



Why we should stop using the word leprosy

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Leprosy is endemic in more than 100 countries worldwide, with over 200 000 new diagnoses each year and more than 4 million people living with some form of impairment related to leprosy. The term leprosy, as used in the Bible, designated a multitude of diseases with skin manifestations. Biblical leprosy carried huge stigma and was considered synonymous with impurity and divine punishment. Global actions to eliminate leprosy have been implemented but have yet to succeed, with stigmatisation and discrimination against people affected by the disease being recognised as two of the biggest obstacles. In Brazil, leprosy was officially renamed *hanseníase* (Hansen's disease) in 1975, and the Brazilian experience of renaming leprosy during the past four decades has given clear signs of the benefit of this measure in fighting stigma and discrimination. More recent actions by WHO and many years of advocacy by patient organisations have followed, but concrete and effective measures to dignify language and terminology need to be implemented as soon as possible.

The word leprosy

Today, more than 4 million people live with leprosy (Hansen's disease) or with the physical impairments and disability associated with leprosy, and 200 000 new cases are diagnosed every year, of which 80% occur in India, Indonesia, and Brazil.¹ Many more cases are likely to have gone undiagnosed, greatly increasing the risk of impairments and disabilities related to leprosy.² There is a consensus among scholars that leprosy, as presented in the Bible, is not the same condition as the disease classified and described by modern medicine because the clinical features of leprosy do not resemble the characteristic signs of biblical leprosy.³ In the Old Testament, leprosy appears as a plague of divine origin aimed at punishing humans for their sins. Leprosy is cast by God over people who have disobeyed his spiritual and social rules of conduct. Instead of describing a specific disease, leprosy is used as a symbol that aggregates all of the harmful consequences of impious behaviour.⁴ Furthermore, the translation of the Old Testament's Hebrew word *tsara'ath* into leprosy is now widely recognised as a mistake.⁵ *Tsara'ath* did not refer to a single disease but to cutaneous manifestations of a diverse set of diseases, such as parasitic infections, pyoderma, psoriasis, vitiligo, and pemphigus.^{4,9}

The word leprosy is attributed to Hippocrates, yet it is highly probable that he applied the word to other diseases or that he didn't apply it to the disease that we know today as leprosy.⁸ The distinction between leprosy and other dermatological conditions happened much later than the time of Hippocrates, including a pivotal moment in the late 19th century when the causative agent for leprosy was discovered by Gerhard Hansen and named *Mycobacterium leprae*. Hypothetically, if the bacillus had been given a different name or been named eponymously, the modern history of the disease might have been quite different. Instead, the disease caused by the bacillus identified by Hansen was fated to represent leprosy to the present day.⁹

The modern era

Shortly after the discovery of *M leprae* in 1873, a unified response by European experts and national governments (based on the idea of the contagion) gave rise worldwide

to the establishment of thousands of sanatoriums or so-called colonies. Many countries implemented a policy of compulsory internment, separating people affected by leprosy from their families and communities. In some countries, segregation was applied to the children of people affected by leprosy, and healthy newborn babies were taken from their parents to be raised far from their families and communities.¹⁰

In more than 36 countries, many of the discriminatory national laws implemented during this period are still in force today.¹¹ Although the years immediately after World War 2 signalled the abandonment of compulsory segregation, this segregation policy endured in some countries until the late 20th century, and there are still thousands of segregated settlements around the world.

Awareness of the enduring effects of stigmatisation as a barrier to diagnosis and treatment has grown among key stakeholders since 2001, when WHO announced that leprosy had been eliminated as a global public health problem. Two historical breakthroughs framed the first decade of the 21st century and current approaches to the disease. In 2010, WHO introduced guidelines for strengthening the participation of people affected by leprosy in the planning, delivery, and evaluation of leprosy services, recognising these people as powerful agents of change.¹² In the same year, the UN General Assembly adopted resolution 65/215 on the elimination of discrimination against people affected by leprosy and their family members.¹³ This resolution was the founding moment in the global acknowledgment of leprosy stigmatisation as a human rights issue.

In accordance with these breakthroughs, WHO's global leprosy strategy 2016–20 included measures and targets aimed at stigma reduction and social inclusion, such as the target to abolish discriminatory laws.¹⁴ Effective actions in this area are difficult because their success depends on behavioural change and on interventions outside of the health-care sector. These challenges and the persistence of discrimination led the UN Human Rights Council to adopt resolution 35/9,

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appointing a special rapporteur on the elimination of discrimination against persons affected by leprosy and their family members.¹⁵

Hansen's disease

Understanding the importance of addressing discriminatory language to reduce stigma dates back as far as 1931 when, at the International Leprosy Congress in Manila (Philippines), a recommendation was made to ban the term leprosy and replace it with Hansen's disease. In the 1940s, patients affected by leprosy in the USA who had been segregated into the leprosarium in Carville, LA, demanded that the name of the disease be changed to Hansen's disease, while denouncing the humiliation, exclusion, discrimination, and impossibility of social reintegration caused by the stigma attached to leprosy.^{16,17}

Unfortunately, this early promise of global change was realised only in Brazil, mainly through the efforts of a determined Brazilian dermatologist, Abrahão Rotberg, a failure that was acknowledged by him with some regret in the 1980s.¹⁸ Rotberg had campaigned against the segregation of people with Hansen's disease as part of his campaign against what he called leprostigma.¹⁹ He endeavoured to abolish the word leprosy in Brazil and worldwide, instead defining the new term *hanseníase* and arguing that the bacillus should be renamed *M. hansenii*.^{20,21} In 1975, Rotberg published an article denouncing the self-interest and profit associated with use of the term leprosy in charitable fundraising, in what he called the leprosy industry.²² In the same year, his efforts led to a presidential decree in Brazil that officially changed the name leprosy to *hanseníase*.²³ In 1995, as a consequence of a long struggle by the Brazilian Movement for the Reintegration of Persons Affected by Hansen's Disease (known as MORHAN),²⁴ a federal law was passed prohibiting the use of the word leprosy in all official documents and in every institutional practice.²⁵ Brazil's experience in the field of antidiscriminatory measures related to this disease is unique, and opinions on the effectiveness of these measures for reducing stigmatisation are largely positive.^{26,27} Although not something that can be tested quantitatively, it is probable that changing the name has been an important factor in improving the social image of the disease in Brazil and in reducing stigmatisation at the personal level for people with Hansen's disease.^{28–30}

Stigma and discrimination

In 2019, the UN special rapporteur identified the persistence of discriminatory language as a factor in the perpetuation of stereotypes around Hansen's disease and discrimination against people with the disease and their family members.²⁷ With more than 600 contributions from more than 35 countries, this report showed that ongoing and systematic human rights violations against this

vulnerable group were often rooted in religious and traditional beliefs.²⁷ Across diverse cultures, a common theme was the notion that the disease named leprosy (or its local synonym) was attributed to sins committed in current or past lives by the person affected by the disease or by their ancestors; to God's punishment of the individual or their family; to a curse placed by ancestors; to sorcery; to possession by evil spirits; and to a punishment for adultery or sexual promiscuity. Leprosy was also attributed to particular races or castes, and to female gender. Finally, misconceptions that originated in late 19th century medicine still prevail, such as that leprosy was a hereditary disease, was highly contagious and transmitted by touch, and was incurable.²⁷

Despite increasing secularisation of societies, moral beliefs attached to leprosy and its use as a metaphor for all that is impure, immoral, and dreadful are still very much present in public imagery, as exemplified in comments by two world leaders.³¹ The Brazilian case suggests that there are major benefits to making the terminology less stigmatising.²⁸ However, changing terminology alone is not sufficient. To permanently eradicate all stigma and discrimination, sustained joint efforts from policy makers, health-care workers, civil society organisations, and individuals affected by the disease are required. In September, 2019, the Global Forum of People's Organizations on Hansen's disease brought together representatives of patient groups from 23 countries, building on regional assemblies in Africa, Asia, and Latin America and the Caribbean. The Global Forum produced a joint statement affirming that, as a step towards reducing stigma and discrimination, the non-stigmatising term Hansen's disease should be adopted worldwide as the official term for the disease traditionally known as leprosy.³²

The linkage between terminology and social responses to diseases is acknowledged in WHO's best practices for the naming of new human infectious diseases,³³ which are consistent with the Hippocratic Oath of first, do no harm.³⁴ Use of antidiscriminatory measures to address persistent, harmful stereotypes and ongoing discriminatory language against people affected by the disease and their family members is key to achieve a world free from the disease, given that the stigma attached to a disease presents a barrier to its elimination by preventing access to diagnosis and treatment.

Humanised medicine

In the past decade, behavioural innovations have been introduced into medical practice based on the concept of humanised medicine, which incorporates anthropological and psychosocial perspectives and recognises the importance of human rights. Health care also recognises the importance of participation of patients and patient organisations in establishing comprehensive and high-quality medical practices and policies.¹⁰ Taking

into consideration the demands of people affected by Hansen's disease means looking at stigmatisation as part of the health and disease process. Hansen's disease is not unique as a stigmatising skin condition, and it is now being included with other so-called neglected tropical diseases in programmes that aim to shift focus from medical treatment to prevention, early intervention, and public health. Stigma reduction initiatives within these programmes could learn from Hansen's disease in addressing negative terminology for other stigmatising conditions.

Hansen's name as a replacement term for leprosy has been questioned because Hansen acted unethically in performing various experiments on people with the disease.^{35,36} Alternative terminologies based on clinical aspects of the disease have been suggested.³⁷ Substitution of the eponym for an anonymous or a positive term seems reasonable but is far from the consensus, and might further delay actions to reduce stigmatisation. The fact is that leprosy, and its distinct moral and cultural meanings, has given rise to systemic and structural human rights violations that mostly affect vulnerable groups who do not own the means to fight against discrimination. Hansen's disease is a term already used by many people affected worldwide as an empowering instrument. People from different cultural traditions have given a meaning of their own to Hansen's disease, which has become a symbol of their right to dignity. As such, decision making should focus on the wellbeing of those who are vulnerable to discrimination related to leprosy rather than on the origin of the term Hansen's disease.

The Brazilian experience

In Brazil, physicians no longer learn about leprosy, nor are patients diagnosed with it, but both groups work and live with the vernacular *hanseníase*. This term might not be the most suitable for the rest of the world, meaning that each country might need a debate about suitably dignified terminology in their own language and in accordance with best practice.³³ We are not arguing that a name is a root cause of, or incites, stigma and discrimination, rather that the beliefs and practices associated with the name can perpetuate stigma and discrimination. Clearly, there will be synonyms of the English word leprosy in the myriad of local languages, and these will need to be challenged if they carry the same negative connotations.

Further examination of the Brazilian experience in renaming leprosy can show important lessons for the development of strategies to tackle stigmatisation. Without entering a debate on possible alternative terminology, which could lead to further endless controversies, we would like to emphasise two points. First, the importance of using dignified language in clinical practice to counteract internalised stigma, interpersonal stigmatisation, and structural discrimination, and second, the positive example provided by Brazil's unique experience.

The Brazilian experience teaches us three important lessons: reducing stigma cannot happen without meaningful engagement and participation of the people who are affected; eliminating harmful stereotypes and discriminatory language needs bold decisions, such as changing the name of the disease; and change can only happen through sustainable strategies and over several generations. The fight against the disease can only succeed alongside the fight against stigmatisation. We call on the global health community and the World Health Assembly to elaborate and implement immediate measures to eradicate discriminatory language against persons affected by Hansen's disease.

Contributors

PD and AC contributed equally to the writing and revision of this Personal View.

Declaration of interests

We declare no competing interests.

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