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Justice of Listening: Japanese Leprosy Segregation

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1. Human rights abuse and Japan's leprosy segregation

Human rights relating to illness are quite often counter-intuitive. There is a need to carefully examine whether the stigmatic experiences of patients in certain contexts constitute an unjustifiable human rights abuse, or whether the abuse becomes legitimized in such circumstances. Leprosy—or Hansen's disease—has been associated with stigma since ancient times, because, of course, for centuries no cure existed. However, there is insufficient understanding of how this stigma continued to threaten and trample human rights in modern times. With regard to infectious diseases, such as leprosy, tuberculosis, severe acute respiratory syndrome, and influenza, the medical and political debate has continued to focus on the legitimacy of liberty-limiting interventions, especially patient isolation. Although isolating patients with infectious diseases is not universally considered wrongful conduct from a medico-ethical perspective, forced isolation can constitute a human rights abuse when it is implemented in excess of the permitted degree, without adhering to the specified conditions.¹ Japan's leprosy control policy exemplifies this type of excess implementation, and it took several decades and lawsuits against the country for the policy to gain widespread social recognition as a form of human rights abuse.

One way to evaluate human rights abuses surrounding illness focuses on the “lived experiences” of afflicted patients. Lived experiences often include details about the severity of their suffering within a unique set of circumstances—to which healthy people are little sensitized. Another crucial approach is to concurrently examine the logic of the “perpetrators.” Human rights abuse surrounding illness is occasionally implemented by the very persons expected to aid patients—medical practitioners and policymakers. They are obligated to act in ways suited to the characteristics of the illness as well as to the medical, legal, temporal, and social contexts surrounding it. Thus, the ethical legitimacy of their actions must be questioned.

Lifetime isolation

In 2001, the Kumamoto District Court made a landmark ruling that the isolation policy and its legal basis, the Leprosy Prevention Law, had violated the fundamental human rights guaranteed in the Constitution of Japan. The next year in 2002, I made my first visit to the National Leprosarium Kuryu Rakusen-en. This leprosarium was located on a beautiful plateau with quiet, green surroundings. My impression corresponded with the worldview presented in Thomas Mann's *The Magic Mountain*. In Mann's story, the character Hans Castorp visits a

tuberculosis sanatorium where his cousin is being treated. This highland sanatorium's world is extremely different from the outside world. Hans, a visitor to this dizzying world, eventually gets infected and becomes a resident of the sanatorium. Like many other patients, he is unshaken by his fate and accepts life in the isolated world he finds himself in. Similarly, the residents I met in the leprosarium also seemed to have accepted the confined lives that they had been forced to lead for years.

However, according to the patients' writings, admission to Kuryu Rakusen-en was far from the calm process described in *The Magic Mountain*. As a newcomer to the "Hansen's disease problem" after the Kumamoto ruling, I knew that a large number of patients' writings and interviews were archived in various forms. Some had been published by major publishing houses, others by each leprosarium or its patients' association (*jichi-kai*) as in-house journals and booklets with small-scale circulation. Trial records and government documents including patients' testimonies were also accessible. The majority of the patients' writings and testimonies include sentimental descriptions about a variety of topics including leaving their families, losing personal relations with friends and colleagues, and giving up their plans for living a full and normal life. As if that were not enough, when leprosy patients experienced forced isolation, they were often treated with hostility. During the first half of the 20th century, when the majority of patients were detained, they were treated like criminals. For example, one patient describes how, during transportation to the leprosarium, he alighted from the train at a station and awaited a vehicle. While waiting, his attendant drew a chalk circle around him and ordered him not to step outside the circle. He was not permitted to sit on a station bench or drink water.²

From a medical ethics perspective, the isolation of patients is legitimate if their disease is highly infectious, the symptoms are severe, and the disease cannot be prevented or cured. The debate over whether leprosy is an infectious or another type of disease (for example, a hereditary disease) ended in 1873, with the discovery of *Mycobacterium leprae*. Nineteenth-century doctors became aware that leprosy is not highly infectious or fatal and the symptoms do not worsen in all patients.³ Leprosy primarily affects the skin, peripheral nerves, eyes, and upper respiratory tract. The physical deformities that occur as a result have spawned dread and horror in most places since ancient times. However, treatment for leprosy with sulfone drugs was established from the 1940s; therefore, eliminating the need to isolate patients.

In spite of this, forced isolation of leprosy patients continued in Japan until the end of the 20th century. Even though leprosy was treatable, the Leprosy Prevention Law, revised in

1953, did not state any clear conditions under which a patient might be released. Therefore, if patients were diagnosed with leprosy, they were isolated in a leprosarium and were not allowed to leave, even after they were cured. The continuation of this isolation policy was linked with *Muraiken Undo* (literally, the No Leprosy Patients in Our Prefecture Movement). In response to the government's adoption in 1936, of a 20-year plan for the eradication of leprosy, municipal governments in Japan encouraged citizens to find and report leprosy patients to the authorities.⁴ As a result, by 1955, 11,057 people—an estimated 91% of all leprosy patients—were admitted to leprosaria. Patients likened this isolation policy to Nazi Germany's policies to eradicate the Jews because they thought the aim was to solve the problem not by eradicating the disease, but by eradicating the *people* with the disease.⁵ For them, segregation was not only a “forced isolation,” but also a “lifetime isolation” that continued even after a patient was cured.

Forced labor

The greatest difficulties in implementing lifetime isolation for all leprosy patients occurred when patient numbers were the highest. There was no effective treatment for leprosy until the mid-20th century; however, the illness was not fatal, and many patients survived until they were middle-aged or elderly despite being physically disabled. Thus, the isolation of patients over many years entailed huge financial costs. From the end of the 19th century until the early 20th century, several countries, India for instance, considered forced isolation, but did not implement it.⁶ Along with the morality of respecting patients' rights of self-determination, the cost was prohibitive. However, Japan's policymakers attempted to overcome these financial hurdles by forcing patients to work for low wages. At the National Leprosarium Tama Zensho-en, located in the suburbs of Tokyo, work for patients began on a voluntary basis, with the leprosarium offering an incentive for patients to engage in work. According to a survey conducted at this leprosarium in 1912, the patients admitted to this facility had worked in more than 70 professions such as farming, fishing, commerce, blacksmithing, carpentry, stonemasonry, mechanics, printing, managing bookstores and restaurants, and teaching.⁷ At this leprosarium, these patients' wages consisted of contributions from the leprosarium's operating costs. Their wages were confiscated by the leprosarium to prevent, for instance escape, and then exchanged for vouchers that could be used only within the leprosarium. In the 1940s, when Japan was involved in the war, there was a severe shortage of resources, and patients had to maintain the leprosarium itself, partly by caring for other patients. At the time, at Kuryu Rakusen-en, located in the mountains of the

Gunma Prefecture, the most demanding work was allocated to patients. To save on automobile fuel, patients carried 15–45 kg of charcoal for heating from a village 10 km away. Although some patients injured the soles of their feet during this process, they remained oblivious because of their sensory disturbance. A patient wrote that when he took off his boots, the snow was stained red with the blood that gushed out.⁸

Sterilization and abortion

The control policy of Japan's leprosy differed from that of other countries because of its measures for controlling reproduction among patients. The notion that leprosy patients should not have children was shared to a degree among those involved in patient care at the time. Not only Japanese doctors but also foreign nationals working for the salvation of leprosy patients in Japan held this opinion. British missionary Hannah Riddell, who opened Kaishun Hospital, a private leprosarium in Kumamoto, stated that men and women should be separated.⁹ However, Japan's doctors asserted that physically separating men and women was unrealistic. Instead, doctors in Japan used sterilization and performed vasectomies on male patients. This strategy has often been attributed to eugenics, which had gained popularity in the medical world at the time;¹⁰ however, doctors believed that sterilization was in the best interest of the patients themselves. In 1915, Kensuke Mitsuda, the Director of the National Leprosarium Nagashima Aisen-en, performed the first vasectomy on a male patient at that leprosarium. According to Mitsuda's memoirs, this patient had great respect for Mitsuda. Despite having deformed fingers, the patient gained admission to Zensho-en by binding a pen to his fist to write the application letter. At the time, he was nearly 50 years old, and he married a woman he fell in love with at the leprosarium. Mitsuda asserted that this patient requested a vasectomy and depicted this situation in an idealized way as love between patients that does not involve children.¹¹ In his opinion, retaining sexual desire and functions while preventing children from being born was a benefit that doctors should provide to leprosy patients.

This control of reproduction had a serious impact on the lives of many patients. One female patient related her tragic experiences in an interview.¹² She said that she became pregnant prior to her husband undergoing sterilization. When she was seven months pregnant, she was summoned by the leprosarium's doctor. At the time, abortions were legally permitted up to eight months into the pregnancy. She said that she wanted to consult her husband first, but the doctor refused to allow her to do so. Following the operation, a nurse showed the woman the still-alive fetus, saying, "What a cute girl—she looks just like you!" The nurse

then smothered the fetus's face with a piece of gauze, suffocating her. Several decades later, this female patient remained unaware why the doctor and nurse acted in such a manner. By the time this woman and other female patients reached old age, it became legal for them to leave the leprosarium. However, there were no children or grandchildren to greet them in the outside world, and this discouraged many women from leaving.

Arbitrary punishment

Leprosy patients voiced their dissatisfaction to staff over their poor treatment in leprosaria. However, in the context of the time prior to the Second World War, their complaints were suppressed through physical force. This consisted of punishments extended beyond the rule of law and were left to the doctors' discretion. Doctors working in leprosaria were agitated about the police's insufficient action against disobedient patients. Therefore, they petitioned the government to establish a designated prison for leprosy patients; however, their request yielded no results. When the Leprosy Prevention Law was revised in 1916, leprosarium directors were granted police authority. Among the various punishments for patients, the most severe was confinement in a *kankinjo* (guardroom) built in each leprosarium and the reduction of meals. In addition, doctors set up a special prison at Kuryu Rakusen-en where they could mete out the harshest punishments to patients. While these were officially called *Tokubetsu Byoshitsu* (literally, special sickroom), in reality, these were prisons without any heating facilities, without light, and from which patients did not easily emerge alive. Many of those imprisoned died in winter, when the snow lay thick on corridors open to the sky between the eight cells of Tokubetsu Byoshitsu. The room temperature sometimes dropped below -3° or 4°F. According to records, between 1939 and 1947, 93 people were imprisoned. Among those, 22 died either during imprisonment or shortly after release.¹³

Tokubetsu Byoshitsu has subsequently been discussed as a symbol of human rights abuses by patients seeking changes in the leprosy control policy. However, none of the survivors of Tokubetsu Byoshitsu have spoken about their experiences. This may be a common phenomenon observed in those who have suffered extreme duress. Survivors of Tokubetsu Byoshitsu left few records and would not discuss their experiences even privately with patients they were close to. Only written testimonies of those who had contact with former prisoners are available. For example, Michita Yamai was a working gaffer at a washhouse in Tokyo's Tama Zensho-en.¹⁴ Although the patients worked in boots, many of

the boots provided were old and tattered. It was difficult for leprosy patients with sensory disturbance to endure wet feet; therefore, the patients requested that the boots be exchanged for new ones. This request, which was denied, was made to leprosarium officials by gaffer Yamai. After the denial of this request, the patients decided to go on strike. Yamai was taken into custody by 20 officials and sent to Tokubetsu Byoshitsu. Yamai's tearful wife pleaded with the officials for forgiveness; however, they responded by imprisoning his wife as well. Yamai was imprisoned on June 6, 1941 and released on July 18. Upon his release, he was extremely weak and unable to walk. He died on September 1.

2. Writing for human rights

People can now learn about the patients' ill treatment by reading their experiences in books and court records. However, we need to focus on the audiences. As Catherine K. Riessman states, "[E]vents perceived by the speaker as important are selected, organized, connected, and evaluated as meaningful for a particular audience."¹⁵ What types of audiences (actual and supposed) have the patients' writings reached? Did a specific audience exist from the outset? Unquestionably, for Japanese leprosy patients, their lived experiences have served to report the realities of human rights abuses. Although survivors of Tokubetsu Byoshitsu did not record their experiences, many other leprosy patients continued writing in the closed world of the leprosaria. Their activities began during the era of Japanese imperialism, when freedom of speech was not guaranteed. Some accounts were written as diaries and letters in an everyday context, some were written as petitions to leprosaria managers and the government in a legal context, demanding revisions to the law, and others were written as novels or poems in a literary context. Patients' writings were active enough to give rise to the genre of "leprosy literature;" however, the writings left a gap between the patients and their audience—between those who recorded real-life accounts and those who read or listened to them.

Crying for human rights

Patients who had been isolated in leprosaria for extended periods and who were forced into harsh labor began voicing their dissatisfaction. At the time, most patients nationwide were admitted to leprosaria; therefore, the number of isolated patients exceeded leprosaria capacity. According to the aforementioned memoirs of Mitsuda, in the National Leprosarium Nagashima Aisei-en in Okayama, approximately 1,200 people had been admitted by 1936, in

spite of the facility's capacity of only 890 patients.¹⁶ This overcrowding became a causative factor in what was later called the Nagashima Riot. On August 11, 1936, 90 patients appealed for wages, which had been cut, to be restored to their previous levels. This led to a dispute, and the patients convened a meeting in a chapel, following which they made four demands: (1) improvement in their living conditions, (2) a raise in reward for their services, (3) the formation of a patients' association, and (4) mass resignation of employees. On the morning of August 13, approximately 800 patients abandoned their work and went on strike. Some even broke windows and commenced a hunger strike. The incident was widely reported; as a result, the necessary funds were provided to raise the wages and deal with the overcrowding. Although the formation of a patients' association was refused because the National Leprosarium Nagashima Aisei-en was a public facility, patients were granted autonomous control over labor and stores. This event was historic in modern Japanese medicine and marked an important achievement; patients mobilized to assert their rights and, to a certain degree, achieved their goals.

Triumph of doctors over patients

After the Second World War, with the guarantee of freedom of speech and assembly included in the new constitution, the patients' rights movements increased and became more organized. Their demands were centered on Promin, a sulfone drug used to treat leprosy. In poverty-stricken postwar Japan, the government attempted to reduce the budget for Promin, but over 140 patients began hunger strikes in their asylums.¹⁷ This drug, developed in a US leprosarium, is highly effective and has been nicknamed the "Miracle of Carville" after a book written by a female patient.¹⁸ Obtaining this drug should have allowed patients to obtain freedom from their lives of isolation in leprosaria. However, this was not the case. Arguments regarding leprosy drugs between patients and doctors resembled a political, not a medical, dispute. This manifested itself in the offensive and defensive maneuvers surrounding revisions to the Leprosy Prevention Law in 1953. In the Diet, three leprosaria directors testified about the need to maintain (or strengthen) forced isolation. Patients surrounded the Diet Building and staged a sit-in, demanding the easing of forced isolation, while some engaged in a hunger strike.¹⁹ The patients presented their case on the basis of scientific evidence. They correctly argued that leprosy is treatable and, in fact, is not even highly infectious. In contrast, the doctors' arguments were largely political. Mitsuda gave the following testimony to the Diet:

We must act quickly in admitting the remaining patients, but there are many who refuse. Under the current circumstances, it is not possible to forcibly admit these kinds of people. In this respect, we need to revise the law. If we do not invoke state power in this matter, the situation will remain unchanged for many years to come and infections within households will continue unchecked.²⁰

Eventually, the doctors' demands were accepted into the 1953 revisions to the Leprosy Prevention Law. As before, the law promoted forced isolation, prohibition from leaving leprosaria without permission, and punishments for rebellious patients. In spite of leprosy being curable, rules for patients' discharge from leprosaria were not clearly set out in the law. The great gap between Japanese experts and international experts is revealed in records from the 7th International Leprosy Congress, held in Tokyo in 1962. At this congress, two main points were discussed: (1) common knowledge on early detection, early treatment, and ambulatory treatment, and (2) the abolition of laws prescribing forced isolation. However, a bureaucrat from the Japanese Ministry of Health and Welfare, speaking on behalf of the government, stated that "While the peak for infections has passed, there are many patients still at home who have not been admitted who are acting as a source of infection. Therefore, it is desirable for them to be admitted at an early stage."²¹

Leprosy literature

Even though the voices of patients' were silenced by those of powerful doctors and bureaucrats, patients still managed to write about their daily experiences in a range of forms. Despite often being denied of public education, leprosaria patients were taught how to write by volunteers. Thus, they were encouraged to indulge in creative writing. In particular, many engaged in literary writing, which even formed a discrete literary genre called "leprosy literature."²² Whether explicit or implicit, their literature was thematically based on patients' experiences of their illness. Their writings included lived experiences of the illness, elucidating many aspects of the patients' lives, such as their lives before and after arriving at the leprosarium, family partings, harsh experiences at the leprosarium, experiences that led to the discovery of joy and love, the deaths of other patients, and the deaths of family members from whom they were separated. All these aspects were depicted with literary passion.

A poem composed in 1941 by an anonymous sixth-grade elementary student expresses a theme that elicits sympathy—sorrow at being forever separated from family members.

When it rained
My mother always
Roasted beans for me.

I hear the sound of the rain
Like beans roasting
And realize my mother is no longer by my side.²³

How was this poem read? Or rather, who was the audience? Readers today would probably feel a sense of realism and pity at how the sound of rain conflates with the sound of beans being roasted by the child's mother. At the time of this poem's composition, outstanding works from among the patients' poems were selected by professional poets who provided the patients with literary guidance. Yuji Kodama, a patient who later became one of the first court plaintiffs to challenge the national government, continued writing poetry for many years. He recalled the first time he met Mitsuo Ohe in 1952. Ohe was a non-patient poet who had singled him out and with whom he had corresponded over several months. During their first meeting, Ohe muttered that he wanted to take Yuji to his home, but that it would be difficult.²⁴ Even though a few readers outside the leprosaria were sympathetic to the patients' plight, their sympathy was based on the assumption that the patients' isolation was unavoidable. Very few of the patients' readers questioned leprosy's supposed incurability and the patients' need for isolation in leprosaria.

Approximately three months before his death from intestinal tuberculosis in 1939, Kaijin Akashi published *Hakubyo*, one of the most widely read leprosy literature poetry collections. At the beginning of this collection, which sold 250,000 copies, Akashi wrote that "[l]eprosy fell upon me like a divine scourge."²⁵ However, when his illness became so severe that he was beyond recovery, he viewed it as a "divine revelation." The reasons he gives are as follows:

I was over 30 when I learned to write *tanka*²⁶ and, as I reflected anew upon myself, other people and the world, I felt in my heart the beauty and the grandeur of existence. In poem after poem, I released years of bitter hardship, sometimes weeping, sometimes dancing for joy as I celebrated that spark of soul incarnate in my body.

I gained such insight into the human condition that I became familiar with a love that exists apart from the bonds of flesh. Only after I lost my sight did a vision of blue mountains and white clouds flare up within me.²⁷

Akashi's loneliness—metaphorically represented “like those luminescent fish dwelling in the sunless depths of the sea, I would not have light until I illuminated myself from within”²⁸—particularly resonated among Japanese readers. However, within this expression of autonomy and endeavor to find value within oneself, readers observe an expression of acceptance of life as a patient forced into isolation. Akashi's graceful, poetic acceptance may have led readers (and some writer-patients) to forget that this harsh isolation was artificial and systematic.

In Tamio Hojo's 1936 novel *Inochi no Shoya* (literally, *The First Night of Life*), of the notion of striving to find values within oneself is depicted from a perspective closer to that of outsiders (non-patients). This short story is one of the most widely read works among those written by leprosy patients. Hojo employs a first-person perspective to realistically depict a young male patient (somewhat autobiographically) during his first few days in a leprosarium, when he is treated with indifference by the leprosarium staff. He closely observes other patients and is shocked at the “faces like rotten pears” of those seriously afflicted by the disease.²⁹ The young man loses hope and tries, but ultimately fails, to commit suicide. A patient who witnesses his attempt tells him that leprosy patients “are not human. They are life itself.” This patient continues, “However, we are phoenixes. When we have new ideas or gain new insights, when we obtain the life of a leper, this is when we are resurrected as humans.”³⁰ In 1936, the novel was published in the influential journal *Bungakkai* and won the journal's prize for newcomers, a stepping-stone to success in Japanese literary society. Hojo took a young non-patient novelist Yasunari Kawabata, who won the Nobel Prize for Literature in 1968, as his literary teacher and wrote 66 letters to him. Kawabata recognized his talent and sent 24 responses, recommending that he read Dostoevsky, Tolstoy, and Goethe.³¹

Hojo's work reached a high degree of excellence, which earned him acclaim from influential members of literary circles. As evinced by the fact that Hojo himself hated his works being referred to as “leprosy literature,” the works of leprosy patients were ultimately expected to transcend the genre. Hojo's success and reputation, however, illustrates how Japanese society responded to the “life-writing” and its representations of the “lived experiences” of patients. Susan L. Burns pointed out the gap in attitude toward leprosy literature between writers (patients) and readers (critics).³² According to a former patient Hiroshi Shima, one of the patients who sued the Japanese government, “writing was the only

means to pass beyond the walls of the leprosarium.” In contrast, Otohiko Kaga, a non-patient novelist stated in 2002, “...since it is extraordinarily rich, I thought, isn’t this a great gift to Japanese literature. In ‘Hansen disease literature,’ there is the style that burst out of the bodies of those who were sick.” Burns questioned Kaga’s attitude because “Here Kaga’s concern is not to explain why patients wrote but the validity of labeling these texts ‘leprosy literature’ and the significance of this genre for ‘modern Japanese literature.’”

Audiences in judicial contexts

With the end of the Second World War in the 1940s and appearance of wonder drugs in the 1950s and 1960s, did approaches to reading 1930s leprosy literature change? By the end of the 1940s, the effects of the sulfone drug Promin had been recognized. Patients commenced movements demanding that they should receive the drug in response to revisions made to the Leprosy Prevention Law in 1953; however, they suffered setbacks. One of these was caused by the case of a young male patient in Kumamoto, who was arrested as a suspect in a murder case that occurred in 1952. The trial was conducted within the leprosarium as a precaution against infection. Although the defendant continued to deny the murder charge and there was insufficient physical evidence to implicate him, in 1962, the defendant was given a death penalty on the basis of the unreliable testimonies of two witnesses and the defendant’s statement, which the prosecutor is suspected of having forged.³³ This led to a social movement seeking to ensure the patients’ right to a fair trial. In the 1970s, the therapeutic value of Rifampicin was recognized, and fewer leprosaria doctors kept patients isolated on the grounds of contagiousness. In the 1980s, the World Health Organization promoted the use of multidrug therapy. As a result, leprosy became completely curable, and the isolation of patients was finally recognized as irrational. However, over the past few decades, former patients have become old. Fujio Ohtani, a former Ministry of Health and Welfare bureaucrat, regretfully recalled that it was difficult to allow old people suffering the after effects of leprosy to leave leprosaria without the provision of social welfare. He thought, rather than abolishing the segregation policy, ameliorating leprosaria conditions would be in their best interests. According to Ohtani, his “misjudgment” might have aided the Leprosy Prevention Law’s continuation until the 1990s.³⁴

In 1990, an event occurred among lawyers that changed audiences’ attitudes to writings and testimonies of former patients. A letter arrived at the Kyushu Federation of Bar Associations from former patient Hiroshi Shima, containing the following:

For the past decade or so, I have been criticizing the inhumanity of Japan's leprosy policies, and have appealed for the abolition of the Leprosy Prevention Law and for revisions to the Eugenic Protection Law [this law gave approval for the use of sterilization and abortions for leprosy patients]... I cannot understand how those in legal circles, those who are supposed to have the profoundest of involvements in matters relating to human rights, express no views on this matter and continue to stand by and watch.³⁵

Hiroshi Shima's letter prompted the lawyers to visit the leprosarium and collect testimonies of patients. Although the Leprosy Prevention Law was abolished in the following year, 1991, the lawyers felt that the negligence over the long-standing failure to take action should be subjected to trials. Shima was motivated to write his letter by a letter he had received from Noriyasu Akase, a plaintiff in a lawsuit over AIDS, which he had contracted through contaminated blood. In his letter, Akase said, "Why don't Hansen's disease patients get angry?"³⁶ The subsequent AIDS lawsuit focused on the negligence of officials from the Ministry of Health and Welfare and hemophilia specialists who, despite knowing that the imported blood was infected with HIV, continued to administer it to patients. Thus, hemophilia patients were driven to take the Japanese government to court. This helped Shima and other former patients decide to highlight their unfair treatment in a judicial context as well. Therefore, by the latter half of the 1990s, patients' stories had been overwhelmingly situated in judicial contexts. When claims were filed for national compensation, many life stories of former patients, in the form of testimonies, were relayed nationwide. In 2001, a landmark decision by the Kumamoto District Court recognized state negligence among the dominant voices supporting the plaintiffs. Within the context of the court, the patients' testimonies were heard with enthusiasm, leading to the "discovery" of vast quantities of writings from the past. The dominant voices supporting the plaintiffs permeated newspaper and television reporting. Furthermore, as a result of the judgment, a large section of the Japanese public began reading the writings of former patients.

Once the government had abandoned its appeal, following which Junichiro Koizumi, the Prime Minister, met with former patients at his official residence, media attention surrounding the "Hansen's disease problem" began to dwindle. The former patients' judicial victory seemed to signify the end of the "problem." However, in November 2003, former patients reemerged into the media spotlight. Former patients of the National Leprosarium

Kikuchi Keifu-en were refused a room when they tried to stay at a hotel in Kumamoto prefecture. This incident revealed that the attitudes of the public had changed greatly within a short time. Initially, criticism of the hotel owners dominated, until they visited Kikuchi Keifu-en to apologize. The former patients, deeming the hotel owners' explanation of events insufficient, refused to accept the apology. Once the refusal was reported, Kikuchi Keifu-en was inundated with letters, faxes, and emails that employed vile language to abuse the former patients.³⁷ To these anonymous critics, the former patients had "gone too far." They had won national compensation and "should behave with the modesty befitting weak people who require care." One of the hotel owners stated, "As long as discriminatory sentiments exist among people, as hotel owners, we have no choice but to refuse certain people." These words thinly veil feelings toward leprosy that have remained unchanged for thousands of years.

Following this incident, my colleagues and I arranged a lecture to be conducted by Yuji Kodama, a former patient, wherein he stated, "As we were continually subjected to verbal abuse from members of staff at the leprosarium, we were used to it. However, this recent incident was tough." He was astonished by how people outside the leprosarium could adopt such an unsympathetic attitude. Were the audiences of the former patients' testimonies in the 2001 court case and the anonymous critics of 2003 different people? Or had the same audiences assumed a different face?

Concluding remarks

In this chapter, I have argued how, in Japan, liberty-limiting interventions perpetrated on people with leprosy constituted human rights abuse. Only through the patients' writings and testimonies could we feel and know how "lifetime isolation" traumatized them: They had to give up the life they expected, planned, and, in many cases, were actually living. They accepted and endured forced and exploited labor in the leprosaria. They were coerced into sterilization and abortion and the painful memories of these traumas. They had to act submissive, frightened by the arbitrary punishment that led to 22 patients' deaths at Tokubetsu Byoshitsu.

I have also described how the victims' and perpetrators' stories were interpreted differently, according to context. In the political context, patients likened the isolation policy to Nazi Germany's Final Solution, but the doctors believed isolation was in the best interests of their patients. When the effective drug Promin became available in the 1950s, patients appealed for it on accurate scientific grounds that leprosy is curable. Yet, the doctors testified before the Diet in extremely political ways; they could not justify the legitimacy of isolation

scientifically and ignored proven facts. The verbal battle ended with the doctors' triumph. Thereafter, the patients' stories were seldom heard by politicians, lawyers, journalists, academicians, and all others who remained silent or indifferent to the "Hansen's disease problem." Only in the 1990s, when the patients' stories were put into the judicial context were they actually heard.

In the literary context, some patients' stories were celebrated as "leprosy literature," and as a great gift to Japanese literature. The stories vividly depicted patients' life experiences. But even leprosy literature did not gain patients a hearing, partly because the patients' stories had to be elaborate works that captured some degree of literary universality; therefore, leprosy literature remained only within a literary context. Readers seldom questioned the assumption that the patients' isolation was unavoidable and unchangeable.

Some argued that the delay in terminating this flawed policy was inertia and other obstacles that had to be overcome first.³⁸ However, a better question to ask is whether the delay was ethically acceptable. The Japanese segregation of leprosy patients showed that decades of delay responding to scientific facts as well as the fact that medico-political regulations can lead to traumatic human rights abuse. By failing to take prompt action for decades, policy makers ensured that people with leprosy became old and died—isolated from what they loved and from most of what makes life worth living. In conclusion, I invite readers to thoughtfully consider a field that I call the "justice of listening": When a person speaks to others, should she have the right to choose the context of her story's hearing? When she is unaware that her story is received in a context not in her best interest, should someone else indemnify her and her story from harm?

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Endnotes

¹ As Christian Enemark and Michael Selgelid remark, ethicists have to consider the possibility of conflict between the promotion of public health and individual rights and that between the protection of national security and individual rights. Christian Enemark and Michael J. Selgelid, “Introduction,” in *Ethics and Security Aspects of Infectious Disease Control: Interdisciplinary Perspectives*, ed. Christian Enemark and Michael J. Selgelid (Surrey: Ashgate, 2012).

² This case is detailed in Kuryu Rakusen-en Kanja Jichikai. *Fusetsu no mon: the 50-year history of patients at Kuryu Rakusen-en* (Gunma: Kuryu Rakusen-en Kanja Jichikai, 1982, in Japanese), 208.

³ Cited in Sanjiv Kakar, Leprosy in British India, 1860-1940: Colonial Politics and Missionary Medicine. *Medical History* 40 (1996):217.

⁴ Kensuke Mitsuda. *Kaishun byoshitsu: Kyu-rai goju-nen no kiroku* (Tokyo: Asahi Shimbun, 1950), 155-57.

⁵ In 1977, the nationwide patients’ association Zenkankyo published a chronicle of their activities for a quarter–half century. It stated that Japan’s leprosy control policy “distinguished people who are necessary to the nation and people who are unnecessary: Patients with Hansen’s disease were regarded as worthless people, and aimed a fundamental solution.” Zenkoku Hansenshi-byo Kanja Kyogikai (Zenkankyo). *Zenkankyo undo-shi : Hansen-shi-byo kanja no tatakai no kiroku* (Tokyo: Ikkosha, 1977, in Japanese), 37-38.

⁶ Jane Buckingham. *Leprosy in Colonial South India: Medicine and Confinement* (Basingstoke: Palgrave Macmillan, 2001), 157-88.

⁷ Tama Zensho-en Kanja Jichikai. *Kue Issho: Kanja ga tsuzuru zensho-en no nanaju-nen* (Tokyo: Ikkosha, 1979, in Japanese), 12-32.

⁸ Kuryu Rakusen-en Kanja Jichikai. *Fusetsu no mon* (Gunma: Kuryu Rakusen-en Kanja Jichikai, 1982, in Japanese), 210-12.

⁹ Takaaki Ikai. “*Sei no kakuri*” to *kakuri seisaku: Hannah Riddell to Nihon no sentaku*. Kumamoto Shuppan Bunka Kaikan, 2005, in Japanese.

¹⁰ Yutaka Fujino. “*Inochi*” no *kindaishi: “Minzoku joka” no na no moto ni hakugai sareta Hansenbyo kanja*. Kyoto: Kamogawa Shuppan, 2001, in Japanese.

¹¹ Kensuke Mitsuda. *Aisei-en nikki: Rai to tatakatta rokuju-nen no nikki* (Tokyo: Mainichi Shimbun, 1958, in Japanese), 71-73.

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- ¹² Setsuko Horie. *Ningen de atte ningen de nakatta: Hansen-byo to Tamashiro Shige* (Toyama: Katsura Shobo, 2009, in Japanese).
- ¹³ Kuryu Rakusen-en Kanja Jichikai. *Fusetsu no mon* (Gunma: Kuryu Rakusen-en Kanja Jichikai, 1982, in Japanese), 501-507.
- ¹⁴ Tama Zensho-en Kanja Jichikai. *Kue Issho: Kanja ga tsuzuru zensho-en no nanaju-nen* (Tokyo: Ikkosha, 1979, in Japanese), 136-138.
- ¹⁵ Catherine Kohler Riessman. *Narrative Methods for the Human Sciences* (Los Angeles: SAGE, 2007), 3
- ¹⁶ Kensuke Mitsuda. *Aisei-en nikkii* (Tokyo: Mainichi Shimbun, 1958, in Japanese), 166-176.
- ¹⁷ Detailed in Kuryu Rakusen-en Kanja Jichikai. *Fusetsu no mon* (Gunma: Kuryu Rakusen-en Kanja Jichikai, 1982, in Japanese), 271-77; Zenkoku Hansenshi-byo Kanja Kyogikai. *Zenkankyo Undo-shi* (Tokyo: Ikkosha, 1977, in Japanese), 34-36.
- ¹⁸ Betty Martin. *Miracle at Carville*, New York: Doubleday, 1950.
- ¹⁹ Detailed in Zenkoku Hansenshi-byo Kanja Kyogikai. *Zenkankyo Undo-shi* (Tokyo: Ikkosha, 1977, in Japanese), 50-56.
- ²⁰ This testimony was my translation from the official record of the *Proceedings of the 12th Kosei Inkai, House of Councillors, The National Diet of Japan*, vol. 10, November 8, 1951.
- ²¹ Paul Fasal. "The VII International Congress on Leprology," *AMA Archives of Dermatology* 80 no.1 (1959): 91-92. The bureaucrat's speech was documented in Verification Committee Concerning Hansen's Disease Problem. *Final Report* (Tokyo: Japan Law Foundation, 2005), 622.
- ²² Susan L. Burns. "Making Illness into Identity: Writing 'Leprosy Literature' in Modern Japan," *Japan Review* 16 (2004):191-211.
- ²³ K. M. (initial letters of the anonymous author). "Amefuri" (Rainfall), Nagashima Aisen-en Kyoiku-bu ed. *Nozomigaoka no kodomo-tachi*. Tokyo: Sangabo, 1941. It is included in Shunsuke Tsurumi, ed. *Hansenbyo bungaku zenshu* (Collected Works of Hansen Disease Literature), vol. 10 (Tokyo: Koseisha, 2003), 270.
- ²⁴ Yuji Kodama. *Shiranakatta anata e: Hansen-byo sosho made no nagai tabi* (Tokyo: Poplar-sha, 2001, in Japanese), 67-71.
- ²⁵ Kaijin Akashi. *Hakubyo*. Tokyo: Kaizo-sha, 1939. Anonymously translated in "Illuminating Ourselves," *IDEA* 8, no. 1 (2003): 2.

²⁶ *Tanka* is a genre of Japanese poetry comprising five lines with a pattern of 5–7–5–7–7 syllables in the respective lines.

²⁷ Ibid.

²⁸ Ibid.

²⁹ Tmio Hojo. *Inochi no shoya*. Tokyo: Sogensha, 1936, in Japanese. Reissued by Tokyo: Kadokawa Shoten, 1955, in Japanese.

³⁰ Ibid (Tokyo: Kadokawa Shoten). 40-41.

³¹ Ryoji Mitsuoka. *Hojo Tamio no hito to seikatsu*. in Ibid (Tokyo: Kadokawa Shoten), 246-54.

³² Susan L. Burns. “Making Illness into Identity: Writing ‘Leprosy Literature’ in Modern Japan,” *Japan Review* 16 (2004):191-211.

³³ In November 2012, Zenryokyo (the nationwide former-patients’ association that took over Zenkankyo), Zengenkyo (the council of plaintiffs of the lawsuits against the country), and Kikuchi Keifu-en Nyusho-sha Jichikai (former-patients’ association in the National Leprosarium Kikuchi Keifu-en) appealed to the Kumamoto District Public Prosecutors Office for a retrial of his case. This case has been called “Fujimoto case” or “Kikuchi case,” detailed in Sawako Hirai. “Fujimoto jiken ni tsuite: ‘Shinso kyumei’ to saishin.” *Kyudai-hogaku* 84 (2002): 161-235, in Japanese.

³⁴ Fujio Otani, *Rai yobo-ho haishi no rekishi: Ai wa uchikachi joheki kuzure ochinu*. Tokyo: Keiso Shobo, 1996, in Japanese, 250-56.

³⁵ Hansen-byo iken kokubai sosho bengo-dan. *Hirakareta tobira: Hansen-byo saiban wo tatakatta hitotachi* (Tokyo:Kodansha, 2003, in Japanese), 25-50.

³⁶ Ibid.

³⁷ Kikuchi Keifu-en Jichikai. *Kurokawa Onsen Hotel shukuhaku kyohi jiken ni kansuru sabetzu bunsho tsuzuri* (Kumamoto: Kikuchi Keifu-en Jichikai, 2004, in Japanese).

³⁸ Hajime Sato. “Abolition of Leprosy Isolation Policy in Japan: Policy Termination through Leadership,” *Policy Studies Journal*, 30 no. 1 (2002): 29-46.