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Editorial

The Possible Reparation: Respect for the Human Rights of People with Leprosy

A reparação possível: o respeito aos direitos humanos das pessoas com hanseníase

La reparación posible: el respeto a los derechos humanos de las personas con lepra

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Abstract

Leprosy is one of the oldest known illnesses, with records dating back to antiquity. Over time, people with the disease have been stripped of their human rights through policies of isolation, exclusion and even eugenic policies, separating their children from their mothers and fathers who are carriers. The challenge today is the promotion, by Nations that have experienced the disease in their history, of promoting policies aimed at preventing abuses and affronts to human rights and repairing, including with compensation, the evils suffered during historical apartheid.

Keywords: Leprosy; Human Rights; Compensation and Reparation; Health Law.

Resumo

A hanseníase é uma das enfermidades mais antigas que se tem notícia, com registros que remontam a antiguidade. Ao longo dos tempos, as pessoas com a doença foram despojadas de seus direitos humanos por meio de políticas de isolamento, exclusão e até de cunho eugênico, apartando seus filhos do convívio com pais e mães portadores. O desafio, na atualidade, é a promoção, pelas Nações que

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viveram a moléstia em sua história, de políticas voltadas a prevenir abusos e afronta aos direitos humanos e reparar, inclusive com indenizações, os males sofridos no apartheid histórico.

Palavras-chave: Hanseníase; Direitos Humanos; Compensação e Reparação; Direito Sanitário.

Resumen

La lepra es una de las enfermedades más antiguas conocidas, con registros que se remontan a la antigüedad. Con el tiempo, las personas con la enfermedad han sido despojadas de sus derechos humanos mediante políticas de aislamiento, exclusión e incluso políticas eugenésicas, separando a sus hijos de sus madres y padres portadores. El desafío hoy es la promoción, por parte de las Naciones que han experimentado la enfermedad en su historia, de promover políticas destinadas a prevenir abusos y afrentas a los derechos humanos y reparar, incluso mediante compensaciones, los males sufridos durante el apartheid histórico.

Palabras clave: Lepra; Derechos Humanos; Compensación y Reparación; Derecho Sanitario.

Leprosy is one of the oldest known diseases, with records dating back to ancient times. In the book of Leviticus in the Bible, there are public health rules for identifying leprosy and how to deal with it.

In 1848, the publication by Norwegian doctors Daniel Cornélius Danielsen and Carl Boeck(1) was considered the first scientific work on the disease, recognizing it as a hereditary illness, while also urging other scientists to further investigate the topic, given the acknowledged limitations of the published research.

And despite the numerous studies and research carried out, especially since 1850, it wasn't until the middle of the 20th century that an effective treatment against the disease was discovered (the antibiotic dapsone), and from 1982 onwards that treatment for leprosy became effective, with the implementation of multi-drug therapy.

Before this advance in science, the policies adopted were isolation and exclusion of the sick, which, as well as being segregating, violated human rights. The isolationist triad consisted of asylums/colonies, preventive clinics and dispensaries. The central function of the dispensaries was to take a census of people affected by leprosy, provide isolation in the asylums/colonies, subject all family members, friends and cohabitants to periodic examinations and send healthy children to the preventive clinics (2).

In Brazil, in 1923, Law nº. 16.300(3) regulated the National Department of Public Health and authorized, within the scope of the Inspectorate for the Prophylaxis of Leprosy and Venereal Diseases, that the children of people with leprosy should, whenever possible, be separated from their parents immediately after birth.

According to Goffman(4), asylums, colonies and leprosarium's could be understood as total institutions, i.e. closed, full-time institutions. In these spaces, the inmate was completely deprived of their rights and the management team could make decisions about these people who were incapable of raising their children.

In this perspective, Curi(5) states that the lives of all the people who were part of the family and support network of a person with leprosy were controlled and stigmatized. This applied especially to their children:

> Complementing this practice, preventive clinics were set up for the lepers' unharmed children and leprosy dispensaries to monitor and control other family members, friends, relatives and others who had lived with the person who was being

> hospitalized. [...] Preventories, dispensaries and asylums-colonies were, respectively, their destinations. (translated by the translator) (5 p. 10).

At critical moments in its history, Japan experienced the task of dealing with the disease and also adopted segregationist and eugenic policies, which lasted from 1907 until 1996, with its “Leprosy Prevention Law”. In 2020, Japan still had a population of 1,100 leprosy patients living in segregated sanatoriums, many of them with physical and/or psychosocial difficulties, victims of the policies applied over the years(6).

In an attempt to minimize the violation of the human rights of leprosy sufferers and their families, which has been adopted as state policy over the years, reparation laws have been passed. In 2007, Brazil enacted Law nº 11,520(7) which provided for the granting of a special pension to people affected by leprosy and who were subjected to compulsory isolation and hospitalization. In 2023, the legislation was amended by Law 14.736(8), to extend the granting of the special pension to children who were separated from their parents due to isolation or hospitalization.

In Japan, the Supreme Court ruled in 2024 that the government should pay compensation to the victims of forced sterilization, authorized by a law in force between 1948 and 1996, which sought to prevent the increase of an 'inferior' population from a eugenic point of view, including people with leprosy(9).

Today, there is a desire for compensation and even reparation - as if that were possible - for the suffering caused by the policies adopted in the past for those affected by Hansen’s disease, but it is known that it is never too late to rethink the past and create new realities for the future.

Although it is a medieval disease, we still live with leprosy today and the best solution is to openly discuss the issue and teach universities, schools and society what the disease means, its characteristics and the symbolic violence that is attached to it, not least because cases are still diagnosed every day around the world.

The example of Japan and Brazil, in their efforts to compensate the current generation for the suffering and annihilation of the most basic rights imposed on their parents and grandparents, is only a small step towards eliminating the disease in the world, but a huge step towards recognizing and guaranteeing the human right to health of these patients and their descendants.

Conflict of interest

The authors declare that there is no conflict of interest.

Authors’ contributions

Montagner MI and Alves SMC contributed to the conception/design of the article, data analysis and interpretation, writing of the article, critical revision of its content and approval of the final version. Okuda W and Delduque MC contributed to the critical review of its content and approval of the final version.

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