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Chapter

Spirituality and Hansen's Disease: Spirituality' Conceptual Structure and Hansen's Disease History - Part Two

Makiko Kondo, Mikako Yamaberi, Hitomi Yamao, Masato Muguruma, Kayoko Furochi, Shiho Oka and Aiko Matsushita

Abstract

There have been suicides at the Hansen's disease sanatoria in the past. What is the level of suffering that makes a person think of suicide? Through the analysis of a Hansen's disease survivor's life, we clarified that the nature of sufferings is spiritual pain that is brought by the "loss of autonomy and independence for carving out my life." The patient was stuck in a negative cycle for about 20 years: All my dreams and hopes cut off → Despair → I want to die but cannot die easily → Lethargy·Desperation·Nihilistic → Momentary pleasure by gambling → I do not feel like living → I ask myself why am I alive → Self-criticism → Repeat again. Recovery from spiritual pain was achieved with time and by reflection. The bellwethers led to a turning point that helped to change the flow of his life. He also started using time effectively. Spiritual well-being of aging survivors has a trilinear structure, comprising the following: (1) establishing the existential foundation of a sustained self; (2) living in the moment while contemplating the future; and (3) dovetailing within the society and transcending space and time. It indicates that they can achieve the developmental tasks related to old age, personal integration containing spirituality, and the wisdom and strength to get over difficulties. This study consists of the first report and the second report.

Keywords: Hansen's disease, spirituality, spiritual pain, suicide, spiritual well-being, gerotranscendence, life review, Leprosy Prevention Law

1. Introduction

Due to social stigma, people with Hansen's disease are usually targets of discrimination, exclusion, and persecution. In modern times, those suffering with Hansen's disease were targeted by forced detention and lifelong isolation and in a manner of speaking were socially quarantined. Due to living in this extreme state, the experiences of Hansen's disease survivors actualize the existence of spirituality as spiritual pain and express human strength and the

development of individuality as spiritual well-being. Therefore, their experiences are very important and similar to those experienced by Auschwitz or atom bomb survivors.

In this two-part study (see **Table 1**), we discuss spirituality through the experiences of Hansen's disease survivors. In the first report, we discuss the conceptual structure of spirituality and QOL and explain the history of Hansen's disease. In the second report, we answer the following questions through an analysis of a Hansen's disease survivor's life review: What is the level of suffering or 'spiritual pain' that makes a person consider suicide? What causes spiritual pain in those suffering with Hansen's disease? Furthermore, why do people with Hansen's disease experience spiritual well-being and development of individuality despite their spiritual pain?

Part one	Part two
<p>Spirituality's conceptual structure and Hansen's disease history</p> <p>1. Introduction</p> <p>2. Quality of life and spirituality</p> <p>2-1. What is quality of life (QOL)?</p> <p>2-2. What is spirituality?</p> <p>2-3. Development of spiritual pain into cancer terminal care</p> <p>2-4. Spiritual pain and total pain</p> <p>2-5. What is spiritual well-being?</p> <p>2-6. Quality of life and total pain</p> <p>3. Overview of history of Hansen's disease in Japan</p> <p>3-1. From the ancient times to the end of the feudal era (-1867)</p> <p>3-2. From establishing a modern nation (the Meiji government) to the end of World War II (1868-1945)</p> <p>3-3. From developing the magic bullet 'Promin' to abolishing the Leprosy Prevention Law (Act No. 214 of 1953 らい予防法) (1943-1996)</p> <p>3-4. After abolishing the Leprosy Prevention Law (1996-)</p> <p>4. Life review of Hansen's disease survivors</p> <p>4-1. Introduction to the National Sanatorium Oshima Seisho-en, where the survivors who have shared their life review live</p> <p>4-2. The life review book of Hansen's disease survivors</p> <p>5. Conclusion</p>	<p>Accounts of spiritual pain and spiritual well-being by Hansen's disease survivors</p> <p>1. Introduction</p> <p>2. Spiritual pain experienced by a Hansen's disease survivor</p> <p>2-1. The life review of Hansen's disease survivors</p> <p>2-2. Overview of Mr. Takahisa Yamamoto's life review</p> <p>2-3. Analysis method for construction</p> <p>2-4. Construction of Mr. Takahisa Yamamoto's spiritual pain</p> <p>3. The process of recovering from spiritual pain for a Hansen's disease survivor</p> <p>3-1. What sustained Mr. Takahisa Yamamoto through the suffering?</p> <p>3-2. Relieving sufferings; preparing to accept turning points</p> <p>3-3. Turning point 1: Changing the flow of life</p> <p>3-4. Turning point 2: Meeting a friend for life (Ceramics)</p> <p>3-5. After the turning point</p> <p>4. Spiritual well-being of aging Hansen's disease survivors</p> <p>4-1. How do individuals live energetically despite having experienced extreme situations?</p> <p>4-2. Construction of spiritual well-being; Introduction of the study</p> <p>5. Conclusion</p> <p>Appendix</p> <p>Mr. Takahisa Yamamoto's life review (An excerpt only from the section that discusses spiritual pain)</p>

Table 1.
Table contents about the first report and the second report about 'Spirituality and Hansen's disease'.

2. Spiritual pain experienced by a Hansen's disease survivor

2.1 The life review of Hansen's disease survivors

Our book contains life reviews of 19 Hansen's disease survivors living in Oshima Seisho-en (see **Figure 1**) [1]. The significance of publishing the book is explained in the first report. Each survivor talks about their childhood before having Hansen's disease, the shock and suffering that followed the diagnosis, till the time that they entered the sanatorium, discrimination and exclusion in their hometown, the parents affection and worry to protect them, inconvenience faced by their brothers and sisters, various symptoms and cures, the bad experiences in the sanatorium, romantic alliances, support from friends at the sanatorium, fighting against the government, and current feelings and thoughts in their old age. The subject of the book is summarized as "*Deeply Deeply Closing Our Eyes in Order to See What We Truly Should See*," which is the subtitle of the book and has been penned by poet Ms. Yoshiko Takagi.

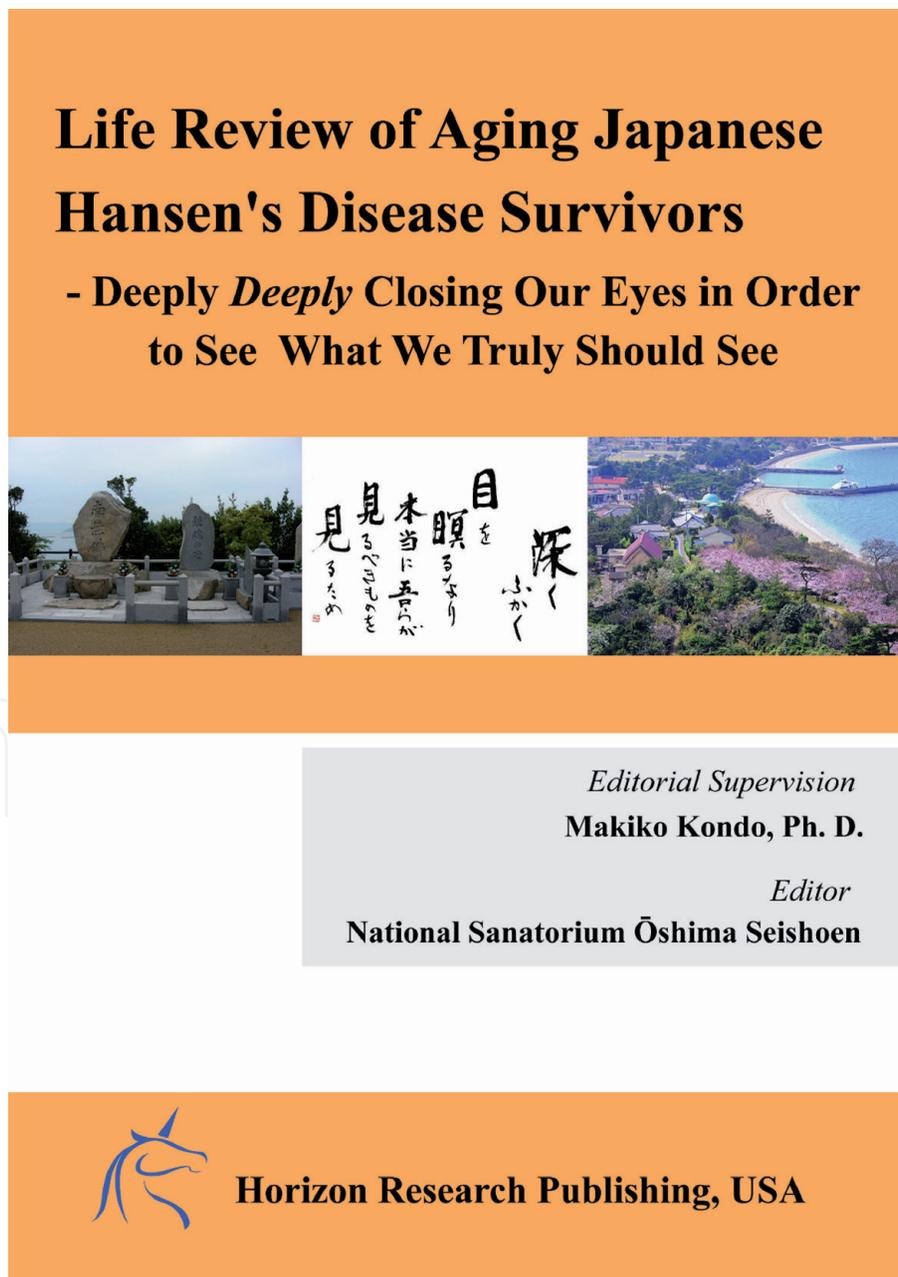


Figure 1.
Our life review books [1].

In this paper, we select the life review of Mr. Takahisa Yamamoto, who discusses the reality of spiritual pain. His detailed account is added as an Appendix 1.

2.2 Overview of Mr. Takahisa Yamamoto's life review

Mr. Takahisa Yamamoto was a bright boy who aimed to enter the national university to become a doctor or join a trading company. He was hopeful that his parents would give him the independence to achieve his dream. He was diagnosed with Hansen's disease at the age of 15. He received treatment from Dr. Noboru Ogasawara at Kyoto university hospital and at home. Dr. Ogasawara opposed forced internment and advocated outpatient treatments. Yamamoto decided to enter the sanatorium at the age of 19. After entering the sanatorium, he indulged in reprobate conduct and began gambling and tried to escape from working. He also suffered and felt lonely as he could not go out. He married at the age of 31. The friends of his wife opposed the marriage and his wife asked him, "Will you change your habits after getting married?" but his reprobate conduct continued. The turning point for him was at the age of 48 when he was selected as a representative in Oshima Seisho-en for the National Hansen's Disease Sanatorium Residents' Council, and he moved to Tokyo. He came back to Oshima Seisho-en at the age of 52 and became the chairman of Residents' Committee in Oshima Seisho-en. At the age of 60, he was introduced to ceramics, and that became his passion. When he told us about his life, he was 81 years old. He spent the rest of his life as the chairman and continued making ceramic products. He died at the age of 83 in 2016, and his remains were collected in a handmade ceramic cinerary urn and kept at the ossuary in Oshima Seisho-en.

2.3 Analysis method for construction

First, we underlined his experiences about spiritual pain and created a shadow summary to explain it. Second, we extracted a shadowed summary and sorted it based on similar meanings. Third, we schematized Mr. Yamamoto's experience. Perspectives analyzed were: "why did Mr. Yamamoto have spiritual pain?" and "what was the identity of the spiritual pain?" Lastly, we checked if the figure could show his experience and clarify the mechanism of why he had spiritual pain and the essence of his spiritual pain.

2.4 Construction of Mr. Takahisa Yamamoto's spiritual pain

We illustrate the construction of Mr. Yamamoto's spiritual pain in **Figure 2**. *Italic letters* show the same concepts as **Figure 2**.

Mr. Yamamoto was *full of enthusiasm for the future and wanted to become independent and set out on my own*; therefore, he was a boy with *strong autonomy and independence*. When he was *diagnosed with Hansen's disease*, and he knew *I cannot go out of the sanatorium till I die*. He realized that *all his dreams and hopes cut off*, and *he cannot set out on his own and carve out his life*. He *crashed by despair*, he thought "*My life is over and I can only keep breathing*." Mr. Yamamoto *wanted to die*, but he *could not die easily*. Therefore, he felt *lethargic, slapdash, desperate, let things take their own course, nihilistic, and "no matter what I do, it will all be in vain,"* and he began to *shirk patient labor, getting momentary pleasure by gambling, and stay outside the system and rule*. He *did not feel like living*, and he *asked himself 'why am I alive'*, and he *wallowed in self-criticism; he scolded himself about spending without purpose again today, saying "Are you even human? Is it not normal to die?"*

This negative cycle was *enhanced* by comparison with others. To begin, he *compared himself and his classmates who were setting out on their own*, and he thought "*I was the only dropout*" and felt *miserable*. In addition, he noticed that *there were*

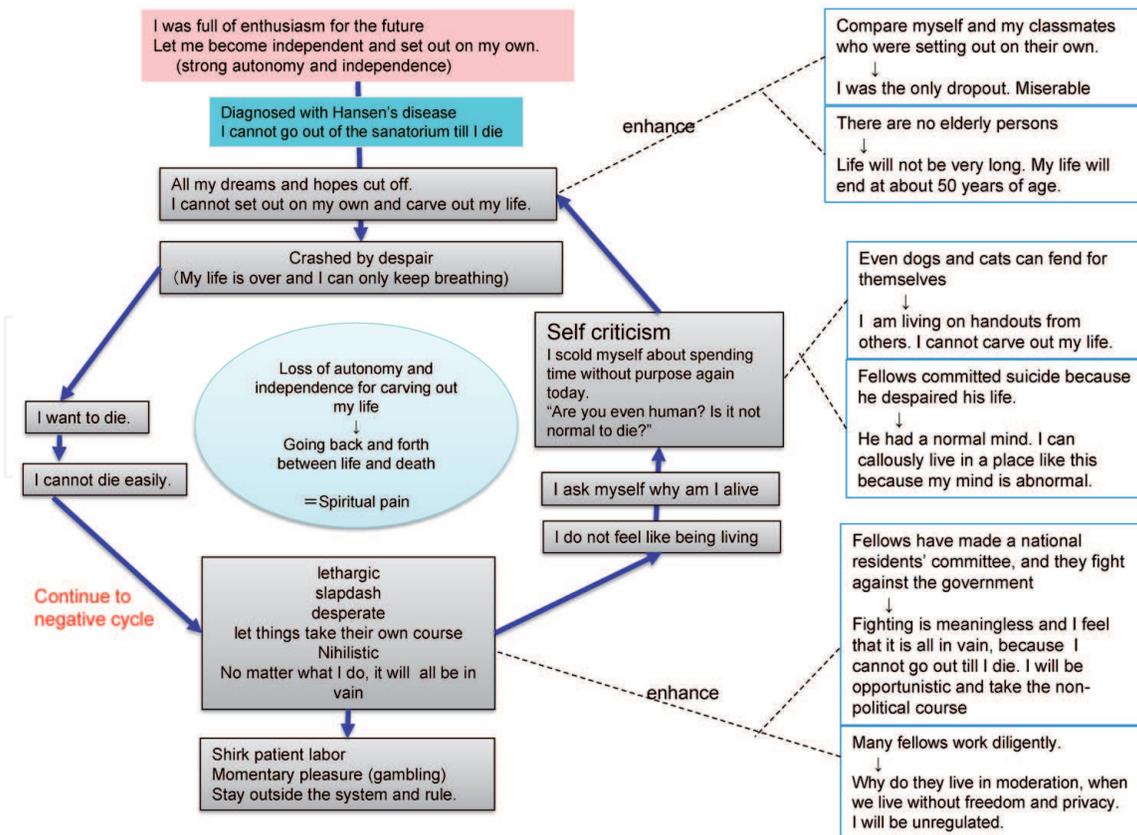


Figure 2.
 Spiritual pain experienced by Hansen's disease survivor Mr. Takahisa Yamamoto.

no elderly persons in the sanatorium, and he realized “life will not be very long, my life will end at about 50 years of age,” therefore he thought “my life is over”, and this deepened his despair.

Next, although fellows made a national residents' committee, and they fight against the government, he believed that this fight was meaningless, and I felt that it was all in vain, as I cannot go out until I die. I will be opportunistic and take the non-political course. In addition, although many fellows work diligently, he thought “why do they live in moderation, when we live without freedom and privacy. I will be unregulated.” These thoughts enhanced his irresponsible attitude.

At last, he compared himself with fellows who committed suicide because they despaired their life, and Mr. Yamamoto thought “fellow had a normal mind. I can callously live in a place like this because I have an abnormal mind.” In addition, he compared dogs and cats, and thought “Even dogs and cats can fend for themselves. I am living on handouts from others. I cannot carve out my life.” This comparison enhanced self-criticism.

Negative cycle (I cannot set out on my own and carve out my life→Crashed by despair→I want to die→I cannot die easily→slapdash · Nihilistic→ I do not feel like living→ I ask myself why I am alive→self-criticism) continued for 10 to 20 years. Essentiality of the negative cycle, in other words, Mr. Yamamoto's spiritual pain is Loss of autonomy and independence for carving out my life, and for that reason, he was Going back and forth between life and death.

3. The process of recovering from spiritual pain for a Hansen's disease survivor

Mr. Yamamoto's recovery from spiritual pain can be seen at two turning points. The first, when he visited the Tokyo office of the National Hansen's Disease Council

at 48 years. The second, when he discovered his love for ceramics at the age of 60. These turning points, respectively, came about 30 years after his diagnosis at 15 years and entering the sanatorium at 19 years.

The analysis of his recovery from spiritual pain was conducted in the same way as the analysis of construction of spiritual pain. His life review about recovering from spiritual pain is omitted because of lack of space. The process of Mr. Yamamoto's recovery from spiritual pain is shown in Figure 3.

3.1 What sustained Mr. Takahisa Yamamoto through the suffering?

Mr. Yamamoto's spiritual pain indicated a negative cycle: I cannot set out on my own and carve out my life→Crashed by despair→I want to die→I cannot die easily→slapdash · Nihilistic→I do not deserve to be alive →I ask myself why am I alive→Self-criticism. The first period of sustained suffering of 30 years was for the affection of his family. He had no one to blame for his sickness and he had no opportunity other than to vent to his mother. He blamed his mother; she accepted his lashing and continued to visit him regularly. His brothers could not tell their spouses and children about his disease, but his sisters visited and expressed their affection as they felt sorry for him. In his married life, his unrelenting misconduct had an impact on his wife, but her maturity and common sense prevented the marriage from breaking. In addition, the elders in Oshima Residents' Committee and the group for the blind continued to care for him even though he did not have a good reputation in the patient community in Oshima Seisho-en.

The second period of suffering was seen in his gambling and the glimmers of love with a student nurse during his adolescence. Gambling brought momentary pleasure and helped him to forget the despair temporarily; therefore, he got the opportunity to let off some of the negative energy from the negative cycle.

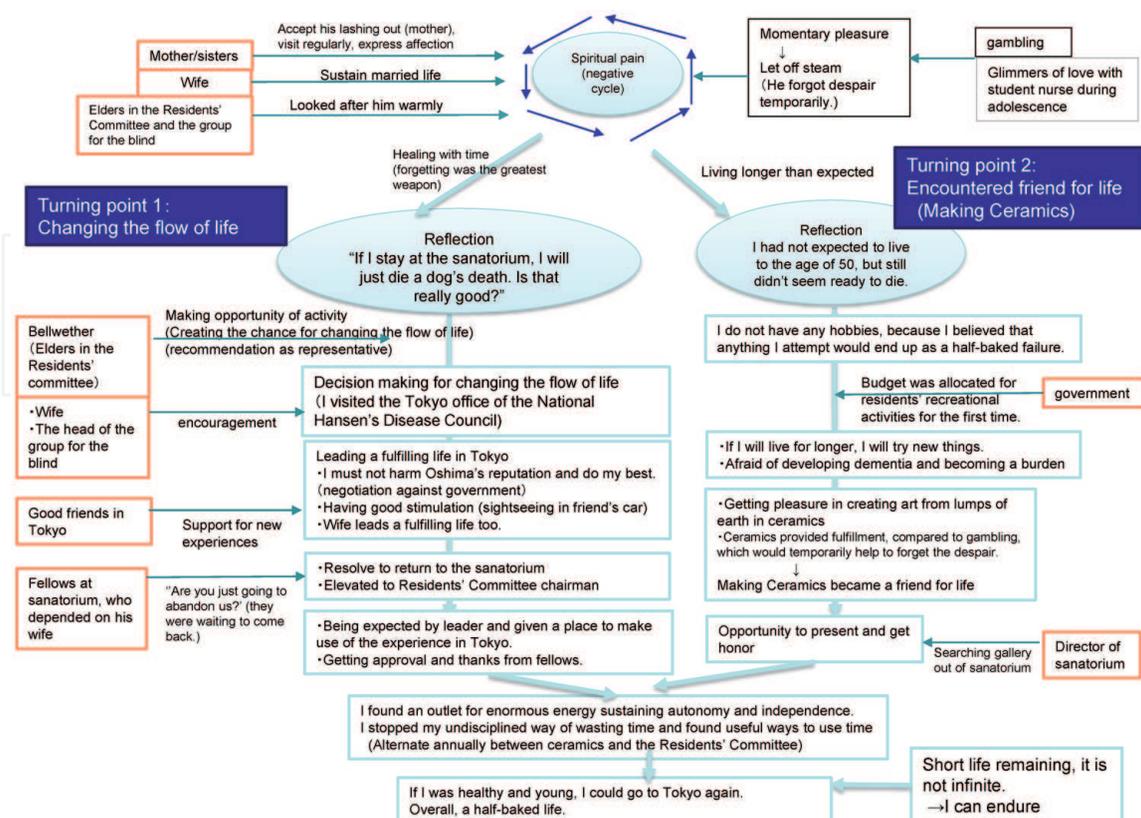


Figure 3. Recovery from spiritual pain of Hansen's disease survivor, Mr. Takahisa Yamamoto.

In addition, he met a nurse from the nursing school that was established in Oshima island in 1953, and this brought a little pleasure in his insipid life.

3.2 Relieving sufferings; preparing to accept turning points

Although the turning points in his life occurred about 30 years after entering the sanatorium, for about 10 to 20 years, the negative cycle did not change, and gradually the feeling of despair decreased. Mr. Yamamoto said "Forgetting was the greatest weapon to survival and the insight that eased suffering," maybe this indicated that he was on the path of healing. In addition, as the suffering eased, he reflected "If I stay at sanatorium, I will just die a dog's death. Is this really good?" and he started to review himself objectively.

3.3 Turning point 1: changing the flow of life

The first turning point was the visit to the Tokyo office of the National Hansen's Disease Council. This opportunity was created by the elders in the Residents' committee. As they had looked after him during his period of suffering, they could notice his reflection and the internal changes. They knew that they could change the flow of his life in anticipation of the better times ahead; therefore, they are referred to as "bellwethers." In addition, his wife and the head of the group for the blind agreed that this would be a chance to change his life. This was contrary to his expectations and it encouraged him. Mr. Yamamoto himself was ready to proceed to the next step by reflecting that it was time for a change, but he did not have the power to make the change in his flow of life.

Living in Tokyo was a fulfilling experience for him. He negotiated with the government and did his best to not harm the reputation of the Oshima Residents' committee. On vacations, his good friends took them for sightseeing in their car and his wife enjoyed this time as well. She also led a fulfilling life in Tokyo.

After 4 years here, his friends at the sanatorium, who were waiting for him to come back said "Are you just going to abandon us?" and Mr. Yamamoto and his wife resolved to return to the sanatorium. After returning, he was elevated to the position of the Residents' Committee's chairman in the sanatorium. This implied that he was expected to be a leader and was given a position where he could use his experience. This was a sign of approval from his friends and associates and a way of expressing gratitude.

3.4 Turning point 2: meeting a friend for life (ceramics)

The second turning point was his introduction to "ceramics" (see **Figure 4**). When he entered the sanatorium, there were no elderly patients. Therefore, he had not expected to live to the age of 50; this strengthened his despair and he turned to gambling to dissipate the negative energy. After he crossed the age of 50, he realized that he still did not seem to be ready to die. A budget was allocated for residents' recreational activities for the first time. He did not have any hobbies, because he believed that anything that he attempted would end up being merely half-baked. At this point, he thought that "if I will continue to live, then I will try new things." In addition, he was also afraid of developing dementia and becoming a burden on others. This is when he started making ceramics.

Making ceramics brought him pleasure as he realized that he could create something from a lump of earth. It gave him fulfillment that could be compared to the same that he got from gambling. This could temporarily make him forget the



Figure 4.
Ceramics made by Mr. Takahisa Yamamoto.

despair. Therefore, ceramics became his friend for life. When he successfully made a shape, he wanted other people to see his artwork. The head of the sanatorium sent his work to a gallery off the island, and this gave him the opportunity to present his work and get honor.

3.5 After the turning point

Mr. Yamamoto was a boy with a strong sense of autonomy and independence to carve out his life, and he hoped to have the independence to do so at an early age. His spiritual pain occurred as he was trapped in an environment where he could not carve out his own life. In other words, his strong desire to carve his life was lost and he stagnated; as a result, he blamed himself, and this negative energy brought despair. Gambling helped him to get rid of this negative energy. Being the Chairman of the Residents' Committee and making ceramics helped him to channelize his energy. It gave him an outlet for the enormous energy, and he stopped wasting time and found useful ways to use his time.

Although initially he could not endure the same as life seemed to be dull and infinite, he believes that he can endure it now, as he believed that as he had aged, and he did not have as much time left. Therefore, if he was still healthy and young, he could go to Tokyo, again, but at this age, he preferred to stay at the sanatorium. Finally, he generalized his life saying that it was "Overall, a half-baked life," and he therefore did not have the sense of accomplishment of having carved his own life.

4. Spiritual well-being of aging Hansen's disease survivors

4.1 How do individuals live energetically despite having experienced extreme situations?

Half of the life of Hansen's disease survivors was filled with suffering because of discrimination and exclusion, containment and lifelong isolation, human right violation in sanatorium, loss of opportunity of coming back to the society by delay

or abolition of the law, etc. Now the average age of these survivors is 86, and some of them have dementia, while others exhibit withdrawal symptoms. On the other hand, there are some survivors who are living energetically. How do they manage this despite having experienced extreme situations? In this section, we introduce the aging Hansen's disease survivors' spiritual well-being, which is clarified by five survivors selected strictly from 77 survivors (at that time of interview) of Oshima Seisho-en.

4.2 Construction of spiritual well-being; Introduction of the study

Construction of spiritual well-being as shown in **Figure 5** [2].

Purpose: To clarify the spiritual well-being of aging survivors of Hansen's disease and explore the question "How do individuals live energetically despite having experienced extreme situations?"

Method: (1) Participants: aging Hansen's survivors living in the sanatorium, living with vigor and liveliness, who were selected in a strict manner. (2) Data collection: semi-structured interviews. (3) Analysis: qualitative and inductive methods.

Results: (1) Characteristics of the selected survivors are as follows: relatively younger, fewer unmarried, entered the leprosarium at teenage, had held a managerial position in the sanatorium, fewer sequelae, and believed in religion, compared to all the residents in the sanatorium. (2) Narrative data were integrated through the following seven categories: <1. Continue to have strong bonds with one's spouse and memory of parents' family>, <2. Healed sufferings by living in a sanatorium located on an island with a beautiful view>, <3. Possess the self-confidence to overcome the difficulties>, <4. Live daily life with delight and worth even on a secluded island>, <5. Continue one's efforts despite aging>, <6. Obtain social approval>, and <7. Engage in social interactions with the next generation and outside the island>.

Discussion: The spirituality of survivors of Hansen's disease had a trilaminar structure, comprising the following: establishing the *existential foundation of a sustained self, living in the moment but contemplating the future as well, and dovetailing within the society and transcending space and time*. The participants had achieved the developmental task of ego integrity in old age. If compensatory mechanism is met, we might be able to develop an existential foundation for the sustained self and

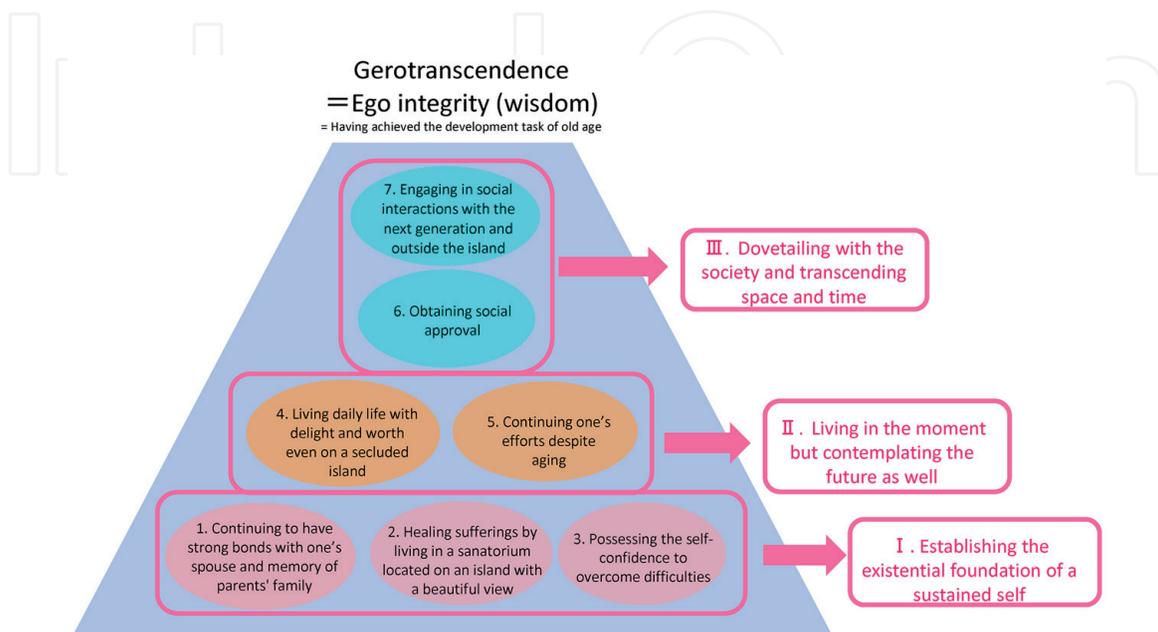


Figure 5. Structure of spiritual well-being in aging survivors of Hansen's disease. Transcription from Yamao et al. [2].

achieved ego integrity at old age despite having to live in unfortunate circumstances. Thus, if we support such individuals, we can promote compensatory mechanism.

5. Conclusion

In this study, after discussing the conceptual structure of spirituality in the first report, we conducted an analysis of spiritual pain and discussed Mr. Takahisa Yamamoto's experience as a Hansen's disease survivor. In addition, we introduced our research on the spiritual well-being of aging Hansen's disease survivors.

Mr. Yamamoto's spiritual pain was because of *Loss of autonomy and independence for carving out my life* and *Going back and forth between life and death*, and he was stuck in the negative cycle for almost 20 years. In a psychiatric study on differences between the mental condition of condemned criminals and life imprisoned criminals, condemned criminals acted violently and were easily distracted and stressed, while the life imprisoned criminals exhibited emotional paralysis and regression. [3] The reason for this difference is that while condemned criminals faced their death every day, because the date of execution is notified to the condemned criminal only on the morning of the appointed day, life imprisoned criminals repeat the same daily life until they die. In other words, the life of condemned criminals is condensed to 1 day, while that of life imprisoned criminals is diluted across their lifetime. Mr. Yamamoto's sufferings are similar to that of criminals imprisoned for life, as both experience difficulties with delight and hope, owing to a repetitive and unchanging daily life. As a matter of truth, Hansen's disease is not crime, although it is one of the many diseases in which human rights were violated. We must hand down this information and stop it from being forgotten, because Hansen's disease has a cautionary tale to ensure that the same mistake is never repeated.

Next, Mr. Yamamoto's recovery from spiritual pain was achieved with time and reflection, and then the bellwethers, who continued to be there during his time of suffering time, led to a turning point to change the flow of his life, and he spent a substantial amount of time to get approval from others and to meet their expectations. By then, he had stopped his undisciplined way of wasting time and had found out how to use his time productively. Some aging Hansen's disease survivors tend to withdraw as they are not able to get a catharsis against the past bitter experiences. In addition, right now, some young people have lost or cannot find their reason to live, and they withdraw or become desperate, therefore recovering from spiritual pain is a universal issue throughout ages. In Mr. Yamamoto's recovery process, there were some people who were affectionate toward him and were concerned about him. These people included his mother and sisters who expressed their affection, his wife, who sustained their married life, the elders in the residents' committee who created the opportunity for changing the flow of his life, good friends in his new world, and old friends who were awaiting his return. It is evident that humans can only be healed by humans. Success in recovering from spiritual pain is dependent on people who continue to support a person during their suffering and recovery. If we think about the support for people who are lost or unable to find the hope to live, creating a support system in the period of suffering and recovery is important. In the current times, human relationships are sparse and require patience.

The construction of spiritual pain and recovery from it in the chapter is from the point of view of one survivor; therefore, the analysis cannot get be universal. We must continue to analyze the information. In addition, a certain survivor said, "I will take real my sufferings to my graveyard." Talking about sufferings is difficult for Hansen's disease patients/survivors. We must realize that it is also difficult to understand the real pain of the suffering, and we must have intellectual humility.



Figure 6.
Oshima at springtime (the green roof in the center is the ossuary) (Photograph by: Kiyoshi Wakibay).

Finally, the spiritual well-being of aging Hansen's disease survivors is a trilaminar structure, comprising of the following: *establishing the existential foundation of a sustained self, living in the moment but contemplating the future as well, and dovetailing within the society and transcending space and time.* Development tasks of old age include integration vs. despair (wisdoms). The existence of spiritual well-being in aging Hansen's survivors shows two things. The first, when we experience unbearable hardship, if the compensatory mechanism works, we can sublimate sufferings and achieve incomplete development tasks at each stage. The second, "integration" of old age's development task means the person completes integration with spirituality. This shows that "gerotranscendence" as stated by Erikson [4] is seen in Hansen's disease survivors. Although a lot of negativity has been focused on Hansen's disease, utilizing the survivors' wisdom and strength for solving problems in future will help to regain their reputation. Finally, we append "Oshima at springtime" through photographs, taken by Mr. Kiyosi Wakibayashi during his life. He is one of Hansen's disease survivors who is an example of spiritual well-being (see **Figure 6**).

Acknowledgements

We thank Mr. Yamamoto and Hansen's disease survivors living in Oshima Seisho-en. This work was supported by JSPS KAKENHI Grant Number 18H03075. We would like to thank Editage (www.editage.com) for English language editing.

Conflict of interest

We have no financial relationships to disclose.

Appendix: Mr. Takahisa Yamamoto's life review (an excerpt only from the section that discusses spiritual pain)

Transcription below:

Makiko Kondo. Oshima Seisho-en: Life Review of Aging Japanese Hansen's Disease Survivors - Deeply Deeply Closing Our Eyes in Order to See What We Truly Should See. USA: Orizon Research Publishing; 2019

Chapter 3: The Story of Hansen's Disease Survivor Takahisa Yamamoto (Listener: Mikako Yamaberi)

I. Troubled times

1. From contracting the disease until arrival at the sanatorium

1) Contracted the disease during junior high school under the old system (7th–11th grades); hospitalized at university hospital; returned to hometown to continue school

-Contracted the disease in 9th grade; diagnosed with macular leprosy at university hospital

Yamamoto: I contracted the disease at the end of 9th grade. Once 9th grade ended, I immediately submitted a request for a leave of absence from school and was examined at the Kyoto University Hospital. I was told, "There's no mistake, this is macular leprosy." When I asked, "do you have inpatient facilities," I was told they did. Instead of returning home, I assembled the items I would need as an inpatient from a rental bedding store and was admitted to the hospital immediately.

Listener: Wasn't Kyoto University Hospital where Dr. Noboru Ogasawara was, who opposed forced quarantining?

Yamamoto: Yes, Dr. Ogasawara was there, although I did not have much direct contact with him.

-Hospitalization for one year at the university hospital; return to hometown and to schooling

So, I was hospitalized at the university hospital. Since my condition did not change after more than a year had passed, and because I was young and hospital life was boring, I decided to return home. At the time of my return, the doctor said to me, "You must be careful. You won't be able to have peace of mind without being careful for 3–5 years, so even if you go home you will have to go to the hospital again. If you don't want to come here, send money for the medicine and we will send it to you."

By the time I was back home, the educational system reform had changed the schools. The school that I commuted to by train had been incorporated into a high school built in my local area. A teacher from that school came to invite me to enroll, saying "How about resuming your education? You can come back at any time without having to take a test." I entered that new high school.

2) Disease worsens; prepare to enter the sanatorium

-Money for medicine spent for fun; new macules; it was too late, there was no choice but to enter the sanatorium

I started school, but instead of sending the medicine money from my parents to Kyoto, I had a fun life with my friends. I had just one red macule [as one of the initial symptoms of Hansen's disease, white or reddish-brown, flat or slightly raised spots called macules appear on the skin and are not characteristically painful or itchy] on my thigh, but then one appeared on my face too, and I thought, "Ah, now it's all over."

I made up my mind. I learned enough information while I was at the hospital that I realized that I had no choice but to enter the sanatorium.

3) Overcame parental opposition and decided to enter the sanatorium

-Parents said the staff would have no patience for me, and if I go to the sanatorium I had better prepare to run away and never come back

But my parents opposed this and said, "Even if you go to the sanatorium they will have no patience for you there." At the time, the general public had strong judgments about macular leprosy, so I was told, "If you run away there and then come back you will shame the family and we will no longer be able to live here. If you go, be prepared to never come back."

-Full of despair that my life was over; was indecisive for one year before entering the sanatorium

Before I went, I was filled with indecision, had no desire to study, and was in just complete despair. I believed all my hopes and dreams had been extinguished.

I thought that my life was over no matter what I did, and it did not matter when I entered the sanatorium since I had no future anyway. I'd just be kept alive until I die like a cow or a pig. I milled about with indecision for nearly a year, but in the end, I persuaded my parents and came here myself. That was April 1, 1952.

4) Surprise at the beauty of the sea around Ōshima

-Surprise at the beauty of the sea around Ōshima; people from mountain villages do not know the sea

When I came here, I thought that it would be a poor place for human habitation. My strongest impression when I arrived was surprise at how beautiful the ocean scenery was, since I was from a mountain village and had never known the sea.

5) Hard to determine how to shirk patient labor

-Difficult living here; was given a lot of slack in my upbringing so I was especially slipshod and let things take their own course

I strongly felt that it was a lot of trouble to live here, at least at that time. Before I came here, I lived comparatively free, as you could say that I was given a lot of slack in my upbringing, so my lifestyle here was inevitably much too negligent. What I understood from others here was that I did not do a single thing; this is because I did not feel like doing anything and so I slacked off every day, living a haphazard life and really letting things take their own course.

-How to shirk patient labor

When I arrived, patient labor was waiting for me. I was immediately given my share of work, but all I could think about was how to shirk my duties.

Listener: What kind of work was it?

Yamamoto: It was called outpatient treatment assistance and involved things like wrapping bandages and giving injections after the nurses had changed wound dressings. In the injection room, we had to sharpen the needles and sterilize them by boiling. After this was over, we helped the nurses clean.

The work was easy, but the hygiene was poor. I got out of most difficult work, like attendant work or nursing work at the sick ward, because I had other people do it for me.

-My work was covered by a patient working fervently to support his wife and children living off the island

Listener: Were there people who immediately would do the work for you?

Yamamoto: There were. Unlike me, who had no work experience and came straight from student life, there were people there who were married but their household was not yet on firm footing. They had children and so even though the wages were meager, they would work double or triple shifts to send money back to their wives. This kind of person would even take on unpleasant work, and I would ask people like that to cover my work.

-Poor reputation; pushing around adults despite being young and energetic; did not worry about criticism

I had a bad reputation. People would say, “He’s young and energetic but he doesn’t do work like the others and instead pushes around his elders.” People thought so badly of me they would chew me out, but I did not care too much about that. Since I was living a hopeless life after coming here anyway, I did not worry much about being told what to do.

2. Troubled times

1) My life was over; thought about death

-My life was over, and I could only keep breathing

Listener: After discovering that you were sick and before you formed the resolve to come to the sanatorium, I believe you had significant internal conflicts. What are your thoughts on this?

Yamamoto: Yes, I thought, “1) My life is over. I’ll just let the cards fall where they may. The only thing left for me is to keep breathing. 2) If I find myself going in too dire of straits, I should just end it all right there.” But I wasn’t able to die that easily, either.

-Death was constantly in the back of my mind; I asked myself why I was alive

3) But about death... I constantly had the idea of death in the back of my mind. When I came to the sanatorium there were 11 of us in a 24-mat size room (about 40 square meters). 4) I could only be free during bedtime, so when night fell, I would lay out my sleeping area, get inside, and think about why I was alive until I fell asleep. 5) I always thought long and hard about that, even though it was troublesome, since I did not have any goals or hope for being alive. I could not help asking myself this question.

-Lived a slack life during the day and thought seriously during the night; scolded myself saying, “Are you even human? Isn’t it normal not to remain alive?”

6) I had two selves: during the day I would slack off and live carelessly in the moment, but at night I would think very seriously. One of my selves scolded the other: “I lived another day even though I have no purpose. What are you even thinking about? Are you even human? Isn’t the truth that humans can’t stay alive?”

-Even dogs and cats can fend for themselves, but living off of handouts from others does not feel like being alive

7) “Even dogs and cats can find their own food to eat.” I was in the position of being given my rations, which I ate even while complaining about the taste. I was just living off of handouts from others. I had absolutely no initiative to keep myself alive.

-Going back and forth between life and death; might commit suicide tomorrow

At night, I could not stop thinking about death, and I went back and forth between truly wanting to live and wishing to die. This continued for how long? About 10 years—no, for 20 years...

I would just keep thinking, 8) “Maybe tomorrow I will say goodbye to this world.” I only thought this, however, and never took any action; I could not have anyhow.

2) Knew what kind of future the patients would have; came to the sanatorium as if running away

-Understood the kind of future Hansen’s disease-affected individuals have; left school thinking it would be a problem if others found out

When I returned from the university hospital, I understood to a certain extent what kind of future was in store for people with this disease. After leaving school, everything was just completely dull and uninteresting. I quit school in my second semester of 11th grade. I left thinking, “Ah, this is no good at all. I can’t let people find out.”

-Contacted the sanatorium myself; came as if running and hiding; there were rumors among my school friends, but they thought it best to leave me alone

I disappeared suddenly. This is because I felt I could not just tell my classmates upfront that these were the reasons I had for leaving school and them. I heard about the location of this sanatorium and asked them to come and meet me at a rendezvous point at the top of a mountain. I really felt like I was running to the sanatorium to hide. I suddenly stopped showing up to school, and so there were rumors.

“What happened? He hasn't been here at all lately.”

“I heard he quit.”

“I heard he was quarantined.”

They said, “If that's the case we shouldn't look for him,” and left it at that.

-When I returned from the university hospital, I was slovenly and did not feel like doing anything; this was the bitterest time of my life

Even before I quit school, 9) when I returned from the Kyoto University Hospital, I really had no inclination to do anything and was careless about everything. It was a tough time for me then and for the next 20 years or so. At night, whether I was awake or asleep and dreaming, I thought about this.

-Went back and forth between living and dying

Thinking back after all this time has passed, I lived my daily life in a spaced-out way, so that I cannot remember how I felt when I first got sick. 10) My inner conflict at that time caused me to worry day in and day out. Going back and forth between life and death probably refers to times like that.

3) Suicide of fellow resident—I can callously live in a place like this because I have an abnormal mind

-Suicide of resident; rumored to be due to his younger sister's broken engagement, but it was actually because he despaired his life

There were three people about my age who hanged themselves. At the time, I wondered if it was real.

One person got sick while attending T High School and so was around the same age as I was when I came here. His younger sister was to be married, but it was said the engagement was broken off when the groom's family found out about his disease. 11) People said, “He died because he was bitter about the broken engagement,” but it was not that simple. He really did it because of his despair about his life and abandonment of hope. After all, I was the same way—always despairing. I think that is why I cannot recall what was going on with me back then.

-He had a normal mind so he killed himself; I have an abnormal mind so I could callously live in a place like this

12) Around the time when I arrived, there were a number of older people who hanged themselves on a pine tree. I thought, “Ah, that one has a normal mind.” I'm still alive here, having gotten this illness and having to live out my life in this small space, and I cannot see suicide as the answer. I simply cannot. I felt that, since there is an abnormality in my mind somewhere, I can keep living callously even in a place like this.”

4) I became sick when I was full of enthusiasm for the future

-I was full of enthusiasm for a future in which I would have nothing else to ask of my parents if they let me graduate from college, after which I would become independent

This is a subject I am most emotional about. I contracted the disease at the end of 9th grade.13) I was just so full of enthusiasm.

If my parents let me get through college, I would ask nothing else of them. I believed this from an early age. In the old educational system, after graduating from junior high school, the next step was college. I felt that if my parents put me through college, after that I would become independent. Kids nowadays become high school

students and do not even think about what they want to be in the future. I think that's much too indulgent, and it's because they have too many material things.

5) Became saddened by comparing myself to classmates who were setting out on their own

-The academic advancement and job placement of my classmates vexed me; I was saddened when I compared myself to them

14) I would also think about things that could not be helped, like "I wonder which of my classmates went to college. I wonder which school they went to. I wonder what they've become now that they've graduated." I thought about such things whenever the time came for such events to occur. I did get a certain amount of information from my little sister, which made me feel especially wretched. If I was asked "well what are you then," I was just languishing in the sanatorium. So, it wasn't only 10 years that I lived a tiresome life, but nearer to 20.

6) Even if, by some miracle, I could leave the sanatorium, I would already be late out of the gates in starting my life

15) I had useless thoughts like, "If I endure and work hard, I wonder what unexpected miracle will take me by surprise."

But still, all I could think about were passive, backward-looking thoughts like, "By this point even if there is a miracle and I can leave the sanatorium, I'm already too late out of the gates to start my life."

7) Crushed by the despair of having all my hopes and dreams cut off

-I wanted to be a trading company employee, a federal public servant, or a doctor

Listener: When you were studying, did you know what you wanted to become, like a teacher?

Yamamoto: I would pass on teaching, although I think that if I did become one I would cultivate good students, since I have knowledge of both positive and negative things students might do; this is because when I was in junior high and high school, I did 'bad' things for the thrill of it, half out of mischief and half for fun.

When I took the entrance exams and matriculated at the old style junior high school, I had already decided which university I would go to. I told my parents that if they put me through college, I would ask them for nothing more. If they would only put me through college, I could blaze my own path myself from then on.

I wanted to be an employee at a first-rate trading company or a public servant at the national level. I'm small in stature so I was often very calculating and in planning to first become a public servant (even though I did not know which office I would want to work in), work my way up the ladder to a certain extent and then sidestep into the private sector.

What my parents told me most often—and what I thought perhaps I should do—was to become a doctor. If you become a doctor you never have to go hungry, so my parents told me to become a doctor. At any rate, all this about becoming a doctor or whatever all went out the window in 10th grade.

-I was crushed more by hopelessness than having to give up my academic advancement; it was the bitterness of my hopes and dreams being cut off that I could not overcome

Listener: You were thinking about your academic advancement, and you were forced to give that up. How did you get over that?

Yamamoto: 16) I did not get over it.

Giving up on academic advancement was secondary. More than that, getting sick put me in the position of feeling hopeless about life. Being quarantined and never being able to leave meant that I had to be prepared to give up all the hopes and dreams that I had conjured up by that point, of which academic progress was one part. That is why coming here crushed me so. I did not feel like doing anything at all.

8) An island without elderly people—life itself is not so long

-There were no elderly people; life ends in our 50s, and what's more I could not have hopes for life; became desperate and nihilistic

I was told by my parents too that if I came here, I would be isolated and be forced into a poor, destitute lifestyle, but 17) when I actually arrived, there were no elderly people. I got the sense that life ended for patients at around 50 years of age.

As for my own future, I increasingly thought, "Life itself is not so long." This encouraged in me the idea that I should not have any hopes for the future. "Whatever I do, nothing will come of it." As a result, my life became desperate and my feelings became nihilistic. To do anything was to do it in vain.

9) Forgetting was the greatest weapon to survival and the insight that eased suffering

-Greatest weapon was to forget

18) Bit by bit, thoughts like that started to fade or be forgotten. I thought, "The greatest weapon we have as humans is the ability to forget," and felt strongly that if I cannot forget this then I'll definitely hit a dead end, which would be intolerable.

-After about 20 years, the troubles faded and have now passed by

19) After about 20 years, those kinds of troubles suddenly started to fade. Now I'm pretty old. While I was lying there by myself, I never once imagined this would happen. Now, I do not think that way at all. Things like that have gone away. I've forgotten them.

3. Did not take part in the system

1) Bitterness of having no freedom

-I had no freedom with respect to society or on the island; I had no privacy; the old had power

Listener: After moving here, what was difficult?

20) Yamamoto: I came here in 1952, and what I considered a very severe living situation continued both psychologically and physically for decades. Until the 1980s, I feel like there were some questionable aspects of the living situation at the sanatorium, at least in the case of Ōshima.

The most difficult part of this was the lack of freedom. We were restrained and were legally prohibited from leaving the island, and even on the island there was no recognition of privacy. The older people had all the power, and so there was no freedom either with respect to society or in terms of life on the island. That was the most difficult thing to accept.

2) Did not take part in the system, ignored conflicts

-Stay outside of the system; unregulated

Listener: I would think that having no freedom caused you stress.

21) Yamamoto: In my case, I did not intentionally rebel, but instead as part of my intrinsic nature I could not accept becoming part of this system, so I was fine living a life away from all of that. It was rather constraining to do so, but I wasn't about to give in to relocating.

My life was really unregulated and slapdash, and I let the cards fall where they may, so it was very difficult for me to fit into a single role or to be a cog in the wheel.

-Ignored conflicts at the National Hansen's Disease Sanatorium Residents' Council and the Residents' Committee

When I came here, there was the Residents' Committee, and in the previous year a national organization was formed called the National Hansen's Disease Patients' Council (now called the National Hansen's Disease Sanatorium Residents' Council). Among their activities, including at the Ōshima Residents' Committee, they sought the revision or abolishment of the Hansen's Disease Prevention Law. Our freedom was restricted, we were put to forced labor, and the head of the sanatorium had the power to discipline and detain us through extraterritoriality.

He could detain people who did something wrong to punish them and had the right to reduce meal rations. There was a sense of opposition to these social inconsistencies. These organizations were very active when I arrived. There were often labor strikes and hunger strikes.

22) I had very slipshod feelings at that time and turned my back, thinking “Isn’t it too late to be doing this?” That is why I thought, looking at it objectively, having no freedom was bitter and placed a large weight on my shoulders, but since my daily life involved letting the cards fall where they may, I did not trouble myself over it much.

3) The conflicts of the National Hansen’s Disease Council ended in vain, but things improved gradually in unseen ways

-Despite the hunger strikes and labor strikes, the Hansen’s Disease Prevention Law conflict ended in vain and the law continued until 1996

Listener: Did anything get better because the others had gone on strike?

Yamamoto: Nothing got extremely better. Until the 1980s, there was nothing that suddenly got better one day or improved at a particular time. It happened vaguely and gradually.

There were organizing activities and opposition activities that drove facility operations into an untenable situation, such as hunger strikes and labor strikes, but in the end, they cannot be said to have changed anything. This is because at the conclusion of the conflict over the law, they were not able to deal a blow to the national government. Ultimately, the law remained in place until 1996. Since the conflict with its large goal ended in vain, I feel the people at its forefront must have felt quite despondent by that point.

-Things got invisibly better a little at a time

At any rate, when I say things changed, it was a tiny bit at a time in invisible ways. For example, among medical issues, things like a significant bump in the health care budget, a sudden jump in the number of medical staff, or a groundbreaking reform in the new year did not occur at the Hansen’s disease sanatorium.

Since the residents, who had until then meekly been doing what they were told to, began to use shows of force during the prevention law conflict, the government thought, “We had better think about this situation a little,” and implemented improvements a little bit at a time. Even though, practically speaking, the conflict ended in vain, the government did raise the working wage slightly, increase medical expenditures, and increase the number of workers by one or two people. I feel that the government had an inflated view of these small changes and felt very self-satisfied about them. As these built up a little at a time, if I look back over a long period of time of 15 years, instead of 5 or 10, I can say things got better. This is the extent of the improvement we are talking about.

4) Did not listen to criticism for not participating in the conflict

-Criticism for not participating in the conflict

Listener: During the organized movement, did any of your peers say to you, “Why are you not participating with us?”

Yamamoto: I was not directly scolded like that.

Nevertheless, I had a new acquaintance who said to me, “You are still young and energetic and can do what others can do too. Why are you not participating? Shouldn’t you also join the fight and put in even a small effort to improve your own living situation?”

-Circumstances without freedom; since freedom was in vain, I chose an opportunistic, non-political course

Despite someone saying that to me, I did not join the activities, thinking, “What’s the point now? I’ve been hurtled into these circumstances without freedom where I can’t leave the island, and I have no future, dreams, or hopes of my own. No

matter what I do, it will be in vain, so I'll just let the people who want to participate do so. I'll be opportunistic and stay non-political.”

5) Guilt at reaping the benefits of the conflict without effort

-Guilt at just reaping the benefits instead of joining the conflict

Nevertheless, after things became a little better, I was unable to enjoy those improvements. This is because I often felt guilty that I was benefiting from the work of others at their expense.

6) No medical care—how can I protect my life?

-No medical care; can I secure my own life with meager care?

One of the severe conditions was that, despite being a national sanatorium, there was no medical care. Now, we are all getting old and becoming immobile and there are pressing issues with nursing and caretaking, but when I first arrived, I was young and healthy. Even though I did not suffer in from this disease at the time, there was no care for when I got sick, and so there was a constant uneasy undercurrent over how I would secure my own life amidst this meager medical care. By chance, I have made it to today without getting sick very much, so in that sense I have been very blessed.

4. Whether to have a reunion after 65 years with school friends—too much of a difference in the paths we have taken

-A school friend saw me appear on television and recognized me; invited me to see each other

There is a Hansen's disease forum in Tokushima this year. I sometimes make short appearances on television, so there were people who thought, “Th... that's Yamamoto!” and recognized me. They're already 80 years old and past the mandatory retirement age. One person ended up becoming the principal of an elementary school. Another graduated from one of the national universities and became a school principal. During high school, we were in a group of five buddies who were always together.

-Classmates steadily progressed through lives of their own choosing, while I have been groaning at the bottom of the ravine of life; I thought perhaps it would be better not to meet

These two former classmates contacted me and said, “Let's meet up” at our hometown. This was really depressing. When this sort of thing occurs, you are forced to look at the past. My schoolmates have been steadily progressing through lives of their own choosing, have at least followed their own paths, and are now practically ready to graduate from life. My own circumstances just involved groaning at the bottom of the ravine of life until my own time of graduation came. I thought, “There's no point in meeting. What will we talk about?” I was full of worries like that. “I should just not meet with them,” I decided.

-I was the only dropout; could not leave no matter how much I struggled; was miserable

Of our group of five, one person had worked at a bank and retired when he reached the mandatory age. Another person, who was the smartest of us, was someone I expected to look beyond our local university, and just as I thought he had attended one of the former Imperial universities.

23) In the end, I fell off the cart along the way and the other four all graduated from college. I was miserable that I was the only one who did not make it. Since I could not leave here no matter how much I struggled, I had no inclination to do anything and felt only resignation. Getting this illness really stained everything and nothing could be done about it, because one way or another it all ends up like this. I was invited to our class reunion, and some of those in our group said they went. I was glad I did not go. Even if somebody had become the prime minister, all I would have to say to them would be, “How are you doing?” [Laughs].

II. Changing flow of living

1. By the recommendation of elders who warmly looked after me, I visited the Tōkyō office of the National Hansen's Disease Council

-The flow changed; elders in the Residents' Committee warmly looked after me

Listener: From that hopeless state, was there something that triggered a change or the gradual re-emergence of hope?

Yamamoto: Instead of hope, a kind of flow started forming and that flow is all that changed.

When I say the flow changed, there were some people who warmly looked after me even though I was not living a very admirable life at all. They were Mr. S and Mr. M., who were elders in the Residents' Committee. At the time, I had a terrible reputation of being a slovenly fellow despite my youth and vigor.

-Activities of the Residents' Committee; idiotic

I thought even the activities of the Residents' Committee were idiotic. I thought, "I have no hopes or dreams. What's the point of being active in Residents' Committee activities in this place that I can never leave?" I was really opportunistic.

-Was nominated to be a representative for three sanatoriums to the main office (Tōkyō) of the National Hansen's Disease Council

At any rate, in 1980 there was an organizational problem with our Residents' Committee and we needed to select and send a central executive committee member from our block within the Seto Inland Sea, which consisted of three sanatoriums (Oku-Kōmyō-En, Nagashima Aiseien, Ōshima Seishoen), to the national organization. When it was Ōshima's turn, they were unable to select someone, so one day I was suddenly asked by Mr. S, "Would you go to the main office of the National Hansen's Disease Council for us?"

"You say that, but I've ordinarily taken a non-political stance and I don't know what the objectives of the organization's activities are or what the current situation is. There is no way I can go and do this. It's completely impossible!"

"I'll collect the documents you'll need, so just go for us."

-If I stay at Ōshima I'll just die a dog's death, and since the work will involve negotiations with Nagata-cho and Kasumigaseki [the elected government and the civil service], it might be stimulating

My feelings changed to wanting to go for the completely wrong motivation, which was "If I just stay at Ōshima, I'll die like a dog." If I did what they asked and went to Tōkyō, my main work would be to go to places in Nagata-cho [the center of the elected government] and Kasumigaseki [the center of the civil service] like the Ministry of Health, Labor and Welfare and the Diet Members' Building for legislators. After that, I would write reports to send to the various branch offices about what demands I made under which themes, the results that followed, and the nature of responses from legislators and the Ministry of Health, Labor and Welfare. That is all I needed to do, and the rest would be free time. I thought I might have a different lifestyle in Tōkyō, so I did as Mr. S said and departed.

2. Life in Tōkyō

-Life in Tōkyō: Tough at first

For over a month after I arrived, it was tough for me because I did not know what kind of work it was. At the time, there was a council system with seven Central Executive Committee members, so the seven people were selected and sent from their respective blocks. I learned a lot about the organization's activities, although it was tough at first when I had no previous knowledge.

-Mustn't harm Ōshima's reputation.

I was selected from Ōshima, and it would be out of the question to be noticeably inferior to the other six members, so my work had to be comparable to the others.

It wasn't on par with the Olympics like we have now, but I felt, "I mustn't harm Ōshima's reputation." So I did work hard for the organizational activities.

3. Effect of wife's encouragement and assistance

-Approval from wife approval and friends; wife hoped this would trigger a change in me.

Soon, my wife started wanting to go. I had to raise my standard of living or else our relationship would become a battleground. If I stayed here, I would not do much good for anyone and would live life on the sidelines, since I just played a lot of Mahjong and such. But it seems my wife thought, "maybe going will cause a change." So she said, "Maybe it would be good to try going to Tōkyō. I also want to have a peek at Tōkyō, instead of spending all my time here at Ōshima." I actually thought she would be opposed to the idea. She did have an uncle and aunt here, after all.

I also had thoughts pulling me in the other direction, namely, how could I go to Tōkyō and leave behind the people who were always concerned for me even though I was usually up to no good, like Mr. I and Mr. T, as well as the head of the group for the blind. Nevertheless, those people also told me, "Just go and learn from it. Then, when you return, make use of what you learned." They encouraged me to think more forwardly.

-Four years in Tōkyō; blessed with good friends, visited various places, and had good stimulation

I was in Tōkyō for about four years, and there were a number of people I could get along with who treated me very well. My friends in Tōkyō would take me to all sorts of places in their cars, and I think that time was stimulating for me.

-Wife thought that life in Tōkyō was the best

It seems that it was fun for my wife too. It was tough to be told, "The only good times were in Tōkyō, and after that not a single thing was good."

4. Resolve to return to the island

-Returned to the island without extending my stay so as not to abandon my friends on the island

I was there for four years over two terms, and was asked, "Please extend your stay." Right around the time my term ended, there was a change in the system for the executive office chairperson, and I was asked to stay as the next chairperson. However, Mr. and Ms. O at Ōshima said to us, "Are you just going to abandon us?" It is tough and painful being asked that, and I thought that since they were depending on my wife more than I was to such an extent, she should take care of them. I felt that this would be hard for my wife too.

I asked my wife, "What should we do?" She said, "We can stay, or we can go back," so I decided, "In that case we'll return."

-Life in Tōkyō would have been impossible without my wife's help

Listener: Did your wife support you through this?

Yamamoto: Yes. Working at the head office could not have been successful without her. For someone like me, it would be tough to go alone. I worked all day at the office and so would have to make my own meals when I returned home, and then I would have to clean the rooms and wash the sink and do the laundry. I could not do that myself. There is the saying, "Maggots grow in a widower's home," and there really might have been maggots without her.

5. Return to the island; elevated to Residents' Committee chairperson

-My standing was reversed before and after going to the Tōkyō office; was recommended for the Residents' Committee chairperson at Ōshima to take advantage of what I learned at the head office.

After returning to Ōshima, my standing had undergone a complete reversal from four years prior. I was quickly elevated to Residents' Committee chairperson at

the next election with the hope that I would take advantage of what I learned during my four years of work at the head office. When I returned, there were still over 600 patients here. When I was raised to this high position, my way of life started to change a little.

6. Was able to come to terms with time

-Hadn't done anything decent until then

Until that point, I had not really done a single thing to get praise from others, and even now I'm not doing anything praiseworthy. But after the age of 60, I did some ceramics. Until then I went fishing and when summer came I would go diving.

-It is tough to come to terms with the time I have left; I had lived without goals in a workaday way

At this point, it was clear I do not like work and do not have anything to do day in and day out. This is also something that is bitter to me in terms of being alive—to come to terms with the time I have left. Unless you accept this completely, you cannot come to terms with it at all. I only drank and gambled, so I really lived without goals or meaning in my life.

-Slack way of living

That is why as a human, I saw my way of living as completely slack. I very much regret this now. It would be better if I could come to terms with things through a sense of fulfillment like other people, but it's difficult when you just slack off.

-Work as the Residents' Committee chairperson; avoiding boredom as one way to come to terms with time

By doing the work of the Residents' Committee, I could avoid boredom because things had to get done whether I liked it or not. That process is pretty much the same now, as well. Sometimes there is work that makes me think, for example something that does not make sense, in which case I know I have to do something about it and dive in headfirst. For me, this is a way to come to terms with time, and I can avoid boredom. That's all.

Listener: But I feel like you were actively pursuing a lot of activities.

Yamamoto: I did not normally think about things for other people or fight for human rights. It's just that while I'm alive, I have not been able to come to terms with time very well, so doing these kinds of activities becomes a way to do this.

-Here, the sciences were of no use, but in the liberal arts I could have engaged in literature as a way to come to terms with time

Even while I was a student, I liked math and the sciences more than the liberal arts, and so I was completely useless after coming here. I think, "I could have used my time well in the humanities. What a mistake." Coming here, instead of using my body to do something, I would have made something spiritual, a literary work. A novel or critical commentary would be beyond me, but I think it's possible that making *haiku* or *tanka* poems would be within my reach, although I might be scolded by people who have studied those forms and tell me that I'm underestimating them.

-If I were healthy, I could go to Tōkyō again, but my body was on the decline

There came a time when the main office talked about sending me to Tōkyō again. The organization is in trouble right now, so if my eyes and ears were in good shape I would go at my own expense, but now my sight and hearing are no good. I would not want to always need an attendant to do the work if I went all the way to Tōkyō.

-Short life remaining; even if it must be endured, it is not infinite, so I could just spend it at Ōshima

I think, "I can just stay at Ōshima and do what I can here to pass the time." I do not have that much time left. Even if it is a matter of endurance, there is not an infinite amount of time that must be endured, so I think that leaving things as they are is fine.

7. Overall, a half-baked life

-Looks like life will end with me still a good-for-nothing

At any rate, I'm starting to see that my life will end without having done anything and as still good for nothing. It seems a 'good-for-nothing' remains a good-for-nothing to the end. Even with the work of the Residents' Committee, if you want to do it with a relaxed attitude in your spare time you can do it all in a relaxed way, and if you want to dive in headfirst and do things seriously, you will have to put in the appropriate effort. You have to read books about organizations, social order, and welfare, and study specialized topics. Just understanding these things does not mean that you have the will to put them into action. That is because you will compromise and think, well as long as I can manage to not fall behind, it will be good enough.

-Half-baked way of life; cannot find words to leave behind to the subsequent generations

Listener: If you were to leave behind something of what you experienced at Ōshima to future generations, is there anything you know you would like to say?

Yamamoto: No, I have not thought about such things before. I cannot give a quick answer to questions like that.

If it is about what I have done at Ōshima, until I passed the age of 40, I was obsessed with Mahjong and gambling and that's about all I did. After that, there wasn't anything that I could tell other people, "This is what I've done."

Looking back, my entire way of life has been half-baked. If I myself had lived even a little more ready for my own life, I would now have words or things I wanted to leave behind. I've just been a slacker, and there were few times I could be completely serious; usually it happened momentarily or temporarily. At times when I'm working, I do think in my own way about things like, "Which perspective should I speak from next time," when, for example, I am at a Hansen's disease forum or when someone comes to me to talk. It's pretty haphazard. I do not have the knowledge or room to be irresponsible. Since one should not be haphazard, I do in my own poor way think about what I should say next.

(The following is omitted.)

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