

## Topics: Recent topics in public health in Japan 2024

### < Review >

# A history of Japanese patients: What has been done to them and what have they been doing?

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#### Abstract

Although Japanese patients have suffered various hardships and miseries, they have fought to improve their conditions and won the rights that they rightfully deserve. This paper aims to provide an overview of the history of what has been done for and by patients in Japan.

During a cholera pandemic in the latter half of the 19th century, patients with cholera were quarantined in facilities for evacuating people from disease (“Hibyoin”) and left untreated. With industrialization, tuberculosis became prevalent among the poor, especially among female factory workers around the 1900s; however, adequate treatment was lacking due to a shortage of sanatoria. Sexually transmitted diseases (STDs) were defined as “Karyu-byo,” which are diseases transmitted by geishas and prostitutes. Women have endured two tragedies: one as prostitutes and the other as wives, as a result of Karyu-byo spreading across society through prostitutes to men, and from those men to their wives. From the beginning of the 20th century, patients with leprosy wandering around towns and rural villages were admitted to leprosaria. This treatment was later extended to include all patients, and subsequently, a national policy was enacted to admit all patients with leprosy to leprosaria and to completely isolate them for life. Patients in leprosaria were subjected to imprisonment, reduced diet, confinement, reprimands, and other punishments, were forced to perform “work by the patient,” such as cleaning, laundry, and nursing care for patients with severe conditions, and were occasionally subjected to vasectomy. The early 1900s saw many patients with mental disorders being detained in private homes, which encouraged the establishment of psychiatric hospitals. In psychiatric hospitals, many instruments (handcuffs, shackles, chains, etc.) were used for patients who were out of control. Subsequently, custody in private homes was prohibited, and a system of involuntary hospitalization was established, whereby an individual with mental disorders who presents a risk of harming him/herself or others may be hospitalized in a psychiatric hospital.

In addition to patients with the diseases described above, those with pollution-related diseases, occupational diseases, iatrogenic diseases, rare and intractable diseases, acquired immunodeficiency syndrome (AIDS), and COVID-19 were also subjected to discrimination. In addition, there was a system called “patients for medical use,” in which poor patients were utilized for research and education.

After World War II, patients began to actively appeal to society to address their demands and issues, and this trend developed into the patients’ advocacy movement, which is said to be unique in the world. Patient associations were initially organized by patients in sanatoria and leprosaria. Since the 1950s, patient associations have been established for various diseases, including rare and intractable diseases, pollution-related diseases, etc. In the 1970s, various patient associations that had been established for each disease began to align with one another, and finally, the Japan Patients Association (JPA) was established in May 2005, as a unified body of patient associations.

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The protection of the human rights of patients and the assurance of their livelihood and medical care are now explicitly stated in legislation. However, it has not yet been possible to elucidate the causes of the disease and to establish treatment methods that are specifically required by patients with rare and intractable diseases. To promote research and development, patients should be aggressively involved from the perspective of patient and public involvement (PPI).

**keywords:** patient association, discrimination, leprosy, rare and intractable diseases, patient and public involvement (PPI)

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## I. Introduction

According to Parsons [1], a sick person has two responsibilities: to make an effort to get well and to seek medical advice, as well as to cooperate with medical experts, and these “sick roles” are institutionalized in the modern social system. Therefore, in most countries, people visit a medical institution when they become sick, are diagnosed with a disease by a physician, and are then treated as patients by a physician. However, this system has not necessarily been followed universally. In the not-too-distant past in Japan, patients were assigned various duties and responsibilities, and were put through severe hardships and miseries besides being diagnosed and treated. In addition, patients have been subjected to severe discrimination and exclusion based on the nature of their illness. The reality of discrimination against patients and their exclusion from society cannot be observed without considering the patient’s perspective. Therefore, it is important to clarify the reality and historical transitions of discrimination against patients [2].

However, not only did the patients have to endure these afflictions, they also fought to improve their own situations and won the rights they rightfully deserved. Furthermore, in recent years, various patient-oriented activities have been implemented to reform the healthcare and social systems in Japan.

This issue has not been adequately discussed in the literature, because it involves a history of suffering and distress for patients who were hidden behind the progress of medicine and society. This paper aims to provide an overview of the history of what has been done for and by patients in Japan. When describing the history of patients, focusing on diseases that have caused significant social problems during each period is important [2]. Accordingly, the discussion in this paper focuses on diseases that have had a significant impact on the lives and behaviors of patients.

## II. Patients who were given anything other than treatment

### 1. Patients with cholera to be quarantined and left

### untreated

The first cholera outbreak occurred in Japan in 1822, during the Edo period, which was followed by a country-wide epidemic in 1858 [3-5]. At that time, cholera was called “korori,” which meant “quick death” in Japanese, because patients infected with cholera died within one or two days [2].

After the Meiji Restoration, a cholera epidemic broke out again in 1877 [4-6], and in the same year, the first notification on cholera control (“cholera byo yobo kokoroe,” in Japanese) was issued in Japan [2,4-8]. Finally, in 1879, the Regulations for the Prevention of Cholera were enacted, followed by the Regulations for the Prevention of Infectious Diseases in 1880, which provided comprehensive infectious disease control covering six infectious diseases, including cholera [4-9]. These regulations provided for the notification of the disease, establishment of facilities for evacuating people afflicted with the disease (“Hibyoin” in Japanese), isolation of patients, labeling of houses where residents had been infected, restriction of traffic to such houses, etc. [7,8].

In accordance with these regulations, “Hibyoin” were established throughout Japan; however, the “Hibyoin” was not the “Byoin,” which meant hospital in Japanese [2,3]. Patients with cholera who were admitted to the “Hibyoin” were only isolated and not adequately treated, as the Hibyoin were not adequately equipped or staffed [2-6,8,10]. Consequently, many patients died in the “Hibyoin,” which led to “Hibyoin” being ridiculed as “Shibyoin,” which meant a “hospital to die” in Japanese [2,11].

Because cholera control measures were under the jurisdiction of the police at that time, the isolation of patients, labeling of houses where the disease had struck, restriction of traffic to such houses, and other measures were firmly enforced [2-6,8]. As a result, people feared disclosing the disease and tended to hide its occurrence as much as possible [2,4-6,8,12]. The result was tension between the people and the police or the local authorities over cholera patients being hidden [2]. Eventually, between 1877 and 1890, riots and disturbances against patient isolation and other cholera control measures erupted across the nation, which is now known as the “cholera uprising” [3,5,6,9].

Subsequently, the labeling of houses with cholera patients was abolished in 1882 to prevent the hiding of patients [4,9], and institutional standards for Hibyoins were set in 1895, and facilities and staffing were improved [5]. The Regulations for the Prevention of Infectious Diseases were then repealed, and a new Act on the Prevention of Infectious Diseases was enacted in 1897, which was a compilation of infectious disease control measures that had been adopted up to that time [4,5,7,8]. This Act lasted for approximately 100 years until it was abolished in 1998.

## **2. Patients with tuberculosis to be initially treated differently according to disease conditions, socio-economic status and occupation, and then uniformly managed**

Tuberculosis became prevalent around 1870 [8], and the first private sanatorium was established in Japan in 1889 [2,8]. Although the number of private sanatoria continued to increase [2,7,8], only the wealthy had access to them due to their high cost [2,8,13]. As a result, tuberculosis came to be associated with the upper and wealthy classes [2,13].

As industrialization progressed in Japan from around 1900, factory workers, who were mainly female and young, were forced to work long hours under harsh working conditions and poor working environments, which gradually led to ill health and a sharp increase in the number of people affected by tuberculosis [7,8,13]. In particular, female factory workers were forced to work in extremely poor conditions. Female workers brought to the factory from rural villages were first placed in dormitories attached to the factory, where the living and eating conditions were the worst [2,6]. Once a female worker contracted tuberculosis, she was fired and sent back to her village without treatment [2,3,6,8,13]. Moreover, as such workers were too poor to be admitted to a sanatorium, they had no choice but to recuperate at home [2,13]. Finally, they became infectious agents of tuberculosis, which spread to their families and communities [2,3,6,8,13].

From this time forward, tuberculosis became a social problem, as it was no longer a disease of the wealthy [2]. In 1904, Japan's first law on tuberculosis control was enacted; in 1914, a law to promote the establishment of sanatoria was enacted; and in 1919, the Tuberculosis Prevention Act was enacted with the aim of promoting comprehensive tuberculosis control [7,8,13]. This Act provided for the establishment of sanatoria by local authorities, and for the mandatory admission of patients who were likely to transmit tuberculosis and who were unable to pay for medical treatment [7,8]. The Tuberculosis Prevention Act, which was partially amended in 1937, stipulated that every patient with tuberculosis who might transmit the disease should be

admitted to a sanatorium, regardless of their economic status [7,8]. Furthermore, as the number of military personnel affected by tuberculosis increased, tuberculosis sanatoria for disabled veterans were established in 1937 [8,9,13]. In the days before World War II, the military focused on measures to control tuberculosis as important to ensure the security of soldiers, in contrast to the actions taken with respect to female workers who contracted tuberculosis [2,6].

In 1947, after World War II, the Regulations for the Notification of Infectious Diseases were enacted in accordance with the instructions of the General Headquarters (GHQ), which stipulated that all patients with tuberculosis should be reported within 24 hours of being examined by a doctor [7,8,13,14]. Previously limited to patients with tuberculosis who were at risk of transmitting the disease, this regulation ensured that all tuberculosis patients had to be reported [7,8,14]. A new Tuberculosis Prevention Act was implemented in 1951, which stipulated that, based on the report of infection by a medical doctor, the public health center must prepare a registration form based on which a public health nurse would make a home visit [8,14]. Since 1961, a management system for patients with tuberculosis has been implemented throughout the country. This system has enabled public health centers to monitor the medical conditions, treatment status, and living conditions of all patients with and recovering from tuberculosis, and to instruct patients based on this information to ensure that they continue treatment and are cured [8,14].

## **3. Patients with Karyu-byo to be managed in association with specific occupations and gender**

Syphilis, which is one of the main sexually transmitted diseases (STDs), was introduced in Japan around the beginning of the 16th century. No prejudice or discrimination against patients with syphilis existed, as its etiology and treatment were clear, and anyone could be infected [15]. However, by the Meiji era of the 19th century, STDs were officially defined as "Karyu-byo," which is a disease transmitted in the "Karyu-kai," that is, the society of geishas and prostitutes, and therefore, the measures taken against the Karyu-byo centered on prostitutes [2]. As the first measure to control STDs in Japan, the examination of prostitutes was initiated in several districts in 1867 [6,8] and expanded nationwide in 1876 [2,3,8]. The system of licensed prostitution was established in 1900, and examinations of STDs for licensed and unlicensed prostitutes were also institutionalized [7,8]. In 1927, the Karyu-byo Prevention Act was promulgated, which stipulated that, in addition to licensed and unlicensed prostitutes, barmaids and geisha should also be covered [7,8].

From the Meiji era until World War II, measures against

STDs were established solely at the expense of prostitutes [2]. Prostitutes who were enslaved due to poverty were subjected to the double burden of debt and STDs [2]. Prostitutes in brothels were forced to undergo medical examinations, and those who contracted STDs were compulsorily hospitalized and quarantined [2,6]. However, brothel owners attempted to prevent the detection of Karyu-byo during medical examinations, to avoid absences of prostitutes from work [2]. This practice damaged the health of the prostitutes and led to the spread of Karyu-byo. Karyu-byo spread throughout society by infecting men, and from those men to their wives. Wives who were infected with Karyu-byo by their husbands were often forced to divorce [2,6]. Thus, women had to endure two tragedies regarding Karyu-byo—one as prostitutes and the other as wives [2].

In November 1945, after World War II, a special provision of the Karyu-byo Prevention Act was enacted and promulgated in accordance with the instructions of the GHQ, which resulted in a strict crackdown. Medical personnel were obliged to report patients with Karyu-byo in the same manner as other infectious diseases, and prostitutes were forced to take medical examinations and possess a certificate proving that they did not have Karyu-byo [7,8,14]. However, since the system of licensed prostitution was abolished in 1946 in accordance with the instructions of the GHQ [7,8,14], conducting regular medical examinations for prostitutes has become a challenge [8,14]. Therefore, STDs were redefined as infectious diseases affecting the entire population, rather than simply as Karyu-byo focused on prostitutes [8]. In 1948, the Karyu-byo Prevention Act was repealed, and at the same time, the Act on the Prevention of Sexually Transmitted Diseases was enacted [7-9,14]. Later, in 1999, this Act was merged into the Act on the Prevention of Infectious Diseases and Medical Care for Patients with Infectious Diseases.

#### **4. Patients with leprosy to be completely isolated from society for life**

The existence of leprosy in Japan was described in the *Chronicles of Japan*, which was compiled in the 8th century, and the legislation of the same period stipulated how to deal with people affected by leprosy [16,17]. With the introduction and dissemination of Buddhism, leprosy became regarded as a punishment for karma committed in a previous life [15-18]. Furthermore, because leprosy was often transmitted within families, it came to be regarded as a disease that was transmitted from parents to children through lineage or bloodlines, and finally as a genetic disease [2,16,19-24]. These perceptions regarding leprosy led to discrimination against, and the abhorrence of persons with leprosy for a long time [2,8,15-21]. Many patients with leprosy wandered

around towns and rural villages, sometimes living in their own colonies around shrines and temples [2,8,15,16,21,25-28]. Despite this situation, no measures were taken by the government [2,15], and the private sector was exclusively involved [2,7,8,21,25].

Leprosy did not become a major social problem until the Meiji era [2,8,11,20]. However, this was more of an issue of foreign affairs than public health [2]. In other words, patients with leprosy wandering around were considered an embarrassment when foreigners visited Japan [2,16,21,26]. In 1907, Act No. 11 was issued as the first legislation concerning measures to control leprosy in Japan [2,7-9,16,17,21,26,29,30]. The Act aimed at measures against patients with leprosy who were wandering [7,8,17,21,30,31], and stipulated the obligation of medical doctors to notify patients, the compulsory admission of patients who were resourceless and wandering, and the establishment of public leprosaria [2,8,21,30]. Although private leprosaria had been established before that time [7,8,16,29], five public leprosaria were established in 1909, after the Act came into force [2,7,8,16,21,25-27,29-31]. However, accommodating patients wandering around was not enough to eliminate leprosy [8,21]; therefore, Act No.11 was substantially amended, and the Leprosy Prevention Law was enacted in 1931 [7,8,17,21,25,26,29,31]. This law allowed all patients, whether they could be cared for at home or not, to be hospitalized without any financial burden being levied on their families [7,8,21,25,29,31]. A national policy was initiated to admit all patients with leprosy to leprosaria, exclude them from the community, and completely isolate them for life [17,21,26,29,31].

People with leprosy who were admitted to leprosaria were forced to live a life of hardship. When Act No. 11 first came into force, the treatment of patients with leprosaria was not always satisfactory, and there were many who disturbed the order in the leprosaria or ran away from the leprosaria [2,7,8,21]. To respond to these patients, the director of the leprosarium was given the right to conduct disciplinary inspections in 1916 [2,7,8,17,21,26,29-31], and punishments such as imprisonment, reduced diet, confinement, and reprimands were carried out under the authority of the director [26,29-31], without any judicial or other proper procedures [17,20,21]. Furthermore, to confine and correct patients who were particularly insubordinate at the leprosarium, a heavy confinement cell referred to as a "special ward" was established in 1938 at Kuriu-Rakusen in Kusatsu, Gunma Prefecture, where eligible patients were gathered from throughout the country [2,6,17,26,29-31].

Before World War II, the leprosaria had inadequate budgets, and inmates were forced to live extremely poorly in terms of food, clothing, and housing [2,17,30]. This led to

“work by the patient” to supplement daily living in the leprosarium. It is said that “work by the patient” began when patients became self-sufficient in providing their own food at the “Hukusei Hospital,” a private leprosarium established in 1889 [30,31]. Afterwards, “work by the patient” was subsequently introduced in public leprosaria [17,30,31]. The specific tasks of patient work were diverse and included cooking, laundry, sewing, gauze and bandage recycling, cleaning, waste disposal, housekeeping, construction work, farm work, cremation and burial of patient bodies, patient transportation, and nursing care for patients with severe conditions [17,26,30-33]. The most unreasonable of these tasks was nursing care for patients with severe conditions by those with mild conditions, which should have been performed by licensed nurses [2,30,33]. This was carried out based on the concept of “mutual aid and mutual love” imposed by the leprosarium, which said that “you should serve others when you are well, because your condition will eventually worsen and you will become disabled, and you will need to be taken care of by others” [2,17,30,33].

Vasectomy has been performed on male patients to prevent pregnancy and childbirth in public leprosaria [2,17,20]. In 1915, the first vasectomy on a male patient with leprosy was performed at Zensei Hospital, a public leprosarium in Tokyo [2,26,29,31]. Marriage in the leprosarium was permitted by accepting a vasectomy [17,21,29]. In some cases, male patients were forced to undergo vasectomy without consent, and female patients who became pregnant were involuntarily subjected to abortions [26]. The Eugenic Protection Act of 1948 legitimized sterilization and abortion for patients with leprosy and their spouses [21,26,29,31].

In 1953, the Leprosy Prevention Law was amended [8,9,31]. The main revisions were as follows: (1) patients who were likely to be infectious were to be admitted to the leprosaria, but were first to be convinced by recommendation; (2) patients were not to leave the leprosarium without permission; and (3) the director of the leprosarium could impose a warning or confinement on patients to maintain order in the leprosarium [7,8,14]. However, the Law stipulated no rules regarding discharge, and the policy of complete isolation remained unchanged [21,26,31,33]. In 1956, although it was not specified in the Law, the Ministry of Health and Welfare notified provisional criteria for patient discharge [21,31-33], and the number of patients discharged from the leprosarium after their condition became less severe increased [7,8,14,21,32,33]. Finally, in 1996, the “Act to Abolish the Leprosy Prevention Law,” drafted by the Ministry of Health and Welfare, was passed [21,27,28,31]. In this Act, it was stipulated that the necessary medical treatment should be provided to those who were admitted to a leprosarium and who would continue to be admitted to

the leprosarium, that patients could leave the leprosarium or remain there as long as they wished, and that those who decided to return to the leprosarium after discharge could be readmitted [27,28,33].

### 5. Patients with mental disorders to be in custody in private homes or hospitals

There were descriptions of insanity in legislation in the 8th century, which stipulated that patients with mental disorders were not obliged to pay taxes or serve the military, and that their penalties would be reduced if they committed a crime [15]. However, there was no evidence of persecution or compulsory isolation for patients [15,34]. Treatment for insanity began around the 14th century [35], and a number of shrines, temples, and private institutions provided care for patients with mental disorders during the Edo Era [36]. By contrast, people with mental disorders were often confined in private homes in the Edo Era [3,34,35], and it continued into the Meiji era [2,7,8].

In 1883, the Soma Affair occurred [34-37]. This case involved a lawsuit filed by a clansman from the former Soma Domain regarding the unfair confinement of a feudal lord of the Soma Domain who had developed a mental disorder [2,8,34-36]. This led to the issuance and enforcement of the Act on the Custody of Patients with Mental Disorders in 1900 [2,3,7-9,34-37]. The Act stipulated that: (i) patients with mental disorders must be assigned a person who is responsible for their custody; (ii) no one other than the person responsible for their custody may take custody; (iii) the person responsible for their custody is obliged to carry out the custody; and, (iv) permission from a government agency is required for the implementation of custody [2,7,8,35]. The Act was intended to protect patients with mental disorders from unreasonable violations of their human rights [8,35]. However, it lacked sufficient provisions for the care and treatment of these patients [2,8,35], and placed a heavy burden on their families and relatives, who were often responsible for custody of the patients [38]. In 1918, Shuzo Kure, et al. published “The Actual Situation of Custody of Persons with Mental Disorders in Private Houses” [2,34-36], which revealed that the number of persons confined in private homes had increased since the Act was enacted, that they were often confined in unsanitary conditions, and that medical care was rarely provided to the confined persons [34,35]. Furthermore, they called for the abolition of custody in private homes and the development of psychiatric hospitals [34,35].

The first public psychiatric hospital in Japan was established in Kyoto in 1871 [2,7,8,34,36], followed by a second in Tokyo in 1877 [2,8,9,34-36]. In 1919, the Psychiatric Hospital Act was enacted [3,7-9,34-37], which stipulated



national government subsidies for the establishment of prefectural psychiatric hospitals [7-9,35,37]. However, the number of psychiatric hospitals did not increase sufficiently [8,34,35,37]. Since the psychiatric hospitals of the time were primarily intended to provide custody rather than medical care [2,3,7,38,39], many instruments (handcuffs, shackles, chains, etc.) and methods of restraint were used for patients who were out of control [2,3], and cells were set up inside psychiatric hospitals to confine patients who were extremely violent [2]. In addition, nurses assaulted patients and stole patients' property, among other abuses [35]. Kure worked to gain respect for the human rights of patients with mental disorders and to improve their treatment, by prohibiting such restraints and the abuse of patients, and restricting the use of cells [2,3,34,35].

In 1950, the Act on the Custody of Patients with Mental Disorders and the Psychiatric Hospital Act were repealed, and the Mental Hygiene Act was enacted [7-9,14,34-37] to ensure respect for the human rights of patients with mental disorders and to improve their medical care [7,8]. The Act required prefectures to establish psychiatric hospitals, prohibit custody in private homes, and establish a system of involuntary hospitalization [8,35,37]. In a system of involuntary hospitalization, the prefectural governor may hospitalize a person with a mental disorder who is at risk of harming him/herself or others due to their disorder in a psychiatric hospital [8,35,37]. In 1964, the "Reischauer Affair" occurred, in which a boy who was thought to be schizophrenic injured the Ambassador of the United States to Japan [8,9,34,35,37,38]. Afterwards, in 1965, the Mental Hygiene Act was amended to strengthen the authority of prefectural governors with respect to involuntary hospitalization [8,14,34,35,37].

In 1984, two inpatients died due to violence inflicted by nursing staff at a psychiatric hospital in Utsunomiya, Tochigi [8,37,40], which led to the amendment of the Mental Hygiene Act in 1987 and its renaming to the Mental Health Act [8,9,37], and measures to strengthen the protection of patients' rights were implemented [8,37]. Although the Mental Health Act was replaced with the Act on Mental Health and Welfare for Persons with Mental Disorders or Disabilities in 1995, incidents of misconduct have occurred in psychiatric hospitals, such as injury resulting in death by a nursing assistant, deaths of patients due to inappropriate physical restraints, and isolation and restraint of patients without a diagnosis by a physician, among others [37].

#### **6. Patients with various diseases to be discriminated against for various reasons**

Patients were subjected to discrimination, and the most common diseases subjected to discrimination before World

War II were acute infectious diseases including cholera, tuberculosis, leprosy, and mental disorders [2]. Discrimination against patients with leprosy was particularly extreme [2], and they have long been subjected to both discrimination and abhorrence [2,8,15-21].

In addition to the above, patients with pollution-related diseases, occupational diseases, iatrogenic diseases, and rare and intractable diseases were also subjected to discrimination [2]. These diseases were often subject to severe discrimination and prejudice, because their causes and pathologies were not identified at the outset of their occurrence and were therefore regarded as "weird diseases" [2]. Regarding pollution-related diseases, discrimination against patients with Minamata disease [41,42] and Yusho (oil disease) [42,43] has been mentioned. In the early stages of the Minamata disease outbreaks, the disease was mistakenly perceived as a genetic disease, which may have led to discrimination [41]. Subacute myelo-optico-neuropathy (SMON) was suspected of being an infectious disease when it first occurred, resulting in discrimination against patients with SMON [44-49], many of whom committed suicide due to discrimination [45-49]. Discrimination against AIDS was complicated. Firstly, the large number of AIDS patients among men who have sex with men (MSM) had led to discrimination against MSM and against patients with AIDS [50]. Secondly, discrimination against patients with hemophilia also occurred because many patients with hemophilia who used blood products contaminated with HIV became infected with HIV [49,50]. Recently, discrimination against COVID-19 has remained fresh in our memory [51].

#### **7. Patients to be forced to participate in medical research and medical education**

Although involving patients is essential for the progress of medicine, a system called "patients for medical use" existed in which poor patients were utilized for research and education [2,52]. This system was introduced in 1877 at the University of Tokyo Hospital and subsequently spread to medical schools throughout Japan [52]. Under this system, patients were hospitalized only if they were poor and academically needed and were utilized for academic purposes [52]. While their human rights were not always well-preserved, in accordance with the Declaration of Helsinki adopted in 1964, measures were taken to protect the human rights and safety of patients and subjects participating in research and education, including informed consent [52].

Although slightly different from the system described above, patients who agreed to participate in research to elucidate the causes of diseases and establish treatment methods were also compensated monetarily. In FY1971, a program was introduced to pay 10,000 yen per month as

a reward for research participation among inpatients with SMON [8,46]. This program has been extended to other rare and intractable diseases and modified to compensate for out-of-pocket medical expenses [8,46,52]. Since 2014, subsidies have been provided purely to compensate for the medical costs of patients with rare and intractable diseases, rather than in the context of research participation [52].

### III. Patients who act on their own initiative

As described above, patients have been subjected to isolation, custody, compulsory hospitalization, involuntary work, and discrimination, not only to be treated but sometimes even not to be treated at all. They have also been subjected to unreasonable treatment and violations of their human rights, not as objects of treatment, but as objects of control. Furthermore, they have encountered great difficulties when making any kind of claim to such treatment [2]. After World War II, however, patients began to actively appeal to society, the government, and corporations to address their demands and concerns [2]. This developed into the patients' advocacy movement of Japan, which is said to be unique in the world [53,54].

Although there were incidents in the 19th century in which patients rose up en masse, such as the "cholera uprising" [3,5,6,9], patient associations organized by the patients themselves and the patients' advocacy movements which arose through their activities are said to have begun in sanatoria and leprosaria [2,53,54].

#### 1. Patients with tuberculosis and leprosy to struggle for their rights to life

Although there was a shortage of medical supplies and food in the sanatoria after World War II, in many cases, sanatoria managers and staff sold them illegally [53,55]. Patients began to ask for the release of concealed supplies, the expulsion of particularly abusive staff, and the democratization of the sanatoria [53,55]. By the end of 1945, patients began to form autonomous associations at each sanatorium [54,55]. In 1946, a federation of autonomous associations of several sanatoria in Tokyo was formed, which expanded to a federation of all prefectures by 1947 [53-55]. In the same year, a federation of autonomous associations of sanatoria for disabled veterans was formed [53-55]. In 1948, these two federations merged to form the first nationwide patient association in Japan, called the "Nihon Kanja Domei" in 1949 [53-55]. By virtue of the activities of the Nihon Kanja Domei, more than 10 new drugs for tuberculosis, including streptomycin, have been covered under medical insurance [53,55]. Another activity was resistance to a substantial reduction in the social security budget in FY1954 [7,53,55].

Although the reductions could not be withdrawn, the movement did result in strengthened measures to control tuberculosis [53,55].

In August 1957, Shigeru Asahi, a member of the Nihon Kanja Domei, filed an administrative lawsuit against the national government, claiming that the amount of public assistance benefits for patients in the sanatoria was too low and that it violated Article 25 of the Constitution of Japan, which stipulated that all people should have the right to maintain the minimum standards of wholesome and cultured living [53-55]. This lawsuit became known as the "Asahi Lawsuit," and the Nihon Kanja Domei continued to fully support Asahi [53-55]. Asahi won in the first instance [9,53,55], but lost in the second [53,55]. As a result, he appealed to the Supreme Court, which rejected his appeal in 1967, after his death in 1964 [9,53,55]. Although the Asahi lawsuit has been concluded, it has contributed to the improvement of Japan's social security system, including an increase in public assistance benefits [54,55].

Shortly after the establishment of public leprosaria in 1909, patients with leprosy began demonstrating and rioting to receive better treatment [2,29,30,54]. In 1926, the first autonomous association of patients with leprosy in Japan was established at a leprosarium in Kyushu [30,53,54], followed by the establishment of autonomous associations at other leprosarium sites [2,6,17,29,30,53,54]. After World War II, Promin was introduced to Japan as a new drug for treating leprosy [27,31]. In 1948, patients campaigned for a budget to be secured to obtain Promin [7,9,14,17,26-28,30,31], as new drugs were difficult to obtain either by import or domestic production [26,27,30]. Consequently, the budget was approved, and Promin treatment was initiated [27,28,30]. The movement to obtain Promin also served as the impetus for a revitalization of the autonomous associations of each leprosarium [2,6,21,26,31], and partnerships and unions were promoted among the autonomous associations [17,21,30,31]. Subsequently, a nationwide association of patients with leprosy, called the "Zenkankyo" was established in 1951 [6,7,9,14,17,21,26,30,31,33,53,54].

In 1953, when the Leprosy Prevention Law was amended, the Zenkankyo decided to hold demonstrations, patient work strikes, and hunger strikes to eliminate the policy of complete isolation, although this goal was not fulfilled [7,9,14,21,26,30-33,54]. Subsequently, the Zenkankyo met the requirement for an increase in nursing staff [30,33], and continued to submit several requests to the national government to amend the law [17,21,27,28,56]. At a meeting with the Zenkankyo in 1994, an external expert suggested that the Leprosy Prevention Law should be abolished rather than amended [17,21,27,33]. In 1995, the Zenkankyo proposed conditions for the lives and care of patients

that would be necessary to abolish the law [17,21], and in 1996, the Leprosy Prevention Law was finally abolished [21,27,28,31].

## **2. Patients with rare and intractable diseases, etc. to be engaged in activities to improve their medical care and their lives**

Since the 1950s, patient associations have been established for various diseases [53-55], and the establishment of patient associations was concentrated during 1965-1975 [55]. Patient associations were categorized into: (1) tuberculosis and leprosy; (2) rare and intractable diseases; and (3) pollution-related diseases, occupational diseases, and iatrogenic diseases [53]. Patient associations concerned with (2) require an elucidation of the causes of the disease, establishment of treatment methods, and assurance of livelihood, while those concerned with (3) require a clarification of the responsibility of perpetrators, such as the government and corporations, and compensation for medical care and livelihood [53].

In the 1970s, the various patient associations that had been established for each disease began to align with each other [55]. Regarding rare and intractable diseases, patient associations have been established for muscular dystrophy, SMON, Behçet's disease, myasthenia, collagen disease, etc. [8,57]. In addition, in April 1972, the National Liaison Council of Patient Associations for Rare and Intractable Disease, known as "Zen-Nan-Ren" was established, consisting of these patient associations [8,53-55,57]. Partly due to the efforts of Zen-Nan-Ren, the "Outline of Intractable Disease Measures" was formulated in October 1972 to promote measures for addressing rare and intractable diseases [53,55]. Furthermore, regarding diseases other than rare and intractable diseases, the National Liaison Council of Patient Organizations, known as "Zen-Kan-Ren" was established in November 1975, consisting of Nihon Kanja Domei and the Zenkankyo, among others [53-55]. In addition, local liaison councils of patient associations for rare and intractable diseases have also been established at the prefectural level [53,57,58], whereas Zen-Nan-Ren and Zen-Kan-Ren were national-level councils [53]. Since the first local liaison council was established in Toyama Prefecture in March 1972 [53-55,57], such councils have been established in more than 40 prefectures [57] with the advocacy of local governments [53,55]. In 1974, a liaison council of local liaison councils was also established to promote interaction among local liaison councils [53,55].

Subsequently, Zen-Nan-Ren, Zen-Kan-Ren, and the local liaison councils engaged in communication [57], and in June 1986, Zen-Kan-Ren and the local liaison councils merged to form the Japan Patients Council (JPC) [54,55,57,58]. Finally,

in May 2005, JPC and Zen-Nan-Ren joined to establish the Japan Patients Association (JPA) [54,57-59], thus forming a unified body of patient associations. The JPA defines the roles of patient associations as (1) to understand their own disease correctly and scientifically, (2) to encourage each other not to be defeated by the disease, and (3) to encourage society to create a better environment for medical care [54,57-60], and is actively engaged in activities such as petitioning the Diet [54,58]. As of September 13, 2023, the JPA comprises 100 patient associations [60].

## **IV. Future of Japanese patients: What will be done to them and what should they do?**

In Japan, patients were subject to control, not treatment, because the police had overall jurisdiction over the public health administration [4,5,7,8]. Regarding cholera, the police took the lead in implementing measures such as quarantine [2-6,8]. Measures against Karyu-byo were also under the jurisdiction of the police [2,6,8]. Regarding leprosy, Act No. 11 focused on controlling public morals and ensuring public security [2,7,8,21,29], and both the director and staff of the leprosarium were police officials at the time of its establishment [2,21,26,29,31]. Moreover, the police had the right to permit custody of patients with mental disorders in private homes [7,8,36], and patients with mental disorders could be confined for public security and social protection [2,3,14,34,35,37,38,40]. After World War II, the public health administration was no longer under the jurisdiction of the police [8], and the objects to be controlled were no longer patients, but diseases.

Although Article 25 of the Constitution of Japan, enacted after World War II, stipulated that all people should have the right to maintain minimum standards of wholesome and cultured living, it was necessary for patient associations and patients' advocacy movements to enable patients to actually achieve their rights [2]. In addition, various lawsuits filed by patients regarding pollution-related diseases [8,9,53], drug-induced diseases [8,9,37,53], and leprosy [31,37,56], as well as the Asahi lawsuit [53-55] have always raised the issue of the human rights of patients, not merely their claims for compensation for damages [2,53]. Furthermore, those who support patients in the advocacy of their human rights also play an important role [2], one of which is the ombudsman. The Patients' Rights Ombudsman was first established in Fukuoka City in 1999 [37,61,62], followed by Tokyo in 2002 [62]. Although the Ombudsman in Fukuoka was disbanded in 2017 [37, 62], only the Ombudsman in Tokyo continues its activities [37]. Otherwise, the Medwatcher Japan ("Yakugai Ombudsperson" in Japanese), which was launched in 1997 to monitor and prevent drug-induced dis-



eases [49,63,64], and the ombudsman for psychiatric care, which was initiated in Osaka in 2003 [65-67] continue to be active today.

Partly through the efforts of the patients and their supporters, the protection of their human rights is now explicitly stated in legislation. For example, in the Preamble to the Act on the Prevention of Infectious Diseases and Medical Care for Patients with Infectious Diseases, it is stated that "In the past in Japan, there was groundless discrimination or prejudice against patients suffering from leprosy, AIDS, and other infectious diseases, and those suffering from similar illness." "The Japanese public must take these facts seriously and apply them as a moral lesson for the future." [68] The Act stipulates full respect for the human rights of patients with infectious diseases and other individuals [68], although the quarantine of patients continues to be one of the measures taken against highly communicable and serious infectious diseases.

Although patient associations and patients' advocacy movements have aimed to make various claims or requests to the government and other entities, they should now promote actions to meet their own needs. While the livelihoods and medical care of patients are generally assured through the improvement of laws and regulations, it is not yet possible to elucidate the causes of the disease and establish treatment methods that are particularly required by patients with rare and intractable diseases. Previously, related research and development depended on the government, universities, and researchers. However, the patients themselves should be aggressively involved in research and development. From this perspective, Patient and Public Involvement (PPI), that is, "research being carried out 'with' or 'by' members of the public rather than 'to,' 'about,' or 'for' them" [69], is currently being promoted. Although progress has not yet been made in Japan [70], future development is expected, as the Japan Agency for Medical Research and Development (AMED), which is the funding agency for health and medical research, has prepared the Patient and Public Involvement (PPI) Guidebook [71], the National Cancer Center (NCC) has engaged in a pioneering initiative [72], and the JPA conducted a research project funded by the Health, Labour and Welfare Sciences Research Grants under the jurisdiction of the Ministry of Health, Labour and Welfare in 2012 [54].

It should be noted that patients are affected by the societal context. The policy of absolute isolation imposed on patients with leprosy has been influenced by modernization [23] and nationalism [21], and the treatment of patients with mental disorders has been influenced more by social conditions than by disease conditions [2]. Conversely, the patients' advocacy movement has been influenced by dem-

ocratic trends in Japan since World War II, such as workers' and farmers' movements [53,55]. Therefore, the future of Japanese patients should be monitored in the context of social trends.

In the past, Japanese patients were excluded from society and never returned, because a disease could not be cured and had to be avoided. Currently, Japanese patients are included in society because many diseases are now treatable or controllable, and because systems have been established that allow people to live in society, even when their diseases cannot be completely resolved. Anyone can become a patient, and anyone can be released from the role of patient. The patient is a reversible entity, and there is no rationale for excluding him or her.

### Conflicts of Interest

The author declares that there are no conflicts of interest regarding the publication of this article.

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<総説>

日本の患者の歴史  
—彼らは何をされ、何をしてきたのか?—

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抄録

日本の患者たちは様々な苦難に耐えながらも、自らの境遇を改善するために闘い、権利を勝ち取ってきた。本稿では、日本における患者の歴史、つまり患者に対して行われたことと、患者によって行われたことを概説する。

19世紀後半にコレラが大流行した際、患者は避病院に隔離され、ほとんど治療されないまま放置された。1900年代に入り工業化が進展するとともに、貧困層、特に女工の間で結核が流行するようになったが、療養所が不足していたため十分な治療がなされなかった。性感染症は「花柳病」と定義され、売春婦から男性へ、男性から妻へと社会全体に拡大し、女性は売春婦としての悲劇、妻としての悲劇に耐えてきた。20世紀初頭から、浮浪徘徊するハンセン病患者は療養所に収容されるようになり、その後全てのハンセン病患者を療養所に入所させ、生涯完全に隔離する政策が進められた。ハンセン病患者の中には、監禁、減食、謹慎、譴責などの処罰を受け、清掃、洗濯、重症患者の看護などの「患者作業」を強いられ、断種される者もいた。精神疾患患者の多くは私宅に監置されていたため、精神病院の設立が推進された。精神病院では、手錠、足かせ、鎖などの拘束具が使用されることもあった。その後私宅監置は禁止され、自傷他害の恐れのある精神疾患患者を入院させる措置入院制度が設けられた。

患者に対する差別は、上記の疾患だけでなく、公害病、職業病、医原病、難病、エイズ、COVID-19も対象となった。また貧困の患者を研究や教育に利用する「学用患者」と呼ばれる仕組みも存在していた。

第二次世界大戦後、患者たちは自身の要求や問題を社会に積極的に訴えるようになり、それは世界でも珍しい「患者運動」へと発展していった。患者会は当初、結核やハンセン病の療養所の患者によって組織されたが、1950年代以降、難病や公害病など、様々な疾患の患者会が設立されるようになった。1970年代に入ると、疾患ごとに設立された患者団体が互いに連携するようになり、2005年5月、患者団体の統一組織として日本難病・疾病団体協議会（JPA）が設立された。

患者の人権の擁護や生活・医療の保障については法律等で明文化されるようになった。しかし、特に難病患者が求めている、疾患の原因解明や治療法の確立には至っておらず、患者自身が積極的に研究開発に関与する「患者・市民参画（PPI）」の推進が必要である。

キーワード：患者会・患者団体、差別、ハンセン病、難病、患者・市民参画（PPI）