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Chapter 5

Bioethics and the Experiences of Hansen's Disease Survivors

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Additional information is available at the end of the chapter

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Abstract

Historically, Hansen's disease patients suffered from discrimination because their physical features changed due to the bacterium *Mycobacterium leprae* (*M. leprae*) and made them "ugly" in the eyes of society. Former Japanese governments saw them as a national disgrace and forced them to reside in leprosaria. Since the law requiring isolation continued after the silver bullet was developed, survivors could not leave the leprosaria and return to society. Currently, survivors' average age is 82 and they live in 13 national sanatoriums. When they pass away, the history of Hansen's disease in Japan will end, so we must record their experiences. We conducted qualitative and inductive studies with survivors. In this chapter, we reconstruct them from the perspective of bioethics and propose several theories surrounding them: (1) How former leprosaria and medical administrations in Japan threatened bioethical principles; (2) the wisdom of aging survivors, who lived through extreme situations, and what real restoration of their rights might look like; and (3) the ethical dilemmas of how we will care for the survivors—who have multiple severe sequelae—until they all pass away. Finally, we will introduce our ethical nursing practices in relation to caring and understanding via holism.

Keywords: stigma, Hansen's disease, bioethical principles, wisdom, human caring

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1. Introduction

For many years, Hansen's disease patients' rights were violated, and the four bioethical principles were ignored during the course of their treatment. In **Table 1**, we show part of the life of Ms. Hanako Kadowaki, who is 84 years old, blind, and a Hansen's disease survivor [1].

Listener: What do you think about the Leprosy Prevention Law?

Mrs. Kadowaki: Because I was child, I did not understand it in detail, but enforced isolation means being treated like a criminal. Although my situation was not severe, the policeman and prefecture administrator came to our village many times. My friend's father was forced into truck to be sent to the leprosarium while he was working. He was carpenter, and he asked the policeman, "Please wait until I have finished building this house." They did not wait and forced him into the truck. This is what enforced isolation is like. I cried when I heard it.

When I entered this leprosarium, it was filled with pilgrims who had been captured. At that time, the emphasis was on catching pilgrims, so this facility overflowed with residents. Pilgrims were gathered at the pier on the mainland. Pilgrims without handicaps were sent to another island, and pilgrims with handicaps were sent to this island. Thus, there were many handicapped pilgrims in this leprosarium at that time.

Because they could not live in their hometowns, pilgrims were working and traveling around on both hot and cold days, and sleeping in front of shrines and temples and begging. They traveled with difficulty, and although they had no medical treatment, they were forced to work, so they became crippled by degrees. After decades of pilgrimage, they entered blind and with missing limbs, and I pitied them. There were lice, there were fleas, and there were bedbugs. It was very terrible, and the pilgrims had nothing except their own bodies, but my isolation was not completely terrible.

At that time, dying patients could not be cared for by the nurse, so they died in a terrible situation. They died weak, without food, saying, "I want to die after drinking myself full of wine," or "I want to eat sweets." I felt pity for those dying people at the time. Their funeral was shabby, too.

The meals were skimpy. When the war was intense, there was no food, no clothing, no soap, and no medical treatment. After the war, there was still little food, and I was hungry, so I asked an outside person to buy food for me, as I was ashamed to ask anyone inside.

At that time, the roads were bad, and there was not a bell and white line on the road to support and lead blind people. Blind people had white canes made by a kind man who took branches from the mountain and shaved them down. The blind people worked at exploring with their white canes and walked from one end of the island to another in order to get treatment. They had many difficulties.

There were patients with no fingers. If they had fingers, they were dangling from paralysis or they did not have all five. Now I regret that I did not support them more at the time. Because now my fingers are short, and I am an inconvenience, just like how those patients with no fingers were inconvenient. At that time, because I could still sew with a needle, I was not inconvenienced. I could not understand their inconvenience. And at that time, when we had wounds from washing our clothes or dishes, the doctor cut down the finger immediately, like cutting a radish. A foot was changed out for a prosthetic leg immediately. It was not serious.

Temporarily coming back home from the leprosarium was real difficult at that time. We had to write many difficult things in our petition and submit it and get permission from the chief at the leprosarium. Permission was only for 1 week, so after going home, we submitted another petition and asked to extend it to 2 weeks. We used the local train and it took time, so we could only stay about 10 days, even if we had permission for 2 weeks. If we were late coming back, we had to enter a jail cell. If the returning person did not return, their guarantor had to enter the repentance room. Even if we came back late after all, the guarantor still could not leave the room. It was like a prison: There was a high concrete wall with two cages in it. The repentance room was next to the cage and had a tatami mat. I didn't want to enter the cage, so I came back by the appointed time.

In 1941, one male who was a former soldier came back late, and the staff chased and caught him, and hit his body with stones while he hung from his arms and legs. I saw it from the girls' room. I was disgusted and afraid, because they hit his head with a stone.

(Omission of middle part)

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I think my enforced isolation was not severe, and I lived a long time by entering this leprosarium. There was a little benefit to the law. The law was abolished at1996. After abolishing the law, since all the survivors don't have *Mycobacterium leprae* anymore, we can go to the mainland easily and majestically and be accepted in the general hospital, just like everyone else. Before the law was abolished, we went shopping in a nearby town, and the townspeople would drop our change in order to avoid touching us. They were truly scared of us. Now we are given humane treatment and enjoy shopping. The old leprosarium was a scary place for people, but now it is an open-minded place, and many visitors come in. Although there are now less than two thousand survivors in 13 sanatoria, many supporters have campaigned for enlightenment, and I am very glad of it.

I think patients' families feel better about not having to worry about appearing in public with patients, because the law was abolished and we are without the offending bacteria. Although there are many survivors without family, like me.

Listener: Since this narrative will be published, what else do you want to say?

Mrs.Kadowaki: Although I am not certain, there may be new patients in the future, and I hope these future patients and their families can live ordinary live without difficulties, because in the past, the families had many difficulties. At the time, I was only a child when I got Hansen's disease, and my family was very worried about public appearances. Our surroundings were a real worry to a small patient's mother, who went crazy with worry. There was a family that had several patients in one family; how painful that must have been for the family. It was very hard for us with only one patient in the family. Although the law was abolished, we cannot return to our hometowns, but at least now we can be treated humanely. We hope sincerely that our families can live in society with peace of mind.

This next story is about how I lost my eyesight. I had a high fever due to erythema nodosum leprosum, which I got the year after I entered the leprosarium. I was very tired from caring for several severe patients as my enforced labor, and I was hospitalized several times. Because I was not getting proper treatment for *Mycobacterium leprae*, the disease was getting worse. I think the disease was getting better in the leprosarium, but it got worse in the hospital.

Before the war, we tried a new drug because the chief of the leprosarium heard good things, but it backfired, and many patients died from the side effects. I did not die, but the disease progression was getting worse. I would soon need a tracheotomy, and most importantly, I lost my hair. I was 20 years old and felt very pitiful.

As my condition was getting worse, I thought I would die if I didn't have a strong mind. Promin come to our country in 1948. At first I did not hope, because I had learned my lesson from the former side effects, but now I think I was foolish not to hope. The next year I used Promin and got better and lost the edema in my face, limbs, and larynx. I escaped having a tracheotomy, my wounds healed, and my complexion got better. These good times continued for 3 or 4 years.

Around 1953, we started a new medical treatment using drugs for *Tubercle bacillus*, which is similar to *Mychobacterium leprae*. My good condition had continued while using Promin, but I developed neuralgia, and thought, "If I cannot use my hand due to neuralgia, I will be sad," so I tried the new treatment. Now I regret this decision.

The side effects were very terrible, although I did not take large amounts of the drug, but the condition of my disease got worse again, and I lost my eyesight in both eyes for half a year. At first, my visual power decreased; next I could not open eyes because of the dazzling light and my pupils had become small like the point of a needle. I fell into a dense fog. I had pain in my eyes, but I did not feel the pain, because I was more sad for my lost eyesight. Then I lost my eyesight completely.

Slowly my eyesight got better, but then I started vomiting and I had to have enucleation of the eyeball. I was very sad. Now I cannot even wear a glass eye because of lagophathalmos, so I do not have eyeballs. If I still had my eyeballs now, I could still hope for a recovery of my visual power, but I do not have hope that medical treatment could develop new eyeballs. As a side effect, my condition rapidly got worse. My face got ugly. When my parents came to see me, they were surprised and backed away. You (listener) were surprised to see such severe sequalae when you started working here. I heard they took out my eyeballs because of glaucoma, though the doctor did not say it. The doctor did not measure the intraocular pressure, he just pushed the eyeball by hand. Although there was treatment for glaucoma at that time, the doctor's concern was only for new treatment of Hansen's disease.

I fell down to the bottom of hell when I lost my eyesight. I felt as if I were dead; I call it feeling hell on earth, with how painful it was. My friends, husband, and the association of blind people supported me for a long time. Now that my friends and husband are dead, I feel so obliged to them. When I was hospitalized, my husband cooked and encouraged me to eat. People around us said, "It is very pitiable that he has to take care of a blind wife." Losing my eyesight was sad for him, too. He took care of me though, so that I could live a long life. In 2008, he had kidney disease and hemodialysis and said, "Because I cannot eat my favorite foods, life is not as pleasant." I pitied him, but he endured for 3 years. Maybe he was preparing me to lose my husband for those 3 years. So when he died, I could endure it without crying in front of everyone, persuading myself to believe "He is still alive."

When I had good eyesight, I liked sewing, and made protectors for handicapped people to prevent wounds, and cotton work gloves with only one finger. I have lived 58 years without eyesight, and I can go to the bathroom and everywhere else by using my mouth. My hands can feel nothing, due to sensory nerve paralysis. It is as if I had burn wounds. My feet are the same. My mouth is the only part I have left that can still feel. So I wear a cloth over my mouth when I use the toilet and check for the button using my mouth.

Source: Transferred and modified from: Makiko kondo, Oshima Seisho-en: Life review of Hansen's disease survivors living in Oshima Seisho-en, 423–442, Kazama shobo, Tokyo, 2015.

Table 1. Part of the life of Ms. Hanako Kadowaki.

Hansen's disease, also known as leprosy, is an infection caused by *Mycobacterium leprae* (*M. leprae*). It has been stigmatized since ancient times due to the infected person's changed appearance caused by the deformation, and even loss, of parts of the face and limbs. After developing the first successful treatment, Promin, in 1943, it became possible to recover from Hansen's disease completely. Today, there are no new patients in developed countries. Fourteen countries, all of which are in the developing world, contain 95% of new cases, and 81% of new patients are found in India, Brazil, and Indonesia [2].

In Japan, there were many Hansen's disease patients before the end of World War II. Many of them could not live in their hometowns, so they became homeless or were forcibly placed in leprosaria with the passing of the Leprosy Prevention Law. Unfortunately, World War II was a time of national crisis in Japan, and many patients in leprosaria were treated with little regard for their dignity and human rights. In addition, many Hansen's disease survivors never had the opportunity to return to general society and had to live out their lives in sanatoriums, because the Leprosy Prevention Law, which declared that Hansen's disease patients must be isolated for their entire lives, has only recently been abolished.

We are working on continued research on nursing practices for survivors. This study explores the bioethical implications of survivors' experiences. In the second section, we discuss the lessons we can learn from their experiences. In the third section, we share the insight they have acquired by living through hardship and discuss how to genuinely restore their rights, considering that their dignity has been threatened. In the fourth section, we discuss current issues affecting survivors and how our work needs to embody the principles of bioethics through nursing practices. In the final section, we summarize what we have learned from the survivors' experiences.

2. The old leprosaria and how Japan's medical administration threatened bioethical principles

2.1. About Hansen's disease

The first characteristic [3, 4] of Hansen's disease is that the peripheral nerves are invaded, and the skin of the legs, hands, and face is deformed because the optimum temperature of the

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Mycobacterium leprae is lower than human body temperature. The *M. leprae* cannot move into the main organs, which are located deeper in the body and thus have a higher temperature. As a result, Hansen's disease patients and survivors continue to live with a changing appearance for many years. In addition, *M. leprae* can cause people to lose their hair, eyebrows, and eyelashes; in addition, they can develop erythema nodosum leprosum, a condition that gives patients a bumpy, lion-like face.

The second feature [3, 4] consists of the multiple symptoms caused by peripheral nerve damage. These symptoms are conspicuous and cause curiosity in non-afflicted individuals. Sequelae remain throughout a survivor's life and greatly impact their quality of life, even today. Sequelae include: the inability to feel pain or notice injuries due to sensory nerve paralysis; infections from general bacteria caused by an external wound that can result in cellulitis, sequestrum, and even limb loss; motor nerve paralysis due to hand or leg deformations such as drooping hand, monkey hand, claw hand, drooping leg, and claw toe; facial nerve paralysis such as lagophthalmos, drooping eyebrows and eyelids, drooping lips, and deformation of the lips; atrophy of the nasal septum and nasal choncha, resulting in nose deformations such as saddle nose or flat nose; easily injured corneas due to lagophthalmoses, the inability to close the eye, caused by facial nerve paralysis; loss of sensitivity within the cornea due to the trigeminal nerve's inability to feel pain, which can eventually cause blindness; iridocyclitis (i.e., inflammation of the iris) can lead to blindness and eventual enucleation of the eyeball; and finally, autonomic nerve disorders can cause sweating disorders, problems with heat retention, and neuralgia in the head and face. These sequelae cause additional pain and suffering for patients.

Treatment of Hansen's disease with Promin began in the USA in 1943. In Japan, Dr. MorizoIshidate succeeded in producing Promin 1 year after World War II ended [5]. Today, the World Health Organization (WHO) promotes combination chemotherapy in terms of treating Hansen's disease [6]. Since Promin was developed, patients can achieve complete recovery without any sequelae.

2.2. The history of Hansen's disease in Japan

2.2.1. From ancient times to the early modern era

Historically, Hansen's disease [7, 8] has been one of the most frightening ailments around and was stigmatized throughout the ancient world. It appeared in the oldest civilizations of China, Egypt, and India. The first known written reference to leprosy appeared on an Egyptian papyrus document written around 1550 BC. In Japan, it was described in numerous ancient texts such as *Nihon-shoki* (AC720) and *Taiho-ritsuryo* (AC701). Based on ideas about impurity, Hansen's disease patients were regarded as impure and unclean, and the illness was seen as divine punishment for retributive justice. Furthermore, because multiple cases often occurred within the same family, Hansen's disease was thought to be genetic.

In Japanese history, patients withdrew into their homes so as not to stand out, or they coexisted with the lower classes. If they could not live in their hometowns, they often traveled on pilgrimages and slept under the eaves of shrines and temples; they had to beg because they

were homeless. For example, there are 88 temples along the1200 km pilgrimage route on the island of Shikoku. Pilgrims start at the first temple until they arrive at the 88th and then return to the first one. Since the Buddhist high priest Kukai made this journey in the nineth century, pilgrims thought they were working with him at a spiritual level. People living on Shikoku thought pilgrims were an incarnation of Kukai and delightedly gave them charity. If pilgrims died by the roadside, local people buried them.

2.2.2. The beginning of the modern period

Dr. Armauer Hansen first discovered the pathogenic bacteria *M. leprae* in 1873. The old Japanese government enacted the Leprosy Prevention Law in 1909 (Act No. 11, Rai-yobo-ni-kansuru-ken) to establish five leprosaria across the nation, so that wandering and homeless patients could have a place to live. In 1931, the Leprosy Prevention Law (Act No. 58, old Rai-yobo-ho) was amended, and local governments started campaign to find all patients and forcibly send those living in their homes to leprosaria. This campaign caused local inhabitants to think of Hansen's disease as a terrifying epidemic; as a result, patients were ostracized in their hometowns and villages [9, 10].

With World War II coming, Japan faced a national crisis as modernization picked up and wealth and military strength increased. With the outbreak of war, Hansen's disease was regarded as a national disgrace. This is because (1) homeless, begging, and wandering patients were a symbol of Japan not being a civilized country; (2) based on ideas of ethnic cleansing, weak individuals (such as those with low intelligence or schizophrenia, those who were physically disabled, and those who had Hansen's disease or tuberculosis) were ostracized; and (3) since Hansen's disease occurred frequently in young males, these patients could not become soldiers and contribute to the nation's military force. As a result, Hansen's disease was viewed as a terrifying epidemic and national disgrace, and the government proceeded to enforce policies of lifelong confinement and isolation [11, 12].

The Leprosy Prevention Law was renewed in 1953 (Act No. 24, new Rai-yobo-ho), even though the National Leprosaria Residents' Council (ZenkokuKokuritsu Rai Ryoyo-shoKan-jyaKyogikai) opposed it on the grounds that lifelong isolation threatened patients' human rights [13, 14]. By this point, World War II was over, reconstruction under a new democratic constitution was under way, Promin had been developed, the illness could now be cured, and the WHO recommended that the government reconsider its segregation policy.

The Leprosy Prevention Law was renewed in 1953 with the addendum, "We must reconsider this policy as soon as possible" [15]. However, the law remained in place until 1996, although legal regulations were alleviated through patients' efforts. Patients created self-government associations at each leprosarium, which cooperated with all other leprosaria and negotiated with the Ministry of Health, Labor, and Welfare. In the 1950s, they obtained much-needed medical treatment and pensions for all patients. They ended requirements for patient labor and began employing leprosarium staff in the 1960s, and improved housing for patients in the 1970s. Patient living conditions got better gradually, but these improvements had long been needed [13, 14, 16].

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In 1996, the Leprosy Prevention Law was finally abolished. Survivors won a lawsuit striking down national indemnity, and the court convicted the Japanese government of enacting an unconstitutional law. The nation officially apologized, with formal apologies from the Prime Minister, the National Diet, the Minister of Health, Labor, and Welfare, and the Chief Justice of the Supreme Court. In 2009, the government established a new law, the Act to Accelerate the Resolution of Problems of Hansen's Disease (Act No. 82, Hansenbyomondai no kaiketsu no sokusin ni kansuru horitsu). The new legislation guaranteed that survivors could live at the remaining sanatoria for the rest of their lives, would be given a comfortable life and medical care, would be aided in their social lives and rehabilitated into mainstream society, receive help to restore their reputations, be buried with dignity, and that their relatives would also be supported [17].

2.3. The circumstances of leprosaria under the segregation policy

Although the treatment of Hansen's disease patients has slowly improved, it was inhumane from the time that the first Japanese leprosarium opened in 1907 until the end of World War II [13, 14, 18]. For example:

- In the early days, the director of a leprosarium was not only a doctor, but also a policeman. The police were in charge of enforcing confinement.
- The Leprosy Prevention Law did not allow patients to leave the leprosaria, and they had to remain there their entire lives. Although the leprosaria were medical institutions, they also had crematoria, graveyards, and religious buildings (**Figure 1**).
- In order to prevent patients from escaping, their property was converted into a currency that could only be used within the leprosaria.
- When patients entered a leprosarium, they were compelled to take on a new name and could not use their real one.
- The chief of a leprosarium had a great deal of power, and if patients did not obey the rules or resisted authority, the chief could punish them or send them to solitary confinement at his own discretion.
- Patients were permitted to marry, but not to have children. Before any marriage could take place between patients, the male was required to have a vasectomy.
- When patients entered a leprosarium, they had to sign a letter that stated they accepted to be dissected after death. **Figure 2** shows an artistic depiction of a dissection table used in certain leprosaria. This table was thrown into the sea, but washed back up on shore. Now, the table is on display on the island as a symbol of human rights violations.
- In order to operate leprosaria with as few doctors and nurses as possible, patients were required to work. In 1949, there were 62 doctors and 253 nurses in all leprosaria in the country, while there were 8318 patients. Patients worked various jobs such as caring for severely disabled patients, as medical assistants, conducting funerals for deceased patients, washing, working on engineering projects for the leprosaria, or carrying items for staff or disabled patients.

- The space for patients and the area for those without Hansen's disease were clearly divided. Patients could not enter the disease-free zone, and if a doctor needed to enter a patient's home due to severe illness or injury, the doctor wore rubber boots, despite the Japanese custom of not wearing shoes inside the home.



Figure 1. There are graves of patients in spite of medical institution (Picture provided by Oshima Seisho-en©).



Figure 2. The dissection table used in certain leprosaria, which was thrown into the sea, but washed back up on shore (Illustration by Akika KONDO©).

2.4. Introduction to the study: why did Hansen's disease patients lose their limbs?

In this section, we introduce our study [19], discuss the factors that caused patients to lose their limbs, and examine how patients' daily lives were affected by this occurrence.

<Categories>	Subcategories
<1. Loss of pain as a caution>	(1) I moved too much, because I did not feel pain from my wounds
	(2) I could not notice a heavy burn, even if my skin was charred, because I felt numb
<2. Carrying loads in the same region>	(3) I protected a region of my body that was paralyzed and deformed, so I carried my loads at same region and caused new wounds
<3. Collapsing from within the body>	(4) The bone went stale, and my finger disappeared
	(5) A tumor mass from leprosy erthema nodosum was crushed naturally
<4. Labor is vital because of poverty>	(6) Because I was poor, I could not live without working
	(7) I could not miss work due to perennial wounds
<5. Poor living conditions promoting worsening of wounds>	(8) Because we did not have transportation, I had to walk home from the treatment room, and the bandage came off immediately after treatment
	(9) I was wounded easily, because I worked hard wearing wooden clogs on an unpaved road
<6. Contaminated wounds and lack of hygiene>	(10) Because I could not avoid scrubbing, washing, and field work, my wound was contaminated immediately
	(11) Because gauze, bandages, and drugs were too expensive, I did not have the means to disinfect my wounds when they were dirty from muddy work
	(12) Tweezers and gauze were hard to get
	(13) There were many flies in our food, and maggots breed in the wound
<7. A poor medical system>	(14) Because there were many patients, I was too busy and could not wait to be seen by the doctor
	(15) The doctor did not do house calls, even if we had a serious condition with a high fever or tumor mass from leprosy erythema nodosum
	(16) Because there was no doctor, my wound was treated too late and got worse
	(17) The doctor did not treat me like a human
	(18) I had a bitter experience being experimented on, so I became timid of medicine
<8. Inadequate treatment by untrained individuals>	(19) Patients did amateur wound treatment, so they weren't treated correctly
	(20) Because I did my wound treatment myself, it became infected
<9. Superstition>	(21) Because I held the superstition, "If we cure perennial wounds, we will lose our eyesight," I deliberately created new wounds

Source: Transferred and modified from Ref. [19].

Table 2. Causes of repeated wounds.

This study uses aging survivors' narratives to clarify why Hansen's disease patients had repeated wounds, which led them to lose their limbs, and how they coped with these afflictions until starting Promin treatment. After starting to take Promin, patients no longer developed multiple severe disorders that resulted in new wounds or lost limbs, although they still had preexisting severe sequelae that continued to negatively influence their quality of life.

[Categories]	Subcategories
[A. Acquiring their own style of treatment for perennial wounds]	(a) I checked temperature of people or things with my tongue, which was the only part of my body that could feel hot or cold, as everything else had sensory nerve paralysis
	(b) Because my wound was small at surface, but was deep, I did not know how bad it was by looking at it, so I made a judgment whether I needed treatment or could use a bubble of hydrogen peroxide
	(c) Before my wounds got worse, I started using my own style of wound treatment
	(d) I scraped off necrotized parts of skin without mercy
	(e) I burned tweezers in the fire of a candle and dug into the wound
	(f) I stitched a crack in my skin at finger joint closed by sewing it with yarn myself
	(g) I blended drugs to make effective drugs to either protect or remove skin
	(h) I made drugs from horse teeth
	(i) Because I did not have drugs, I beguiled my neuralgia by continuing to walk around during the middle of the night
	(j) I protected the places that wounded easily
	(k) I devised a way of walking in order to avoid creating a new wound
	(l) I devised a way of not getting my wounds wet or dirty
	(m) I stretched and fixed crooked fingers, in order to prevent blood blisters
[B. Not being able to cure wounds by slack treatment]	(n) I knew I could not be cured by slack treatment
	(o) I was particular about my own style of treatment
[C. Selecting a therapist based on the severity of the wound]	(p) I went to the doctor only when my wound was beyond the control of the patients
	(q) I relied on the nurses, who were getting used to wound treatment, had good skills, and were improving their skills by evaluating the patients
	(r) Patients managed all medical treatments
[D. Relieving suffering through limb amputation]	(s) I allowed my wound treatment to cause atrophy
	(t) I selected cutting off a hand, foot, or finger in order to relieve suffering in the wound
[E. Giving priority to labor, and even choosing to cut off limbs]	(u) I selected cutting off a limb in order to continue working and sustain the lives of my wife and children who live outside of the leprosarium
	(v) I had no choice but to work in order to sustain my own life, so I selected cutting off my own limb
[F. Keeping a limb due to not being able to work or having a work release]	(w) My limbs remain because I could not work due to lost eyesight or neuralgia
	(x) I was supplied from home, so I did not need to work. Thus, my limbs remained

Source: Transferred and modified from Ref. [19].

Table 3. Coping with repeated wounds.

Since Promin was developed during World War II and didn't arrive in Japan until after the war ended, severe sequelae occurred when the entire nation was suffering from the effects of poverty. Our results show that limb loss during this period was caused not only by pathological characteristics such as sensory and motor nerve paralysis in the limbs, but also by a shortage of proper medical care and hygiene, in addition to economic distress. The findings show how

patients lived with Hansen's disease and what multiple severe disorders, wounds, and limb loss meant to patients living in poverty.

Narrative data were obtained from ten survivors and analyzed using a qualitative and inductive method. The average age of the survivors interviewed was 81.8 ± 2.7. Nine individuals had the lepromatous disease type, while one person had the tuberculoid type. Eight individuals had limb deficiencies, nine had hand and leg drooping, three were blind, and all ten had both contracture and neuralgia.

There were nine main causes of repeated wounds (see **Table 2**) and six main ways of coping with them (see **Table 3**). **Figure 3** shows the relationships between the cause categories and coping categories, and reveals that there were three ***core categories*** of relationships. The first core category is the ***negative spiral inducing a deterioration of wounds***, as shown in **Figure 3** with a blue line. The second core category is ***living daily life with perennial wounds in poverty***, shown with a red line. The third category ***is severe sequelae as compensation to survive poverty***, shown with a green line. In **Figure 3**, <> indicates the cause categories, [ ] indicates the coping method categories, indicates supplementary explanations for wounds, and × indicates a disruption in the process.

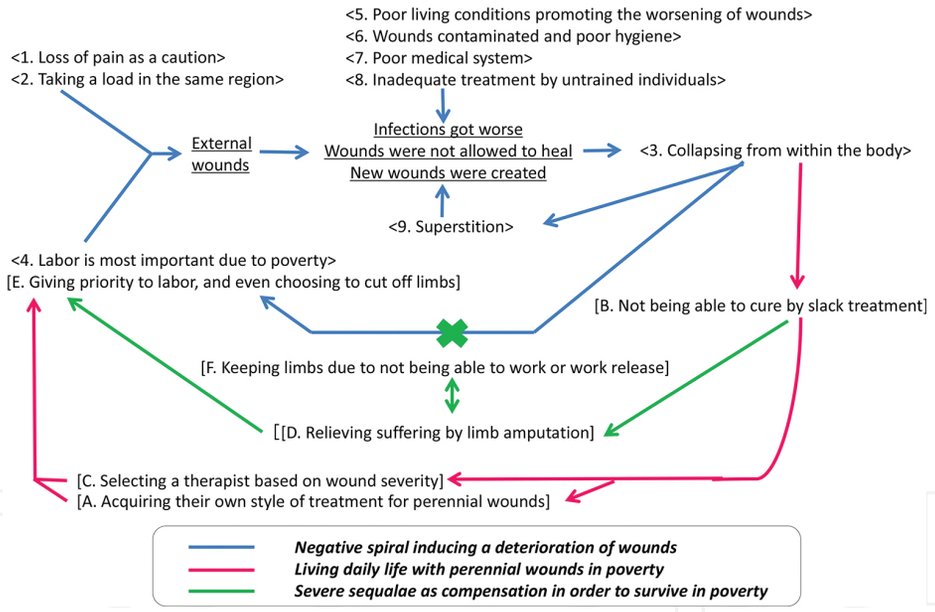


Figure 3. The cycle of repeated wounds among Hansen's disease survivors. Transferred from: Yamaberi et al. [19].

2.4.1. The negative spiral that caused wounds to deteriorate

Hansen's disease patients were wounded easily due to <1. loss of pain; pain signals that a person is hurt> and repeatedly <2. carrying loads in the same region > to compensate for other deformities or paralysis. However, patients also believed that <4. labor is vital because of poverty>. They continued to work under these circumstances, leading to increased external lesions. Furthermore, due to <5. poor living conditions that worsen wounds>, <6. contaminated

wounds and a lack of hygiene>, a <7. poor medical system>, and <8. inadequate treatment by untrained individuals>, existing infections got worse or became infected, wounded areas were not treated or allowed to heal properly, new wounds formed, and limbs deteriorated until they finally <3. collapsed from within the body>. However, many patients continued to [E. give priority to labor, even choosing to cut off their own limbs], and kept working in spite of their wounds, due to <1. loss of pain>. Thus, their wounds became worse, and they fell into a negative spiral. On the other hand, some patients were afraid to lose their eyesight and believed in <9. superstition>, such as: "If you recover from your wounds, you will lose your eyesight." These patients created new wounds on their bodies to avoid fully healing and thus not lose their eyesight. No matter the causes of repeated wounds, it led patients to fall into a negative spiral of deteriorating lesions.

2.4.2. Living with perennial wounds in poverty

Since patients fell into these negative spirals, having lesions was a matter of course, so they called them "perennial wounds." They knew empirically that they [B. could not cure their wounds with slack treatment], so they [A. acquired their own style of treatment for perennial wounds] and routinely attempted to heal themselves. If patients required specific medical treatment, they [C. selected a therapist based on the severity of the wound]. For example, when more severe wounds required cutting off a large bone, patients sought a doctor's help. If a less severe wound required cutting off a small bone at the finger or toe, they often cut it off by themselves or went to a nurse. Thus, patients made decisions about and arrangements for treatment themselves. They received support from nurses, except in cases of intractable severe gashes, when they sought the aid of doctors. With these coping techniques, patients barely maintained their lives in severe poverty, continuing to [E. give priority to labor, even choosing to cut off their own limbs]. Thus, they lived with "perennial wounds."

2.4.3. Severe sequelae as compensation to survive poverty

Although patients could cope with ordinary external wounds by [A. acquiring their own style of treatment for perennial wounds], the wounds <3. collapsing from within the body> were intractable, and they [B. could not cure their wounds with slack treatment]. Patients often chose to amputate limbs to return to work more quickly and easily; they had to work hard to support themselves or send money back to their wives and children who lived outside the leprosarium. Others hoped amputation would [D. relieve their suffering]. On the other hand, when patients could not work (e.g., due to loss of eyesight), the negative spiral was broken. As a result, patients [F. kept their limbs due to not being able to work or having a work release]. Both the loss of eyesight and cutoff limbs meant that patients would live with severe sequelae as compensation to survive poverty.

2.5. What lessons can we learn from the old leprosaria?

Above, we introduced historical facts about the Hansen's disease isolation policy and showed why and how patients contracted multiple severe sequelae. In this section, we will discuss what lessons we learned (see **Table 4**).

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Actions		Threats to the four principles of bioethics		Respect/unavoidable principle of bioethics	
		Reasons the bioethical principles are threatened	Threatened principle(s)	Results of respect or unavoidable principle of bioethics	Respected/ unavoidable principle
(1) Enforced confinement and lifelong isolation					
Enforced confinement	• Protecting homeless patients in leprosarium	—	—	• Protect people in crises (such as the homeless)	beneficence
	• Finding patients in their homes, and enforcing confinement using police power	Exercising compelling power (depriving freedom of decision-making)	Respect for autonomy	—	—
	• Building leprosaria in hard-to-reach places in order to prevent patients' escape	Exercising compelling power (depriving freedom of decision-making)	Respect for autonomy	—	—
Lifelong isolation	• Separating patients from their families	Plundering good (living with their family) from the patient's life	Non-maleficence	—	—
	• Plundering their right to live in society	Plundering the opportunity to contribute to society or the family	Non-maleficence	—	—
	• Causing emotional suffering and thoughts of suicide	Creating existential suffering	Non-maleficence	—	—
	• Actual harm done to families: by patients' forced isolation, the family lost to live with their husband/wife, son/ daughter, father/mother, brother/sister, etc. If patient was sustained family's life by his income, the family had difficulties with economy.	Plundering good (living with family, income) from a family	Non-maleficence	—	—
Isolation based on weak medical evidence	• Enforced confinement for a disease with weak infection power and little need for isolation	Impelling unnecessary isolation (physical restraint)	Non-maleficence	—	—
	• Prioritizing the nation's convenience over patients' needs without sound medical evidence	Neglecting the principle of medical care which determines the necessity of hospitalization based on patients' medical condition	Beneficence	—	—

Patients shouldering this burden unilaterally	• The burden of isolation was solely on patients in order to prioritize the nation's needs to prevent infection, empower the wartime regime, and enhance the national reputation	Imposed burden only on patients due to national policy	Justice and/or equality	—	—
	• Patients endured lifelong isolation to protect the general public from infection	Imposed burden only on patients in order to control infection.	Justice and/or equality	—	—
Failing to abolish the Leprosy Prevention Law	• By fighting patients' association against government, they were permitted temporary going out, but they must prove to disappear mycobacterium leprae into their body and got permission to going out from head of leprosaria.	—	—	• Defend individuals' freedom of action through flexible application of the law	beneficence
	• The government took many years to abolish an unnecessary law that violated human rights	No one in law, medicine, or administration took action	Beneficence	—	—
	• Due to this law, survivors continue to suffer from the old isolation policy	They continued to suffer unnecessarily	Non-maleficence	—	—
	• Patients lost years of opportunity to come back into society, and survivors were elderly when the law was finally abolished	Plundering the good of living in society	Non-maleficence	—	—
Forming negative public opinion	• The leprosaria protected patients from discrimination and persecution	—	Non-maleficence	• Use national power to protect the weak from harm, persecution, and discrimination	beneficence
	• Promoted discrimination and persecution against Hansen's disease patients among the general population through the campaigns to find patients in their homes and forcibly send them to leprosaria	Promote suffering and discrimination) indirectly	Non-maleficence	—	—
	• Spread discrimination and persecution from patients to their families, due to the campaigns to	Spread suffering and discrimination for family and relatives of patients	Non-maleficence	—	—

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	find patients in their homes and forcibly send them to leprosaria				
Avoid spreading information about the living conditions of patients to the public	• The general public did not know about the poor conditions within the leprosaria	The public did not have the opportunity to get important information and make decisions based on good, common sense	Beneficence	—	—
(2) Poor treatment of patients in leprosaria (a) Direct threats					
Vasectomy and abortion	• Abortion	Plundering the life of a child	Non-maleficence	—	—
	• Child bearing was not allowed	Plundering good from a patient's life, such as becoming a parent, the delight of child bearing, and enjoying old age surrounded by child and offspring	Non-maleficence	—	—
	• Patients were not allowed to refuse this treatment	Exercising compelling power and depriving freedom of choice	Respect for autonomy	—	—
	• Sorrow for the loss of a child, sense of humiliation, and shame for the treatment	Psychological laceration	Non-maleficence	—	—
	• The invasive operation itself	Physical laceration	Non-maleficence	—	—
Pathological dissection	• When entering the leprosarium, all patients were required to sign a consent form permitting dissection after death	Exercising compelling power and depriving freedom of choice	Respect for autonomy	—	—
	• Desecration of the dead	Harm the dignity of the dead	Non-maleficence	—	—
	• Medical contribution	—	—	• Elucidate pathological cause of disease	beneficence
Chief at leprosarium held strong power	• Patients had to comply with the chief's orders	Exercising compelling power and depriving freedom of choice	Respect for autonomy	—	—
	• Punishment resulting in physical pain	Causing physical pain	Non-maleficence	—	—
	• Punishment resulting in weakness or death	Plundering a patient's life	Non-maleficence	—	—
	• This power was a warning to other patients, in order that they submit to orders meekly	Exercising compelling power and plundering self-motivation from the majority of patients	Respect for autonomy	—	—

Enforced exchange of property to money that could only be used in the leprosarium	• Forfeiture of property	Plunder economic power	Non-maleficence	—	—
	• Preventing escape by depriving patients of cash	Exercising compelling power and depriving freedom of choice	Respect for autonomy	—	—
Enforced adoption of a new name and giving up one's real name	• Forfeiture of one's own name	Forfeiture of the social life patients had prior to entering the leprosarium and erasing the patient from society	Non-maleficence	—	—
	• Denying patients their identity	Denying personal uniqueness and individuality	Respect for autonomy	—	—
Dividing the leprosaria between patient areas and healthy person areas	• Discriminatory treatment between patients and staff	Cause suffering through discriminatory treatment	Non-maleficence	—	—
	• The purpose of the division was to prevent infection of the medical staff	—	—	• Infection control	beneficence not for the patient, but for medical staff
Enforced labor	• Patients did not have the right of refuse	Exercising compelling power and depriving freedom of choice	Respect for autonomy	—	—
	• Heavy physical labor	Causing physical pain	Non-maleficence	—	—
	• Poor wages for hard work	Unfair exploitation	Non-maleficence	—	—
	• The leprosarium was not able to sustain itself without patients' labor	Only patients had to shoulder the burden of sustaining the leprosarium	Justice and/or equality	—	—
	• Patients were not given suitable care but were used as a labor force	Received poor medical treatment	Beneficence	—	—
(b) Indirect threats					
Conditions caused multiple severe sequalae	• The main cause of limb loss was the pathological characteristics of Hansen's disease	—	—	• Limb loss was unavoidable due to the pathological characteristics of the disease	non-maleficence
	• Severe poverty meant the patients could not live without working, even with wounds	Intentional, willful negligence	Non-maleficence	—	—
	• Even with lost limbs, patients had to work. The only exceptions	Patients could not chose to rest their	Respect for autonomy	—	—

	were for the blind or individuals with another severe medical condition	own bodies, except when they had a severe medical condition			
	• Poor infrastructure and an unclean environment in caused wounds to worsen and patients to lose limbs	Poor physical environment did not protect from mixed infection and additional wounds	Beneficence	—	—
	• There was shortage of medical staff and goods	Received poor medical treatment	Beneficence	—	—
	• New drugs were before there was evidence of their therapeutic effect, so more sequalae occurred	Non-therapeutic drugs were tested on the human body	Non-maleficence	A cure was eventually developed with new drugs	beneficence
	• The entire nation struggled with poverty, war, and earthquakes	—	—	• The bad environment was unavoidable, considering social situation at that time	justice and/or equality
	• Multiple severe sequalae caused by enforced work continues to decrease patients QOL even no.	Causing lifelong, irreversible harm	Non-maleficence	—	—
Creating negative public opinion	• Patients' changing appearance was a source of discrimination and was encouraged by the government's policy	Promoting harm through discrimination	Non-maleficence	—	—

Table 4. The mistakes of isolation policy for Hansen's disease patients through the four bioethical principles.

2.5.1. The four bioethical principles

The foundation of biomedical ethics goes back to the Hippocratic Oath in BC 54. After World War II, the Nuremberg Code was created in 1947, following the consequences of the war and the Holocaust caused by the Nazis; this set of research ethics was developed to protect subjects' will and freedom in future medical studies [20]. In 1964, the World Medical Association (WMA) announced the Declaration of Helsinki, which outlines rules of medical research as based on the Nuremberg Code; it continued to revision [21]. In 1979, the Belmont Report was created by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research and illustrates principles of medical ethics to protect research subjects [22]. The WMA announced the Declaration of Lisbon in 1981, which describes patients' rights [23]. The Council for International Organizations of Medical Sciences (CIOMS) created the International

Guidelines of Biomedical Research Ethics in 2002 [24]. The Belmont Report clarifies biomedical ethics principles such as respect for people, informed consent, beneficence (i.e., evaluating benefits and risks), and justice (selecting subjects). The creation of biomedical ethics placed limits on human experiments and spread throughout the research world and medical practice.

Japan has a long history of medical knowledge, skills, and ethics. The medical book *Ishinbo* was written by Dr. YasuyoriTanba for Emperor Enyuin AD 984 [25]. After World War II, bioethical principles were imported from North America and Europe. Biomedical values from North America are based on the Belmont Report or the ideas of Beauchamp and Childress [26], who emphasize respect for autonomy, non-maleficence, beneficence, and justice. The tenets from Europe are based on the Barcelona Declaration, which was adopted at the Euro-Mediterranean Conference and underscores autonomy, dignity, integrity, and vulnerability. In terms of actual practices, modern bioethics is based on various methods such as the procedure- and narrative-based approaches [27]. In our analysis, we selected principles based on the American tradition, on which medical researchers and practitioners in Japan reached a consensus [28, 29].

The four bioethical principles are fundamental rules meant to address and resolve ethical issues in medicine. The first tenet is respect for autonomy, meaning that we must respect a patient's autonomous decision-making and to remember that informed consent is important in every situation. This belief requires that medical professionals: (1) tell the truth, (2) protect others' privacy, (3) adhere to the duty of confidentiality, (4) obtain informed consent for any kind of physical invasion, and (5) if asked, help the patient make important decisions. The second principle is beneficence, meaning that we must act for the benefit of others. This notion requires that we: (1) advocate for the rights of others, (2) protect others from harm, (3) remove risks that could cause harm, (4) support disabled persons, and (5) help individuals who are facing a crisis. The third rule of non-maleficence prohibits doing harm to others. This principle covers the following rules: (1) do not kill, (2) do not cause pain or suffering, (3) do not hinder another's ability, (4) do not create discomfort for others, and (5) do not steal or destroy the good in another's life. The fourth tenet of justice and/or equality means that social benefits and burdens must be distributed equally. This value requires that medical professionals distribute limited medical resources (such as manpower, goods, or capital) equally. We must avoid baseless discrimination and adequately balance competing requirements.

2.5.2. The mistakes of the isolation policy of Hansen's disease patients through the four bioethical principles

2.5.2.1. Enforced confinement and lifelong isolation

Enforced confinement threatened respect for personal autonomy because the government used its power via the police to compel patients to enter leprosaria and prevent them from escaping. On the other hand, homeless, wandering patients who entered leprosaria experienced a more comfortable life and improved medical care than they had previously; in this way, the leprosaria contributed to beneficence for some patients.

Lifelong isolation threatened non-maleficence because patients were denied the happiness of living with their families and exerting their own abilities in society. Patients' families were

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robbed of important family members and of patients' contributions to the families' incomes; family members could not live with patients throughout their lives, and if a male patient formerly supported his wife and child, his family lost income after he entered a leprosarium.

In addition, because the required isolation was based on weak medical evidence, it also threatened non-maleficence in the sense that patients had to endure unnecessary seclusion, even though Hansen's disease was not highly infectious. It also endangered beneficence because the country's circumstances—namely the idea that Hansen's disease patients were a national disgrace and not acceptable potential soldiers for the war effort—preceded medical requirements. Patients shouldered the burden of lifelong isolation in order to fulfill the nation's policy of controlling infection, and the rights of the state were considered more important than those of patients; thus, justice and/or equality was also breached.

Delaying in nullification of the Leprosy Prevention Law violated beneficence because no one in the fields of law, medicine, or local and national government took action to change this regulation for a long time. However, operational relaxation of the law did allow patients to leave the leprosaria occasionally and contributed to beneficence a little. By delaying abolishment of the law, non-maleficence was violated because patients continued to suffer unnecessary isolation. They also lost years of opportunity to come back to general society. When the law was finally annulled, the remaining patients were almost all elderly.

Enforced confinement by police and the campaign to send patients to leprosaria influenced public opinion and promoted fear of the illness. It led the general public to expel patients from communities and caused families to discriminate against their sick relatives, even though entering leprosaria was supposed to protect patients from public prejudice and persecution. All of this violated non-maleficence.

The lack of information about the realities of life within leprosaria also jeopardized beneficence. Except for some supporters, the general public did not know about or concern themselves with leprosaria, even though many people came into leprosaria and interacted with survivors after supporting the Leprosy Prevention Law. After World War II, Japan rapidly developed both economically and democratically. If more citizens had known about the conditions within leprosaria and the history of Hansen's disease, there may have been many more advocates for patients.

2.5.2.2. Violations of patients' rights in leprosaria

Often, treating patients in leprosaria threatened their rights either directly or indirectly.

2.5.2.2.1. Direct threats

Vasectomies were enforced for men prior to getting married, and pregnant wives were forced to abort their children, which directly violated non-maleficence because these actions either prevented a fetus from becoming a child (which goes against the principle "do not kill") or took away patients' delight in becoming parents and the joy in being surrounded by children in old age. These actions caused patients to suffer the loss of being able to have children and

often a sense of shame and humiliation in having such invasive operations. These surgeries also endangered respect for autonomy because patients could not refuse them.

When patients entered a leprosarium, they were required to sign a letter of acceptance regarding their dissection after death. They could not refuse. This violated respect for autonomy and non-maleficence. Even if patients refused to have their bodies dissected after passing away, their bodies were cut up anyway and their organs removed. They were not able to benefit from operations (e.g., to remove cancerous tumors). In Japan, funerals are very important rituals, and dissection without informed consent constitutes blasphemy. However, dissections did contribute to beneficence because they helped reveal the pathological cause of Hansen's disease.

The chief of a leprosarium had a great deal of power, including the ability to punish patients. This jeopardized non-maleficence because patients who did not obey the rules were imprisoned. Furthermore, this threatened respect for autonomy, because this kind of power not only violated the rights of individual patients, but also served to warn others against breaking the rules.

Changing patients' property to a currency that was only used within the leprosaria threatened both respect for autonomy and non-maleficence. Regarding the violation of respect for autonomy, the goal of this action was to prevent patients from escaping by making sure they could not use their money in the real world if they did manage to flee. In terms of threatening non-maleficence, since property was essential to one's social life, depriving patients of property made it impossible to have a normal social status.

Forcing patients to assume a new name and not allowing them to use their real one threatened non-maleficence because it meant depriving patients of a social life and "erasing" them from society. It also violated respect for autonomy because prohibiting patients from using their real names deprived them of their identities and harmed their sense of individuality.

Dividing leprosaria into areas for patients and healthy people threatened non-maleficence because it resulted in discriminatory treatment. While the purpose was to prevent medical staff and other healthy people from becoming infected, it only contributed to beneficence to help medical staff, but not patients.

Enforced, compulsory labor violated respect for autonomy and threatened non-maleficence because patients suffered physically during their labor and were not sufficiently rewarded for it. It threatened justice and/or equality because only the patients shouldered the burden of maintaining the leprosaria, and it endangered beneficence because the leprosaria did not provide sufficient medical services, despite being medical institutions.

2.5.2.2.2. Indirect threats

Indirect threats to Hansen's disease patients promoted multiple severe sequelae. In our study (see above), the main causes of repeated wounds were the loss of pain and severe poverty, while the main sub-causes were poor living conditions, a lack of proper hygiene, and a deficient medical system. Prior to World War II, there was no silver bullet to cure Hansen's disease, and

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the characteristics of the illness caused patients to easily develop repeated lesions. Thus, we cannot conclude that multiple severe sequelae threatened non-maleficence. However, doctors could clearly foresee that if patients were forced to work hard, they would have repeated wounds and would be forced to cut off limbs. In spite of this, the government still compelled patients to live and work in extreme poverty and did not give them the chance to rest and recover from their injuries. This situation threatened both non-maleficence and respect for autonomy. In addition, by not providing a physical environment or suitable medical care to prevent mixed infections and protect wounds, beneficence was violated. Trying new drugs on patients did contribute to beneficence by offering hope for a cure, but without evidence of any therapeutic effects or informed consent, patients continued to experience severe sequelae, thus endangering non-maleficence. Patients still suffer from multiple, irreversible sequelae today, which negatively affects survivors' quality of life; thus, non-maleficence continues to be violated today.

By allowing policies that resulted in severe sequelae, the leprosaria also indirectly violated non-maleficence, because limbs <3. collapsing from within the body> caused by enforced work in poor conditions led people to discriminate against patients and fear their changing bodies.

2.6. What lessons have we learned from old leprosaria?

There were undoubtedly some humanistic doctors, nurses, and religious men and women in the old leprosaria who cured patients and cared for them with devotion. However, the government's policy on Hansen's disease patients was wrong. We have learned the following lessons from history:

- We must create systems to ensure that medical policies do not violate bioethical principles.
- We must ensure that infection-prevention methods do not increase people's fear, especially in cases of lethal and tragic diseases. For example, Ebola hemorrhagic fever could cause people to fear and ostracize patients.
- We must accurately communicate the pathological causes of symptoms to the public; individuals are often stigmatized for symptoms that are considered unusual or mysterious. For example, limb loss by sequestrum can occur not only with Hansen's disease, but also with diabetes and thromboangiitis obliterans.
- The majority, not the persecuted minority, makes decisions about policy. If the majority is not concerned about how the minority is treated, discrimination and bullying can continue. Thus, we must ensure that the majority has correct and accurate information and that we foster a sense of justice so that persecution is not allowed to persist.

3. The wisdom of aging Hansen's disease survivors, who survived extreme situations

In the last section, we discussed the various violations of the four bioethical principles in medical policy regarding Hansen's disease. In this section, we discuss how patients survived

extreme situations, and what wisdom aging survivors can pass on to future generations. We explain how they survived in detail because we believe that in order to restore human rights, we need to understand survivors' strength and resilience. Their wisdom can be seen as universal, for the benefit of all (see **Table 5**).

Categories	Subcategories
1. Sustaining everyday life through self-sufficiency	(1) There were water shortages and poor water quality, a shortage of food, poor living conditions, and information disruption
	(2) Patients called on all their wisdom and ingenuity in order to obtain clean drinking water, cash, and food
	(3) Patients endured heavy work
	(4) Patients reclaimed new land and water resources
2. The courage to survive extreme hardships	(5) Patients' difficult situations did not weigh heavily on their minds, because they found joy and fun even in hard work
	(6) Patients without heavy sequalae enjoyed having youthfulness and energy
	(7) Patients could appreciate that their difficulties were trivial, because some had previously experienced homelessness and the wandering life of a pilgrim
	(8) Patients were not bothered by their severe poverty, because all residents were equally poor
3. Resourceful people coming together	(9) Patients had held a variety of occupation before entering the leprosarium. Patients were grouped by profession, specifically by professions that were needed to sustain the leprosarium
	(10) Professional patients taught their jobs to novice patients
	(11) If there was no professional in their midst, all jobs were done by trial and error, with patients learning by imitation
	(12) Some patients who had experienced homelessness and the wandering pilgrimage had excellent wisdom for everyone coping with severe poverty in the leprosarium
	(13) Doctors treated patients equally based only on their medical judgment
4. Assembling self-sufficient organizations for self-defense	(14) There was physical and psychological distance from the leprosarium staff, who treated patients inhumanly. The government and leprosarium did little to help the patients
	(15) Patients created self-sufficient organizations, such as a young persons' association, a vigilante corps, and a women's association. The self-governing associations decided terms of payment based on the difficulty of a job, and they systematically prepared to receive pilgrim patients from outside
	(16) Since all residents were assigned jobs, even children, the associations made sure that everyone was doing the appropriate job for his or her skills and abilities
	(17) The patients' organizations created systems to stockpile food and water

Categories	Subcategories
	(18) They made rules about water use during times of scarcity
	(19) If anyone did not follow the rules, a popular leader made sure they did
	(20) When male doctors went away to fight in World War II and medical care was shorthanded, the patients undertook their own care
	(21) Strolling players helped with shopping outside of the leprosarium and gifts from families living outside the leprosarium helped alleviate patients' poverty
5. Patients created a mutualaid system	(22) Patients gathered a portion of all payments for enforced work and distributed it equally to patients who could not work due to severe sequalea such as lost eyesight or other critical conditions
	(23) They shared food and goods with everyone. If someone was in poor physical condition and could not work, somebody took their place
	(24) They were considerate of weakest among them, such as girls who were ashamed of receiving charity or begging, or blind patients who hesitated to receive care from other patients. If an individual had food, they did not eat in front of patients without
	(25) When blind patients received charity from working patients, they often gave the workers a massage as a sign of their gratitude
6. They agitated to compel the government to provide better support	(26) Some survivors decided to fight against the government and encourage the abolition of the Leprosy Prevention Law, deciding to once again be homeless and live in poverty
	(27) After receiving better support from the government, the survivors' daily lives improved dramatically

Source: Adapted from Ref. [30].

Table 5. Wisdom of aging Hansen's disease survivors, who survived in extreme situations.

3.1. Introduction to our study: how did Hansen's disease patients survive severe poverty?

This study [30] used narrative data from aging survivors to clarify how patients survived in poverty before World War II. The subjects are living in the same sanatorium (mentioned in the above study), but that study specifically selected survivors who had repeated wounds and thus contained many people with the LL (Lepromatous) type. For this research, we focused on older survivors. The average age of our subjects was 84.3 years old, and the average age for all survivors living in this sanatorium was 80.2 year sold. The subjects had lived at the sanatorium for an average of 66.3 years, and all survivors in this particular sanatorium had lived there for an average of 52.6 years. We gathered data through semi-structured interviews and analyzed it using qualitative and inductive methodologies.

The narrative data were integrated into six categories of coping methods and types of resourcefulness. < 1. Maintaining everyday life through self-sufficiency> showed that there were water shortages and poor water quality, a dearth of food, poor living conditions, and infor-

mation disruption. They endured heavy labor, and reclaimed new cultivated land and water resources. They were self-sufficient and found ways of coping with a difficult daily life.

<2. The courage to survive extreme hardship> showed that patients' difficult situations did not weigh heavily on their minds because they found joy and even fun in hard work. Those without grave sequelae had youthfulness and energy. Everyone could appreciate that their hardships were trivial compared to worse situations, because some patients had previously experienced homelessness and the wandering life of a pilgrim. Their severe poverty did not bother them because all residents were equally poor. This showed that these patients had the psychological strength to overcome hard labor, illness, poverty, and still have a positive outlook.

The wisdom of <3. resourceful people coming together> was important because patients had held a variety of occupations prior to entering the leprosarium. Patients were grouped by profession, specifically by vocations that were needed to sustain the leprosarium. Professional patients taught their jobs to novice ones, and if there was no expert in their midst, all jobs were done by trial and error, with patients learning by imitation. Some patients who had experienced homelessness had excellent wisdom to share with everyone, who were coping with severe poverty in the leprosarium. In addition, doctors treated patients equally based solely on their medical judgment. They distributed extra food only to seriously ill patients. This meant that individuals with a great deal of insight into how to survive were gathered together in the leprosarium.

<4. Self-sufficient organizations for self-defense> were formed because there was both physical and psychological distance from the leprosarium staff, many of whom treated the patients inhumanely. Since the government and the leprosarium did not help them, the patients created self-sufficient organizations such as a youth association, a vigilante corps, and a women's association. These self-governing associations determined salaries based on the difficulty of a given job and were systematically prepared to receive pilgrim patients from outside the leprosarium. Since all residents were assigned jobs, even children, the associations made sure that everyone was doing work suitable for their skills and abilities. The associations created a system to stockpile food and water and made decisions about water use during times of scarcity. If anyone did not follow the rules, a popular leader would make sure they did. During World War II, medical care was even more shorthanded than before because the leprosarium's male doctor went away to war; only the female doctor was left, so patients undertook more of their own care. When traveling actor came to the leprosarium, they listened to patients' requests and solved their issues the following day. In addition, gifts from families living outside the leprosarium helped alleviate patients' poverty. This all shows that patients were self-sufficient and formed organizations within and networks outside the leprosarium.

Patients <5. created a mutualaid system> in order to gather a portion of all payments for compulsory labor and distribute them equally to patients who could not work due to severe sequelae (such as lost eyesight or other critical conditions). They shared food and goods with everyone, especially the weakest among them. If an individual was in poor physical condition and could not work, someone else took their place. The patients were considerate of girls who were ashamed to beg or receive charity and of blind patients who hesitated to receive care from other patients. If an individual had food, he did not eat in front of those without it. On the

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other hand, blind patients gave massages to workers as a sign of gratitude for their charity. They all worked to embody the ideal of "helping and loving each other."

Whereas the above categories were most evident before and around World War II, much later the patients <6. fought to compel the government to provide better support>. They initially hesitated to fight the government and work toward abolishing the Leprosy Prevention Law because they feared being forcibly turned out of the leprosaria and returning to the discrimination and homelessness of their hometowns. However, after patients obtained the government's support, their daily lives improved dramatically.

The first two pieces of wisdom (<1. maintaining everyday life through self-sufficiency> and <2. the courage to survive extreme hardship>) showed that the patients had the self-sufficiency and psychological strength to cope with severe poverty. The next three pieces of wisdom (the importance of <3. resourceful people coming together>, <4. self-sufficient organizations for self-defense>, and <5. the creation of a mutualaid system>) demonstrated that, as a group, the patients had extraordinary coping abilities. Using these five categories, Hansen's disease patients survived severe poverty up to and during World War II by forming a skilled community that had subsystems for self-sufficiency, self-defense, and mutualaid. Later, by <6. fighting to induce the government to provide better support>, they showed that their community had the strength and ability to cooperate with other leprosaria groups and fight against the government.

3.2. How we can pass on the wisdom of aging survivors to future generations

The public ostracized Hansen's disease patients, who lived with the stigma, that their illness was due to divine punishment or was a national disgrace. They coped by forming a skilled community and survived severe poverty. Their community had subsystems for self-sufficiency, self-defense, and social security. Their community functioned systemically and was headed by leaders who were hard workers with good morals. The patients were able to cope with severe poverty by themselves, without help from the government or the leprosaria. They maintained their autonomy. This revealed their strength, resilience,and dignity in fulfilling their own responsibilities, even when they suffered. They proved that they could function not only as individuals but also as a group. This is similar to Viktor Emil Frankl's "attitude value," Viktor Emil Frankl [31] developed in his book *Man's Search for Meaning* and as part of his logotherapy, a form of existential analysis. When someone undertakes his life bearing a heavy cross, his destiny is sublimated from mere fact to existential meaning, and he has a "will to find meaning," that is, a need to find meaning in extreme situations. Hansen's disease patients embraced their extreme circumstances as their destiny and found meaning in living with the illness.

In old age, the ego's development task is to find integrity and avoid despair by acquiring wisdom [32]. Wisdom means being detached and transcending concerns about one's own life before death, integrating life experiences, and learning how to pass these lessons on to future generations in spite of decreasing physical functions. Today, the average Hansen's disease survivor in Japan is 82. The survivors have self-confidence and pride in having lived through severe poverty on their own, with little help from the government or medical staff. They are

integrating their lives in end-of-life development tasks, and their extreme experiences produce heightened wisdom for posterity.

We think the survivors' knowledge has a universality that can provide suggestions for future difficulties, and is thus valuable for future generations. For example, in the Great East Japan earthquake and tsunami of 2011, many small, depopulated villages were isolated and could not obtain help from outside. The wisdom of the Hansen's disease patients, specifically in forming skilled communities (with subsystems for self-sufficiency, self-defense, and mutual-aid), suggests how isolated villages could heighten their community's resiliency during a crisis. Furthermore, in order to survive in a chaotic society, their wisdom could be used as a business model to create strong teams whose members have good rapport with each other.

What would genuine restoration of survivors' rights look like? Today, their severe experiences are used as a negative example in human rights education. While commendable, we think this is insufficient due to their past and present suffering. We believe that a real restoration of their rights would be utilizing their wisdom to solve future problems. Many people appreciate their knowledge and recognize its value, such as in the spread of logotherapy from Auschwitz. Thus, we hope to pass on not only the negative history of survivors' experiences, but also their insight.

4. Current concerns for survivors and ethical practices for nurses

Above, we discussed the violation of bioethical principles regarding the treatment of patients in leprosaria and the wisdom they gained from surviving extreme situations. In this section, we discuss current concerns for aging survivors and introduce ethical practices for the nurses who work with them.

4.1. Introduction to our research: How will we care for survivors until they all pass away?

Today, the average Hansen's disease survivor in Japan is 82. There were a total of 1718 leprosaria residents in 2015 and 3286 in 2005. Almost all survivors will pass away within the next 10 years. Since former governments attempted to eliminate Hansen's disease by forcing patients to live in lifelong seclusion and to have vasectomies and abortions, most survivors do not have children or grandchildren (except for those who had a spouse and children before entering the leprosaria). As a result, the history of Hansen's disease in Japan will largely end with the death of the last survivor [33] (see **Table 6**).

Survivors are now ensured a comfortable life in their remaining years, thanks to the Act to Accelerate the Resolution of Problems of Hansen's Disease (2008 Act No. 82). As most survivors do not have families, sanatorium staff must care for them. With a decreasing number of survivors, the sanatoriums must now plan how they are going to maintain their facilities. Administrators of the sanatoriums are considering plans to keep them open, such as adding care for the general elderly population. Yet because old leprosaria were built in hard-to-reach places in order to prevent patients from escaping, planning for their future is now difficult.

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Maintaining a sanatorium is expensive. For example, one sanatorium is located on a small island 8 km away from the mainland. This island is only accessible by ship. Even if there are only a small number of survivors, it will be necessary to transport medical, welfare, and clerical supplies by ship. In addition, buildings will need to be repaired.

When we think about cost-effectiveness in relation to the country's tight financial situation, one option is eventually combining the 13 sanatoria into one facility. We must balance focusing on the most important goal—ensuring that survivors enjoy a high quality of life until the last one passes away—while also finding a solution to future problems.

This study [33] was conducted at a sanatorium where a new building was constructed for survivors; they were relocated from the old terrace houses that dotted the island to a central nursing home for the elderly. Their former houses were too old and far apart, and nurses could not fully attend to their patients' health. This study was based on interviews conducted with patients 6 months before their expected relocation to the sanatorium and was analyzed using qualitative and inductive methods. The results demonstrated the unique challenges facing Hansen's disease survivors as compared to the general aging population (see **Table 6**).

Category	Sub category
1. The burden of house moving given the age-related decline in mobility and the community's mutual aid abilities	1. Because the survivors are all aging, their ability to help each other is decreasing (e.g., due to the death of colleagues or spouses, and the decreased functioning of the survivors' self-government association, as well as age-related decreases in individual physical function)
	2. Fear of increasing dementia and early death due to changing environment and overwork from relocation
	3. Indeterminate anxiety due to the impossibility of imagining life after housemoving
	4. Bitter memories of past of relocation
	5. The burden of packing and damaging the living environment by carrying household goods
2. The burden of creating new strategies in order to live with multiple and severe sequelae in a new environment	6. Misgivings about being watched while eating among blind survivors who are embarrassed about eating messily
	7. The burden of living with blindness and sensory paralysis, and losing one's mental map of one's environment and having to create a new mental map of a new environment
	8. Suffering the loss of a good residential environment that accommodated ones' sequelae, neuralgia, thermal regulation disorder, and poor vision
	9. Fear of increasing injuries that are liable to be more severe due to the loss of a living environment that had been adapted to accommodate hand and leg sensory disorders and prevent injuries

Category	Sub category
	10. Loneliness and missing a comfortable residential and personal environment, while in one's final abode
	11. The increasing burden of caring for an aging blind spouse
3. The disagreeableness of having one's life disturbed	12. Misgivings about being disturbed from a familiar daily rhythm built over a long time
	13. Concerns about being disturbed due to living near trouble makers
4. Dissatisfaction with the decision-making process managing building structure and room layout	14. Dissatisfaction about inconvenient building structure and room layout
	15. Anger and resignation about not being able to agree on the process of deciding on the structure of the new building
5. Thinking positively to accept relocation and enjoy the new environment	16. There is no anxiety about moving, if our requests are met
	17. All that is necessary is to enjoy a full and independent life before and after relocation

Source: Transferred and modified from Ref. [33].

Table 6. The meaning of relocation for aging Hansen's disease survivors.

The various meanings of the upcoming relocation for aging survivors were integrated into five categories: <1. the burden of relocating from their old home to their new one given the age-related decline in mobility and the community's mutualaid capacities>, <2. the burden of creating new strategies to live with multiple and severe sequelae in a new environment>, <3. the disagreeableness of having one's life disturbed>, <4. dissatisfaction with the decision-making process for managing building structure and room layout>, and <5. thinking positively to accept relocating and enjoy the new environment>.

The most important of these five categories are the first and second. The first one (<1. the burden of relocating from their old home to their new one given the age-related decline in mobility and the community's mutualaid capacities>) shows the various meanings of aging, not just personal aging, but also community aging. The survivors' community is comprised of old men and women because they were not permitted to have children. They have self-confidence due to having survived poverty and forming a skilled community (see Section 3); even after the government began providing further support, the self-governing committee continued to handle daily problems. With the aging and deaths of its members, the community weakened in its ability to cope and exert mobile power. Although residents recognize relocation will likely bring on dementia and hasten death, community aging is as much, if not more, a concern as personal aging.

The second category of concern (<2. the burden of creating new strategies to live with multiple and severe sequelae in a new environment>) contains six subcategories: <6. misgivings about being watched while eating among blind survivors who are embarrassed about eating

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messily>, <7. the burden of living with blindness and sensory paralysis, and having to lose the mental map of one's environment and create a new map of an unfamiliar setting>, <8. suffering the loss of a good residential environment that accommodated ones' sequelae, neuralgia, thermal regulation disorder, and poor vision>, <9. fear of increasing injuries due to losing a living environment that had been adapted to accommodate hand and leg sensory disorders and prevent injuries>, <10. missing a comfortable residential and personal environment while in one's final abode>, and <11. the increasing burden of caring for an aging blind spouse>.

The second category shows how important the living environment is for survivors who have multiple severe sequelae. We previously introduced the causes behind repeated wounds and limb loss due to survivors' past physical environment (see Section 2). Today, a survivor's living environment is very important in alleviating sequelae. For example, patients with weak eyesight can recognize changing weather, the transition of the seasons, and the time of day from sunlight entering a window. Survivors with neuralgia alleviate overheating in the summer by using the wind from the sea, without increasing their pain. Thus, over the years, survivors have created suitable living arrangements in order to relieve the pain of their sequelae; relocating means losing their familiarity with their environment.

The second most important aspect of this is the difficulty of redesigning the living environment in order to deal with conflicting or numerous conditions simultaneously, the goal being to mitigate the effects of multiple severe sequelae. For example, some survivors have sensory nerve anesthesia and have lost their eyesight. The general population of blind individuals cannot see, but can recognize items by touch. Hansen's disease survivors who have lost their eyesight cannot recognize items by touching them. They have created a mental map of their environment through trial and error over time, often being wounded in the process, until they are able to move through their homes automatically. By relying on this mental map, survivors know their own position and direction within a space; with the help of a spouse who can see, or listening to the sound of the radio, or feeling a deep sensation of resistance from bumping into the wall, they can easily get around. If they have made a perfect mental map, they can move just as well as if they could see. Thus, forming a mental map is a way of adapting to numerous conditions simultaneously, which helps alleviate multiple severe sequelae. However, when relocating, survivors lose this mental map and must create a new one from scratch.

The third most important aspect of the living environment is protecting the body from external wounds. Since survivors have lost their sense of pain, they do not notice when they have external lesions and their injuries can become severe. Survivors contrive ways to compensate for their sensory nerve paralysis and prevent wounds; relocating to a new environment increases the risk of getting hurt.

The fourth way in which the living environment is important to survivors is that although Hansen's disease causes various symptoms and survivors have multiple grave sequelae, the people influenced most severely by relocating are those who have lost their eyesight. In the past, patients who lost their eyesight could not work; they could not earn a living and fell into poverty. Loss of eyesight was considered one of three major causes of suffering in a patient's life and the other two being notified of one's diagnosis and getting a tracheotomy. In the past, blindness was considered the most serious of the sequelae and continues to be today. In

relocating, blind patients must remake their mental map of their environment, but this is difficult because their memory abilities decrease with age.

4.2. What can we learn from this based on a bioethical perspective?

Survivors' living environment can alleviate their multiple overlapping sequelae, but it takes time to adapt a new setting to one's particular needs. This is most challenging for blind patients because changing their environment means they must make an entirely new mental map of their surroundings.

We must now think about how we will care for the survivors until they all pass away. Relocating survivors to one facility may cut costs, but also robs survivors of the setting they have adapted to; this threatens non-maleficence. Survivors need individuals to advocate for their rights, especially as their decision-making abilities and power to acknowledge reality decrease from dementia, making it easy to threaten respect for autonomy. Thus, beneficence is more important now than ever in order to protect the weak.

On the other hand, Japanese medical policy and the medical system must find ways to innovate. As the elderly population grows and the overall population shrinks, the current medical and medical finance systems cannot endure as they are; they must change. Although the law has guaranteed survivors a high quality of life, there may come a day when the nation becomes dissatisfied with shouldering the rising cost of supporting multiple sanatoria. We must seriously consider bringing all remaining patients to one site in order to improve cost-effectiveness.

There is an ethical dilemma in the midst of these circumstances: confronting justice and/or equality, and beneficence and non-maleficence. Unfortunately, we do not yet have a solution. However, we must prevent the public from criticizing and be advocates for survivors. We must find a solution to help sanatoria coexist with society and prosper. If we cannot avoid bringing the remaining patients together at a single facility, we must find methods of decreasing the negative aspects of changing their living environment. We must help society understand the meaning and importance of where survivors live.

4.3. Ethical practices for nurses and end-of-life care

In the section above, we discussed the difficulties of caring for the survivors until they all pass away. In this part, we talk about our efforts to support survivors by providing them with a high quality of life and caring for them until they die peacefully (with support from the Toyota Foundation Research Grant Program 2013). In addition, we discuss the bioethical implications of this practice.

4.3.1. Outline of our projects

At this time, the background of our project is as follows [34]:

a. Aging survivors' deaths cause the community to reduce and collapse over time. There is a negative impact on survivors' physical and mental health as the shrinking of their

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community causes them to feel helpless, hopeless, and lonely. It is a feeling comparable to the enforced isolation from their parents that many survivors experienced as children. We must consider how we can alleviate the survivors' sense of loss and prevent growing negative physical, psychological, and social influences.

b. Many survivors do not have any family except for an elderly spouse, so sanatorium staff must care for survivors until they die, instead of their family.

c. Now is our last chance to record the experiences of aging survivors, but many do not have a means of expressing themselves. However, some survivors have produced literary or artistic works.

d. We will lose these storytellers when they pass away. We must consider how we will pass on their experiences.

4.3.2. Expected effects of our practice

As survivors do not have much time left, we looked for an immediate, effective method of working with them to preserve their experiences and communities. We chose life review. With this technique, we can subjectively construct a narrative of their life experiences. It is a process of reweaving one's own life, supported by a good listener (in our case, supportive nurses in the sanatorium), promoting the rediscovery of the meanings in one's life, conducting a reevaluation of life, and gaining a sense of self-consistency.

The expected effects for survivors are as follows: (a) gaining a sense of self-expression through constructing their own narrative; (b) experiencing a cathartic effect, promoting reevaluation of their lives, and developing new meanings; and (c) having a positive effect on survivors by having nurses serve as supportive listeners. As survivors face their own impending deaths, they are acutely aware that the deaths of their comrades have resulted in a shrinking community, thus creating a crisis for survivors. The expected effects for nurses in the sanatorium are as follows: (a) it gives them a chance to exercise their ability to listen attentively and express empathy; (b) it deepens their understanding of the survivors and what they experienced; and (c) it gives them the opportunity to reevaluate their own roles, as well as a sense of responsibility and pride in caring for survivors. These are all nursing practice abilities that are required in end-of-life care. The expected effects for the relationship between survivors and nurses are: (a) a deepening of relationships on both sides and that nurses caring for survivors on their deathbeds will forge a deeper relationship with the patients. The larger point is that supporting survivors' lives and caring for them until they pass away is a nurse's most important duty in a sanatorium. Moreover, nursing practices directly influence survivors' quality of life.

The significance of creating a survivor's life review is: (a) being able to publish the life review in a book, thus passing on survivors' wisdom and experiences to the next generation, and directly contributing to increasing their dignity and satisfaction; (b) since survivors are aging and gradually passing away, this life review book will be the last record of these storytellers and is thus a valuable primary source; and (c) if we continue our qualitative and inductive analysis of these life reviews as raw data, we will find universal meanings in their experiences and will be able to explain their lives plainly and accurately via abstraction.

We conducted life reviews with 17 survivors, with nurses as listeners, and published them in 2015. We included a portion of the life review of Mrs. Hanako Kadowaki at the beginning of this chapter [1]. These 17 life reviews are powerful and fascinating to read; they are useful for thinking about bioethics and about how society cares for people who suffer from discrimination. We can learn both negative history and wisdom from the Hansen's disease survivors. We hope that students of medicine, nursing, pharmacy, and others in the medical field, those who work in Japan's medical administration, and the general population (both young and old people) will read it and learn from it, so as to not allow the suffering of Hansen's disease patients to be repeated in the future. Having worked on these life review projects in the sanatorium, the nurses now have increased self-confidence and pride in their jobs, and can provide even higher quality end-of-life care.

4.3.3. What does it mean to provide high quality end-of-life care as a nurse?

In another part of our research, one of the survivors had been homeless and experienced the hardships of wandering as a pilgrim before entering a leprosarium. This survivor said, "I think my life had a checkered destiny, but I was not miserable. Now, my comrades and I know that the adversity we faced was nothing serious." Thus, the survivor expressed catharsis. In the 17 life reviews we conducted, many survivors showed bitterness toward their past treatment and the policies under the Leprosy Prevention Law, but are now satisfied with and thankful for their current lives. The reasons for their satisfaction and gratitude are: (1) The nation officially apologized for their treatment and provided reparations. Specifically, the Prime Minister, the National Diet, the Minister of Health, Labor, and Welfare, and the Chief Justice of the Supreme Court all issued formal, official apologies. These apologies made the survivors feel relieved. (2) The survivors do not have economic problems, thanks to the new law that aims to resolve all remaining issues of Hansen's disease in Japan. (3) Medical and welfare staff now provide survivors with ample care.

End-of-life care is based on nursing practices. In nursing, we must understand our patients based on holism, practice healthcare based on scientific problem solving, and provide human care based on philosophy. Holism [35] requires looking at the system as a whole, beyond the sum of its parts. We cannot understand the whole only by looking at each element alone; however, through reductionism, we can understand complex phenomena via fields such as biology. In nursing, we understand the notion of "being whole as a person" from Holism. Thus, we grasp at least three points of view and attempt to integrate our understanding. We view our subjects as physical, psychological, social, and spiritual beings. We approach them with consideration for their own life spans. We understand not only pathological and objective diseases, but also the subjective and phenomenological experience of illness. If we want to understand the current thinking and emotions of Hansen's disease survivors, we must grasp their life histories; hence, our project is based on holism. The main characteristics of caring are reciprocity and mutual recognition. According to Jean Watson [36], the purpose of human caring is protecting, maintaining, and enhancing human dignity. In transpersonal caring, both nurses and patients share a spiritual dimension with each other. In other words, when we respect the patient as an irreplaceable, important person, then the nurse and patient can

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experience humane and affective interactions. If we have a caring mind, we cannot abuse the patient. Thus, caring prevents deviation from the four principles of bioethics. A peaceful death is an extension of daily care for survivors based on an understanding of them through holism and human caring, which is what our project is founded on.

Japan's political leaders apologized to the survivors, but who heals the survivors' suffering and embodies this apology? High quality daily care by medical and welfare staff in sanatoria directly influences survivors' quality of life. Our project aims to enhance their quality of life and allows them to have a peaceful death. Our nursing practice embodies this national apology and the principles of bioethics.

5. Conclusion and suggestions for the future

1. At present, Hansen's disease is a progressive illness, and new patients live in developing countries. Patients often face discrimination. We must elucidate how stigma is born and adhere to the four bioethical principles in order to prevent discrimination.
2. We think there are three types of people who discriminate: a few support patients, a few persecute them, and the majority do not have correct knowledge of Hansen's disease. If majority agree to persecute patients, they will suffer from greater discrimination. However, if majority support patients, then discrimination lessens. It is important to educate the public and promote awareness of Hansen's disease. Since it is possible that the main people who discriminate have their own psychopathological problems, it is important for patients to understand the real causes of discrimination and how it operates in society, thus putting an end to their challenges and those of people who are prejudiced. There is a lot of bullying and harassment in general and among children. It is important to teach the public that Hansen's disease is not a stigma.
3. The main source of discrimination against Hansen's disease patients is not only based on unpleasant feelings due to the patients' appearance, but also a fear of infection. In the future, should a pandemic of a lethal, drastic infection—such as Ebola hemorrhagic fever—break out, people may ostracize patients due to their fear. We must find ways of protecting against infection yet also avoid discrimination, based on what we have learned from the past negative treatment of Hansen's disease patients.
4. Survivors' experiences living with stigma not only results in suffering, but also wisdom. Like the life-affirming logo therapy that came from a survivor of Auschwitz, the insight gained from living through extreme situations will hearten other suffering individuals and suggest solutions to future problems.
5. In order to solve ethical dilemmas in caring for aging Hansen's disease survivors, we must understand the pathological causes of their symptoms and how they influence daily life for survivors. A pathological understanding is important for solving the ethical dilemmas in treating any disease. When we make a judgment based on the principles of bioethics, we can avoid unnecessary discrimination.

6. In order to alleviate the hardship of oppressed persons, we need a daily nursing practice based on understanding subjects through holism and human caring, thus embodying the principles of bioethics.

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References

[1] Hanako Kadowaki, Mika Seo: Chap. 17 Life review of Hanako Kadowaki, 411–442. In: Makiko Kondo, Oshima Seisho-en (eds.): Life Review of Hansen's Disease Survivors Living in Oshima Seisho-en, Kazamashobo, Tokyo, 2015.

[2] Global Note: Number of incidents of Hansen's disease in the world, compared with countries 2013. http://www.globalnote.jp/post-3941.html

[3] Fujio Ohtani, Hajime Saito, Eiji Nagao, Kunio Murakami (eds.): Hansen' s Disease Medical Science. Tokai University Press, Kanagawa, Japan, 1997.

[4] Makiko Kondo: Chap 21 Appendix pathophysiology of Hansen's disease, 506–519. In: Makiko kondo, Oshima Seisho-en (ed.): Life Review of Hansen's Disease Survivors Living in Oshima Seisho-en, Kazamashobo, Tokyo, 2015.

[5] Keizo Ebina: Biography of Ishidate Morizo. Shinhyoron Publishing Inc. Tokyo; 1997.

[6] Masamichi Goto, Reiko Nogami, Yoshiko Okano, Masaichi Gidoh, Rie Yotsu, Yutaka Ishida, Shinichi Kitajima, Masanori Kai, Norihisa Ishii, Motoaki Ozaki, Kentaro Hatano: Guidelines for treating Hansen's disease in Japan (Third Edition). Japanese Journal of Leprosy 82, 141–182, 2013.

[7] U.S. Department of Health and Human Services, National Institutes of Health: Leprosy (Hansen's disease)—A history of the disease. https://www.niaid.nih.gov/topics/leprosy/Pages/Default.aspx

[8] Shunich Yamamoto: The Japanese history of Hansen's disease. University of Tokyo Press, Tokyo, Japan, 1993.

[9] Ministry of Health, Labor and Welfare: Main event about Hansen's disease July 10, 2016. http://www.mhlw.go.jp/houdou/2003 /01/h0131-5/dekigoto.html

[10] Defense counsel of litigation for national indemnity about Hansen's disease: threatened human rights and their history—the beginning of the policy on cracking down on patients and threatened human rights July 10, 2016. http://www.hansenkokubai.gr.jp/history/history_02.html

[11] Masanao Makino: History of Hansen's disease medicine, 283–298. In: Fujio Ohtani, et al. (ed.) Hansen's disease medical science. Tokai University Press, Kanagawa, Japan, 1997.

[12] Taeko Miura: Chap. 21 Appendix history of Hansen's disease, 520–531 pp. In: Makiko kondo, Oshima Seisho-en (eds.): Life Review of Hansen's Disease Survivors Living in Oshima Seisho-en, Kazamashobo, Tokyo, 2015.

[13] Oshima Seisho-en: 50 years of History at the National Sanatorium in Oshima Seisho-en. Oshima Seisho-en, Kagawa, Japan, 1960.

[14] National Hansen's Disease Sanatorium Residents' Council: Records of Fighting by National Hansen's Disease Sanatorium Residents' Council (reprinted). Ikkosha, 2002.

[15] Ehime prefectural government office: All body "The Leprosy Prevention Law." July 10, 2016. http://www.pref.ehime.jp/h25500/4404/shinpou.html

[16] Study group welfare problem (ed.): History of a national sanatorium (leprosy), Ministry of Health and Welfare, Tokyo, Japan, 1975.

[17] Ministry of Health, Labor and Welfare: Act to accelerate the resolution of problems of Hansen's disease July 10, 2016 (2008 Act No. 82). http://www.mhlw.go.jp/topics/bukyoku/kenkou/hansen/kokuji/dl/9.pdf

[18] Japan Law Foundation: Final reports—verification meeting about Hansen's disease problems, 2005. http://www.mhlw.go.jp/topics/bukyoku/kenkou/hansen/kanren/dl/4d1.pdf

[19] Mikako Yamaberi, Matsuko Kondo, Kazue Ishikawa, Yoshiko Amano, Makiko Kondo: Causes of and coping strategies for repeated wounds in patients with Hansen's Disease

until promin treatment. Journal of Japanese Society of Nursing Research, 38(1), 59–71, 2015.

[20] United States Holocaust Memorial Museum: United States Holocaust Memorial Museum note—Nuremberg Code July 10, 2016. https://www.ushmm.org/information/exhibitions/online-features/special-focus/doctors-trial/nuremberg-code

[21] World Medical Association: WMA Declaration of Helsinki—ethical principles for medical research involving human subjects. http://www.wma.net/en/30publications/10policies/b3/

[22] The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research: Belmont Report—Ethical Principles and Guidelines for the Protection of Human Subjects of Research. https://videocast.nih.gov/pdf/ohrp_appendix_belmont_report_vol_2.pdf

[23] World Medical Association: WMA Declaration of Lisbon on the Rights of the Patient July 10, 2016. http://www.wma.net/en/30publications/10policies/l4/

[24] J. Gallagher, S. Gorovitz, R.J. Levine (ed.): Biomedical Research Ethics: Updating International Guidelines: A Consultation. CIOMS (The Council for International Organizations of Medical Sciences) Publication, Geneva, Switzerland, 2000.

[25] Toru Sekine: Genealogy of Medical Ethics—The Ancestors' Wisdom for Treating Patients Kindly (revised ed.). Hokujyu Press, Japan, 2008.

[26] Tom L. Beauchamp, James F. Childress: Principles of Biomedical Ethics (Third Edition), Oxford University Press, Oxford, UK, 1989.

[27] Michio Miyasaka: Methodology of Biomedical Ethics—A Principle-based Approach, Procedure-based Approach, and Narrative-based Approach. Igaku-Shoin, Tokyo, Japan, 2011.

[28] Center for Medical Education & Information: The four principles of bioethics July 10, 2016. http://www.c-mei.jp/index.html

[29] Japanese Nursing Association: Information for nursing practices—ethical principles July 10, 2016. http://www.nurse.or.jp/rinri/basis/rule/

[30] Takahiro Tanikawa, Hideko Miyawaki, HitomiShinjyo, Yoshiko Amamo, Makiko Kondo: The meaning of experience in the everyday poverty for the oldest Hansen's disease survivors—through the narratives of residents admitted around World War II into a leprosarium in the Seto Inland sea. Japanese Journal of Leprosy, 84(1), 37–50, 2015.

[31] Viktor Emil Frankl: Man's Search for Meaning. Beacon Press, Boston, USA, 2006.

[32] Erik E. Erikson: Identity and the Life Cycle. WW Norton & Co. Inc., New York, USA, 1994.

[33] Mikuni Oyabu, Hitomi Yamada, Rie Nishimoto, Maki Sanada, Kyoko Tsukimori, Makiko Kondo: The meaning of relocation among aging Hansen's disease survivors in Japan. International Journal of Nursing & Clinical Practices, 3, 172, 2016. doi: 10.15344/2394-4978/2016/172

[34] Makiko Kondo: Chap. 1 Significance of the project, 2–13 pp. In: Makiko Kondo, Oshima Seisho-en (eds.): Life Review of Hansen's Disease Survivors Living in Oshima Seisho-en, Kazamashobo, Tokyo, 2015.

[35] Keiich Noe: Holism. Philosophy Dictionary, Iwanami Shoten, Japan, 1998.

[36] Jean Watson: Human Caring Science: A Theory of Nursing (Second Edition.), Jones & Bartlett Pub, Chicago, USA, 2011.

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