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The Transition of Social Discrimination Behavior for Hansen's Disease Patients in Japan



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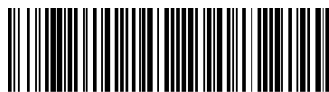
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ABSTRACT

Hansen's disease (leprosy) is a chronic infection in which weak toxic bacteria enter the skin and peripheral nerves. Patients suffering from this disease, former patients, or their families have long been subjected to prejudice and discrimination and the situation continues to this day. Skin symptoms can be unusual in appearance; the incubation period may be long with a sudden onset; it may be mistakenly recognized as a genetic condition. In the past, it has been undeniable that not only at the personal level, but also because of the social attitudes of the country, legal discrimination against Hansen's sufferers has been promoted. In this paper, we will give an overview of Hansen's disease and the actual state of discrimination against those who have it. We will also state our opinions on how to improve this situation in the future.

INTRODUCTION

In Japan, the infectious condition called Hansen's disease (leprosy) is still a hot topic, even though this particular epidemic seems to have ended. This is because patients with this disease or their families have been socially discriminated against in the past at the private and national level. Historically, Hansen's disease has been misunderstood as a disease that is not completely cured and is highly infectious due to its noticeable effects of physical deformation and disability. For this reason, Hansen's disease patients were forcibly excluded from society¹⁾. For the sake of their relief, these patients used to be voluntarily gathered in one place, or they were forcibly gathered in one place, which resulted in leper colonies. Some of these facilities were established as sanatoriums for Hansen's disease. Additionally, legislation that is unequal to patients, such as the Leprosy Prevention Law and the Eugenic Protection Law were enacted. This treatment severely hurt the patients' dignity and impacted their rights as human beings; it allowed for even more severe discrimination from society toward them and their families¹⁾. The above laws were subsequently abolished, and there have been situations in which patients or their families received compensation²⁻⁴⁾. In November 2019, the Hansen's Disease Family Compensation Law was enacted as well as enforced⁴⁾. It can now be said that there is no discrimination at the national level.

However, at the private level, patients and former patients are still subjected to discrimination. Refusals of taxi rides and hotel stays have been documented in this regard. Unfortunately, the fact that protests by former patients and supporters are reported in the news confirms that the name of this disease is still popular and famous as mentioned earlier. In this paper, we will present an overview of Hansen's disease and explain the laws that have been enforced in Japan in the past, as well as what we think should be done in the future.

Overview of Hansen's disease

Hansen's disease is a chronic infectious disease caused by the acid-fast bacterium, *Mycobacterium leprae* (Japanese name: *Rai bacterium*)¹⁾. This disease is named after Armauer Hansen, a Norwegian doctor who discovered *Mycobacterium leprae* in 1873. This affliction is caused by the infestation of the bacterium in the macrophages and peripheral nerve cells of the skin.

In Japan, it was called *Rai* or "*Rai* disease" based off of the Japanese name of the pathogen,

yet there are many people who feel that it is discriminatory, and it is common not to use it except for explanation of past historical matters. The reason is that it is a term which was used when there was excessive discrimination against these patients due to their appearance along with the public's fear of infection. This originated in an era of poor understanding of medicine and disease, and that is why the patient or their family were deeply affected by discrimination. The main route of infection is the invasion of *Mycobacterium laprae* into the human body via the nasal or respiratory tract. The bacterium has a very low rate of infectivity, and in the current state of treatment, it has no serious sequelae or source of infection. However, if the appropriate treatment is not available, severe skin lesions may occur and infect others—and yes, there are still new cases in Japan. According to 2016 World Health Organization (WHO) statistics, there are 210,000 new diagnosed cases of Hansen's disease worldwide. On the other hand, the number of new patients in Japan has been reduced to between zero and one per year and is now considered a rare disease (Table 1)⁵⁾.

Table No. 1: Changes in the number of new Hansen's disease patients and registered patients In Japan and around the world

Year	Newly infected person			Number of registered patients
	Japanese	Foreigner in Japan	In the world	In Japan
1993	8	10	590,933	6,729
1994	9	6	560,646	6,484
1995	8	10	529,376	6,172
1996	6	18	566,567	5,961
1997	6	8	684,961	5,205
1998	5	5	804,357	4,918
1999	8	11	738,112	4,676
2000	6	8	719,330	4,595
2001	5	7	763,262	4,404
2002	7	9	620,638	4,090
2003	1	7	514,718	3,758
2004	4	8	407,791	3,521
2005	0	7	299,036	3,307
2006	1	6	265,661	3,100
2007	1	10	254,525	2,890

(Based on the content of Reference 5).

The medically established findings for Hansen's disease as of 2019 are as follows: 1) Hansen's disease is not inherited. 2) Hansen's disease is an infectious disease, but its infectivity is weak, and it rarely develops even after infection. 3) Even if the disease develops, it can be completely cured by the administration of oral specific drugs (Promin, rifampicin, etc.) and outpatient treatment in the initial stage. At present, an effective vaccine for Hansen's disease has not been developed, and it is difficult to prevent its onset. Accordingly, it is not a disease that can be completely eradicated - at least right now. Moreover, because of this along with the lack of understanding of this disease, people who were former patients have been subjected to discrimination for many years due to misrecognition, and there are situations in which discrimination is repeated even for new patients.

A summary of past social discrimination at the private level

There are various factors as preconditions for discrimination against Hansen's disease patients. First, due to its apparent features, this disease was mistaken in Japan as a malady that affects those who have been cursed by the religious gods as well as the Buddhas or who are being punished for their transgressions in their previous lives. Second, the establishment of the infection is characterized by continuous and frequent close contact with *Mycobacterium leprae* carriers. This reminded certain children of sexual abuse with regard to their close relatives and subsequently promoted misunderstanding and prejudice. Third, it has a very long incubation period, which is usually between four and five years but it can be sometimes as high as 20 to 30 years. Given these long incubation times, it was difficult to think of an infection. The government's policy of eugenics, which is the prevention of those who are deemed unsuitable to reproduce, has spread the misperception that it is a genetic disease. Fourth, nasal chondritis causes saddle nose and nasal deficits, and accordingly there was a time when it was believed that Hansen's disease was the same disease as syphilis as the symptoms were similar. From these contexts, patients are perceived to be obscene and not even human, and it is thought that this has led to or promoted discrimination at the private level. In other words, it can be said that ignorance has made for a lot of unhappy people.

Even today, prejudice against Hansen's disease patients still occurs; notably, the prejudice and discrimination are becoming more personal and insidious. As an example, there was an incident concerning a former patient who was refused accommodation at a hotel. The

prefecture issued a notice that Hansen's disease was not included as part of the legal definitions of "infectious diseases." The Ministry of Health, Labor and Welfare, which has jurisdiction over inns, hotels, and sanatoriums, also stated that Hansen's disease was an infectious disease per the hotel business and public bath laws and so a "not included" directive was issued. In another case, the Ministry of Health, Labor and Welfare issued a notice that Hansen's disease was not included in the infectious disease category under the Hotel Business Law and Public Bath House Act. When the Minister of Justice mentioned Hansen's disease to the prefectural assembly, she apologized for revealing that he had repeated the old expression, *Rai*. There have been other cases such as when a hospitalized patient was found to have Hansen's disease and was expelled from their ward; there have been silent phone calls or threatening phone calls saying "get out of this place"; refusals to play against sanatorium sports teams; denying residents to enter a coffee shop; and a case of denying entry to an elementary school for children of sanatorium residents. As a reaction to this behavior, there are cases where people hide their physical symptoms as they enter a store, or do not disclose that their relatives, who are medical professionals, have patients with the disease. These are just a few examples of what has actually happened and still happens today.

It should be noted that at the time when discrimination against Hansen's disease patients began, the details of this condition and its treatment were not well understood. But even so, it is true that stricken patients were treated inhumanely. For Hansen's sufferers and former patients, sometimes they have to deal with secondary mental disorders such as anxiety, suicidal ideation, depression, and various personality disorders which are caused by social discrimination issues and stressful, long-term stays in sanatoriums.

Overview of discrimination at the national level and its elimination

In addition to the law, we confirm in a time series what the country has been doing in regard to this issue. As previously mentioned, in Japan, Hansen's disease patients were provided with relief and sanatoriums were built during the Meiji period. Public sanatoriums were established in 1907 according to the law, and two years later, they were established nationwide. A sanatorium is of course intended for treatment, but at the same time it is also meant to be a place to forcibly isolate a patient. The patient's family and relatives were unable to get along with their neighbors and were unable to buy things, which hindered their lives and had to move to another location. As of January 2013, there are 13 national sanatoriums

along with a private one in Japan. Currently, there are no facilities because some people are forced to enter. It is a place for people who have the sequelae of Hansen's disease and need assistance, or for those who need to remain there because of their loss of social infrastructure and insulation from their family.

As a legal precedent, the Case on the Prevention of *Rai* Disease was established in 1907. The law was put in place to allow patients and former patients called “Wandering *Rai*” - people who move around indiscreetly and are thought to spread infection - to enter Hansen's disease sanatoriums⁶⁾. However, because there was a low number of sanatoriums and the amount of subjects was limited, only about 5% of all patients were admitted to these facilities. In 1931, the *Rai* Prevention Law of 1931 was enacted. This law was a rework of the previous law, which sent all Hansen's disease patients throughout Japan to sanatoriums⁶⁾. The “Non-*Rai* Prefectural Movement (Campaign to eliminate Hansen's disease patients in the prefecture)” was conducted before and after this law began an extinction policy through forced isolation in order to eliminate Hansen's disease—as if there is no patient in front of you. The Eugenic Protection Law was passed in 1948, and patients were then allowed to marry and live as couples in sanatoriums, but they were subjected to infertility surgery or artificial abortion (Table 2)^{6,7)}. In 1953, the new *Rai* Prevention Law was enacted^{1,6)}.

Table No. 2: Sterilization and abortion figures related to Hansen's disease

Year	Sterilization totals		Number of artificial abortions
	Men	Women	
1950	37	66	*
1955	14	115	303
1960	7	58	191
1965	0	9	131
1970	2	4	146
1975	1	0	37
1980	0	0	2
1985	0	2	0
1990	0	0	17
1995	0	1	2

Based on data from Reference 5).

*This year was not examined.

The numbers in the table are real numbers for that year, not cumulative numbers for five years.

A sterilization is an operation that eliminates fertility while preserving the ability to have sexual intercourse.

This act was carried out based on the Eugenic Protection Law.

This law is a partial rework of the original Leprosy Prevention Law, and “Forced Quarantine” remains unchanged, and it stipulates that patients are prohibited from working and sanatorium residents are not allowed to go out. In 1996, the Act to Abolish the Leprosy Prevention Law was passed⁶⁾, and the Minister of Health and Welfare has apologized for this late reconsideration. Notably, around 1943, it was known—at least overseas—that *Mycobacterium leprae* was fragile, rarely caused infections, and was completely cured by chemotherapy, even when the patient was ill. In response to the discriminatory treatment of patients in each country, the WHO advocated a reconsideration of the isolation policy the year before the new *Rai* Prevention Law was enacted in Japan, and in 1960 proposed the abolition of the discriminatory laws and advocated outpatient treatment. However, in Japan, the legal activity has continued for a long time¹⁾. In 2001, there was a lawsuit regarding unconstitutional state compensation for the Leprosy Prevention Law²⁾, and the plaintiff wins the case, and the country concludes without appealing. After this, the Act on Payment of Compensation to Inmates of Hansen's Disease Sanatoriums was put in place. Furthermore, in 2008, the Act on Promotion of the Resolution of Issues Related to Hansen's Disease was established³⁾, and it was decided to take measures to improve the welfare of those who were Hansen's disease patients and to restore their honor. In this year (2019), the Hansen's Disease Family Compensation Law was enacted and entered into force on the same day⁴⁾. It has been decided that compensation will be paid not only to patients and former patients but also to their families, and measures will be taken to restore their honor. These long years and many laws are related to the problem of Hansen's disease patients. In particular, it seems strange that Japan was late in responding to information from abroad, and that legal discrimination continued for more than 30 years between 1960 and 1996.

CONCLUSION

There are no Hansen's disease patients among us who are authors. Therefore, we have not experienced how hard a particular patient and their family have been discriminated against. If we think of patients and their families, the response at the national and private levels is unacceptable. Is it okay to treat the sick person inhumanely, like the “witch trials” in the West, even though there is something scientifically unclear? Is it acceptable to eliminate them because they look different from others due to their skin symptoms? Did the Japanese have a sense of superiority in the differences between themselves and these patients and thus looked upon them with prejudice? We are reminded of the ethical issues that we always have to keep in our minds. Nevertheless, it is thought that Japan was able to obtain information from other countries and the WHO at an early stage and stop discriminatory behavior earlier, but it has not actually done so. A similar matter is happening in the phytotoxicity AIDS lawsuit⁸⁾, and the delay in response is noticeable. With regard to Japan, it seems that such discriminatory behavior must be prevented in the future, and efforts must be made to eliminate the discrimination that is still ongoing at the private level. For that purpose, it is necessary to widely distribute ordinary but accurate information, and it is necessary to consider the position of others⁹⁾. The past policy of isolating patients has led to keeping them away from familiar places¹⁾ and by doing so, it may have stopped them from developing and improving. Anyone can be afflicted with an infectious disease therefore symbiosis based on scientific evidence is required.

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