires understanding its social and political aspects.

It is pertinent for this reflection to recall the concept of "structural violence" defined by Galtung[9], one of the founders of studies on peace and conflict resolution. Such violence, albeit not active and deliberate, is produced by economic and political organization and expressed in the unequal distribution of power, resulting in unbalanced opportunities, discrimination and social injustice. The absence of protection and guarantee of individual rights and needs is a case of structural violence that results, for example, in lack of access to health or food, preventing the maintenance of life.

Galtung[12] draws attention to the difference between personal and structural violence, stating that the former is committed by an agent while the latter has no such actor. Although damage may occur in either, while the former relates to people and concrete agents, violence in the latter is embedded in the social structure, appearing as inequality of power and, consequently, unequal chances for individuals.

According to Link and Phelan, *stigmatization is entirely contingent on access to social, economic and political power that allows the identification of differentness, the construction of stereotypes, the separation of labeled persons into distinct categories and the full execution of disapproval, rejection, exclusion and discrimination*[13]. Stigma results from the production and reproduction of unequal power relations; it is conservative, upholding an unjust social order and disregarding different identities. Consequently, it is useful for certain groups and institutions to assert their power over those who are relegated to the fringes of society[14]. Discrimination, in turn, is a behavioral response caused by negative attitudes and has been described in the literature as the practice of stigma[14].

Reassessing stigma and discrimination, as well as the broader structures of inequality and social exclusion, leads to reflection on the structural violence of denying access to healthcare systems, services and practices. Such violence excludes, marginalizes, differentiates and oppresses, contributing to the fundamental causes of diseases. In this context, the struggle for human rights and social justice is justified[15].

Social stigma also interferes in health care, influencing public policy and the behavior of healthcare professionals. It is essential for these professionals to understand that care provided to patients has a strong cultural component and may enhance pre-existing stigmatizations, leading to what White[16] defines as "iatrogenic stigma."

In studies carried out between 2000 and 2005, Parker and Aggleton[15] found that initiatives to tackle the stigmatization of people with HIV/AIDS encouraged social mobilization, configuring collective resistance to discrimination. This finding sheds light on the authors' understanding of social *determination* as opposed to social *determinant*.

Social determination considers the context and background of individual or collective life as factors that influence health. However, the perspective of these determinants tends to emphasize causality, which makes it difficult to establish historical links with everyday life and overestimates epidemiological data that are often unable to pinpoint the social causes of illness[17].

Principle of non-discrimination and non-stigmatization

The *Universal Declaration of Human Rights* (UDHR) outlines basic rights, classified as first-generation. Adopted by the United Nations in 1948, UDHR begins by stating, in its article 1, that *all human beings are born free and equal in dignity and rights*[18]. And, in its Article 7, the document clearly records the concern with discrimination by setting forth that *all are equal before the law and are entitled without any distinction 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 such discrimination*[18].

However, assertion of equality does not imply that humanity is a homogeneous group. Therefore, the text stresses the existence of differences among human beings. Such differences must be recognized and appreciated, without individuals being considered "better" or "worse," as difference does not mean inequality of rights.

While inequality favors exclusion and discrimination, difference is related to heterogeneity, to complementarity in diversity. The ideal of non-discrimination is recognized in several regulations on equal rights, which does not mean treating everyone equally, but recognizing the dynamics of power relations that produce oppression and domination of historically disadvantaged groups. In this context, vulnerability is understood as inexistent or insufficient economic, cultural or political power to access goods and services essential to a dignified life[19].

Another document that addresses non-discrimination is the *Universal Declaration on the Human Genome and Human Rights*, adopted at the 1997 Unesco General Conference[20]. In its Article 6 the document states that *no one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect infringing human rights, fundamental freedoms and human dignity*[20]. The passage warns against the risk of stigmatization resulting from genetic studies that suggest the inherent inferiority of certain groups.

Many situations may lead to discrimination against or stigmatization of human beings. Therefore, respect for the plurality and dignity of humans is a constant challenge. It is in this context that UDBHR[1] draws attention to the importance of social settings in the production of inequalities, proposing principles to combat such inequality.

The preamble to UDBHR[1] lists important documents related to opposing discrimination: *International Covenant on Economic, Social and Cultural Rights*[21], *International Covenant on Civil and Political Rights*[22], *International Convention on the Elimination of All Forms of Racial Discrimination*[23] and *Convention on the Elimination of All Forms of Discrimination against Women*[24]. The *Declaration*[1] highlights the interrelation and complementarity of its principles, including the principle of non-discrimination and non-stigmatization, linked to the principle of solidarity and cooperation (Article 13). This association prioritizes equality in situations conducive to discriminatory or stigmatizing attitudes.

UDBHR also addresses solidarity, an important factor in the provision of citizenship, liberation and emancipation, as a means to minimize social inequalities through the commitment of society to political participation. This would allow existing rights to be expanded, improving the quality of life of individuals and social groups targeted by discrimination[25].

Public policies against leprosy

Also known as Hansen's disease, leprosy is mentioned in ancient records in the East and West, where the main cause of the disease's decline was improvement of social and economic conditions in modern and contemporary history[26]. At least since the 18th century, poverty and adverse living, working and nutrition conditions have been considered causes of the disease. As early as the 19th century, for example, Johann Peter Frank[27] wrote that extensive sanitation, social and economic reforms were essential to protect the population.

The Human Development Index (HDI) and social determinants have a major impact on the transmission levels of *Mycobacterium leprae*, the etiological agent of leprosy and a serious public health problem. Proof that socioeconomic factors influence the prevalence of the disease is the fact that leprosy has an uneven and endemic epidemiological pattern not only in Brazil but also in other countries[28-30].

Scientific development, with the discovery of the causative agent and treatment of leprosy, has been unable to eradicate notions of heredity and "punishment" of biblical leprosy that characterize the stigma and discrimination. Such prejudice excludes people affected by the disease, directly interfering in identity formation and leading to invisibility, neglect of care and violation of human rights. All of this directly affects productivity, social inclusion and, consequently, the quality of life of those affected by the disease, preserving the cycle of poverty and exclusion[31].

The WHO epidemiological bulletin for September 2017 reports that 143 countries and territories reported cases of leprosy in 2016[4]. Of the 214,783 reported cases, Brazil recorded 25,218 (11.7%), ranking second among the most affected countries, after India, which had 135,485 cases (63%)[4]. In Brazil, treatment of the disease is provided exclusively by the Unified Health System and lasts between 6 and 12 months.

Although leprosy is a well-known disease with proven effective treatment, it is still a serious public health problem and efforts to end stigma and discrimination are insufficient. Therefore, in its Global Leprosy Strategy 2016-2020, WHO draws attention to the importance of countries adopting policies to provide the inclusion of these people[32].

Access to basic services goes beyond biological-natural aspects and pre-established epidemiological systems. It is essential to consider the background and life history of individuals and their groups. These factors are behind the social vulnerability that directly and indirectly affects the health-disease process[33]. Leprosy, for example, is directly linked to poverty and poor sanitation and housing conditions. More than that, it can be said that the disease results from restricted access to the health system and the violation of basic human rights.

Leprosy affects marginalized families living in poor regions and deprived of consumer goods essential to physical, mental and social development. These adverse circumstances often prevent the adoption of healthy behaviors and access to basic services, which increases their vulnerability[34].

In the early 20th century the Brazilian government started to control leprosy in endemic areas with the compulsory isolation of patients in colonies. In 1958, experts from around the world, meeting at a congress, issued a document recommending the abolition of isolation. However, Brazil only complied with the recommendation in 1962 (and there are records that the practice only ended institutionally in 1986)[35].

In the 1970s, despite the availability of free treatment and medication offered by public healthcare services, patients remained in many of these “sanatoriums” in a condition of civil death. During this period, there was a consensus among leprologists regarding the need for policies to face segregation, since leprosy was still viewed with great prejudice. Many preferred to hide rather than seek care and some general hospitals refused to provide the necessary care[36].

To reduce the stigma related to the disease, it was proposed to replace the term “leprosy” with “Hansen’s disease.” After a major medical campaign, the Hansen’s Disease Control Policy was established by Ministerial Order 165/1976, which aimed to integrate people affected by leprosy into society, highlighting the importance of banning the term “leprosy” and its derivatives[37]. However, it was only in 1995 that Law 9,010[38] prohibited the use of the word in official documents. The law also recommended outpatient treatment, physical and social rehabilitation of patients and the restructuring of former colony hospitals according to local characteristics.

Although it began in the 1970s, the struggle to change the terminology gained momentum and representativeness in the 1980s with the creation of the Movement for the Reintegration of People Affected by Hansen’s Disease (Morhan) in 1981[39]. Morhan works to reintegrate former leprosy patients and their families, showing that they should lead normal lives within any social group. The movement played a decisive role in the approval of the aforementioned Law 9,010/1995[38].

In a study on the “leprosy” vs. “Hansean’s disease” debate, Femina and collaborators[40] reported that 63.3% of interviewees (patients or former patients) believe that the change of name reduces prejudice. However, patients and society in general still find it difficult to grasp the concept of “Hansen’s disease.” The authors associate this lack of knowledge with the stigma that still limits the access of people affected by the disease to healthcare services, especially those who need physical rehabilitation due to sequelae. Even so, the approval of the law was positive for minimizing discrimination in daily life[40].

Conclusions

Socially produced, stigma reinforces inequalities and aggravates discrimination against specific persons or groups, making it difficult, and in some cases even impossible, for patients to access healthcare services, a kind of structural violence.

In 1982 WHO recommended polychemotherapy as the main treatment for leprosy. However, little has been done since then to overcome the impact of discrimination on the lives of people with the disease, who live in a situation of vulnerability due to lack of public policies. The stigma of leprosy still persists in the popular imagination despite the availability of effective treatment and definitive cure. And this persistence, as noted by Baialardi[41], violates human rights.

Given this context, it is necessary to face the stigma and discrimination permanently and horizontally, drawing on Foucault’s ideas[6] on power and knowledge and the concept of structural violence according to Galtung[9] and Farmer[8]. This also requires stressing the importance of UDBHR[1], a theoretical and practical instrument capable of providing concrete initiatives in defense of the principle of non-discrimination and non-stigmatization.

In the specific case of leprosy, the *Declaration* is especially important for including social, economic and cultural issues directly related to the genesis of the disease in the bioethics discourse. This makes it possible to encourage dialogue based on universal principles that aim to guarantee the active and citizen participation of people affected by the problem, in the quest for autonomy, empowerment and political participation that contribute to reduce inequalities.

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Participation of the authors

Magda Levantezi conceived, developed and wrote the paper. Helena Eri Shimizu contributed to the final revision. Volnei Garrafa supervised the study and took part in all phases.

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