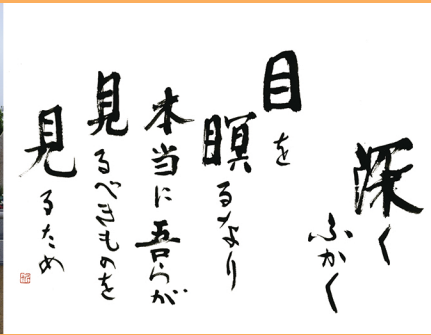


Life Review of Aging Japanese Hansen's Disease Survivors

- Deeply *Deeply* Closing Our Eyes in Order
to See What We Truly Should See



Editorial Supervision
Makiko Kondo, Ph. D.

Editor
National Sanatorium Ōshima Seishoen



Horizon Research Publishing, USA

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Kazama shobo (Japanese Version)

Translation: Editage by Cactus Communications

Horizon Research Publishing, USA

Title: Life Review of Aging Japanese Hansen's Disease Survivors - Deeply
Deeply Closing Our Eyes in Order to See What We Truly Should See

Editorial Supervision: Makiko Kondo, Ph. D.

Editor: National Sanatorium Ōshima Seishoen

Publication Date: February 28th, 2019

Published by:

Horizon Research Publishing
2880 ZANKER RD STE 203
SAN JOSE, CA 95134
USA

<http://www.hrpub.org>

Printed on acid-free paper

ISBN: 978-1-943484-20-1

Price: \$70 per copy (USA)

General Enquiries

Publish with HRPUB, learn about our policies, submission guidelines etc.

Email: book@hrpub.org

Grant for Translation publication

Japan Society for the Promotion of Science (JSPS)

<https://www.jsps.go.jp/english/index.html>

KAKENHI (Grant-in-Aid for Publication of Scientific Research Results)

Grant Number: 17HP6008

Grant for the Project

The Toyota Foundation

<https://www.toyotafound.or.jp/english/>

Research Grant Program in 2013

Grant Number: D13-R-0015

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Brief Introduction

Telling the story of Hansen's disease to the children of the next generation.

How should society care for those who suffer from Hansen's disease and the related discrimination and prejudice? What are the relevant medical ethics? We listened to the life stories of nineteen Hansen's disease patients who survived the most extreme circumstances on an isolated island (Ōshima) in the Seto Inland Sea. This book presents the lessons learned from the wisdom and negative history gleaned from their tragic lives.

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For the Translated Edition

Makiko Kondō

Graduate School of Health Sciences, Okayama University

Telling the story of Hansen's disease to the children of the next generation.

How should society care for those who suffer from Hansen's disease and its related discrimination and prejudice? What are the relevant medical ethics? We listened to the life stories of 19 Hansen's disease patients who survived the most extreme circumstances on an isolated island (Ōshima) in the Seto Inland Sea. This book presents the lessons learned from the wisdom and negative history gleaned from their tragic lives.

This book contains the life stories of 19 Hansen's disease survivors who spent their lives at a Hansen's disease sanatorium called the National Sanatorium Ōshima Seishoen (in Japan).

Around the world, Hansen's disease has been stigmatized and the subject of prejudice and discrimination since antiquity due to the changes in appearance it causes. Until the discovery of the magic bullet drug, Promin, the disease could not be suppressed. In addition, when the causative bacteria were discovered, the plan for safeguarding society, from the perspectives of bacteriology and public health, was through isolation.

The characteristics of Hansen's disease in Japan include the following: 1) the inhumane treatment of Hansen's disease-affected individuals progressed in the era of the crisis for national survival after defeat in WWII, 2) even after the discovery of the magic bullet drug, the abolishment of the Leprosy Prevention Law was delayed, and thus many survivors who had missed their chance to return to society had to spend their entire lives at sanatoria, and 3) the eradication of Hansen's disease was sought through lifelong isolation and sterilization, and thus survivors who were not given the chance to raise children are now elderly, and the history of Japan's Hansen's disease sanatoria will perish with the deaths of the survivors.

These stories from Hansen's disease survivors, who have lived through extreme circumstances, are unique in that they can only be told by someone who had the experiences they did, and thus can be considered part of the shared heritage of all humanity. In order to never repeat the cruel lifestyle of the past as described by Hansen's disease survivors, their stories must be passed down, and we must think deeply about human dignity and medical ethics based on their experiences. In addition, just like existential psychology was born in Auschwitz, the stories of these survivors contain wisdom and human strength that are unique to survivors who have overcome great adversity to reach old age. Now that the average age of

Frontispiece

I. Images from Ōshima during the Strict Quarantine Policy



Patients seine fishing at a beach
(September 1946)



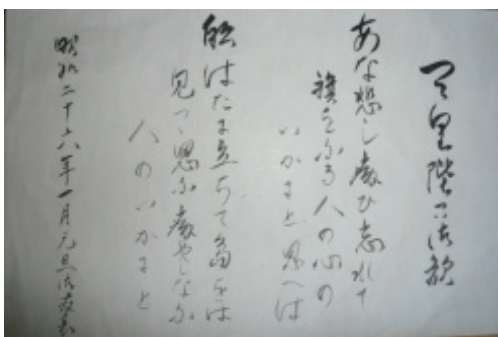
Children admitted to the facility (boys)



Children admitted to the facility



The Showa Emperor's visit to Ōshima



Poem by Emperor Showa (Hirohito)

‘Ana kanashi, yamai wasurete hata-wo
furu, hito no kokoro-no ikani to omoeba’

“How said it is
to think of the hearts of those who
wave their flags for me,
forgetting their illness”

‘Funa-bata-ni, tachite shima-woba
mitsutsu omou, yamai yashinau hito-no
ikani-to’

“I tarry on the deck of the ship as I
look at Ōshima

and think of the hardships
of those who tend to the sick.

Unveiled New Year's Day, 1951

Chapter 1. Significance of the Project

I. Significance of the Project (Makiko Kondo)

1. The significance of sanatorium nurses listening to the life stories of Hansen's disease survivors and of publishing this life review book
 - 1). Hansen's disease and Japan
 - 2). The current state of the National Sanatorium Ōshima Seishoen
 - 3). Hansen's disease survivors tell their life stories to sanatorium nurses
 - 4). The significance and universality of the experiences of Hansen's disease survivors
 - 5). Words to pass on to following generations
 - 6). How to take advantage of insights from Hansen's disease survivors in the future
 - 7). The future of ōshima seishoen and the wishes of Hansen's disease survivors
2. Historical verification and subjective life stories are different dimensions
3. Ethical considerations for the speakers
4. Structure of this book
5. Editing the life reviews
6. I await your opinions, concerns, and/ or comments I await your opinions, concerns, and/ or comments
7. Acknowledgements

II. Purpose of the Grant (Ryuta Oba)

III. Greeting from National Sanatorium Oshima Seisho-en

1. Greeting from Chairman of Hansen's disease survivors' committee (Takahisa Yamamoto, Kazuo Mori)
2. Greeting from Director (Hideyo Shinmori, Yoshiko Okano)
3. Greeting from Chief Nurse (Kyoko Tsukimori, Makiko Watanabe)

Chapter 24. Basic Knowledge of Hansen's Disease

I. Pathophysiology of Hansen's Disease (Makiko Kondō)

II. History of Hansen's Disease (Taeko Miura)

**III. Current State of the National Sanatorium Ōshima Seishoen
(Kazue Ishikawa)**

**IV. Conceptualization of the Future of the National Sanatorium
Ōshima Seishoen and Upcoming Issues (Kyōko Tsukimori)**

I . Pathophysiology of Hansen's disease

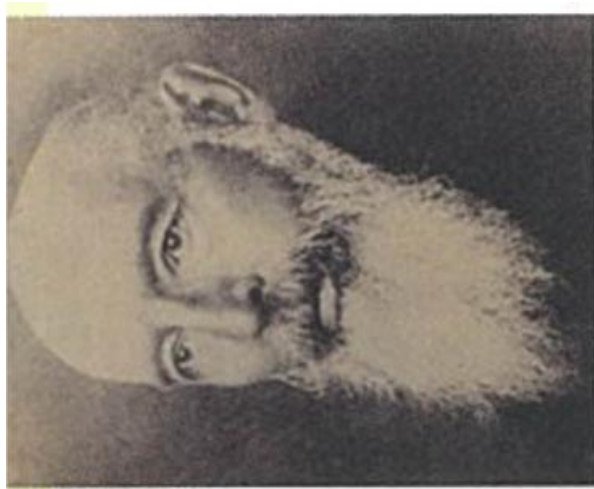
Makiko Kondō

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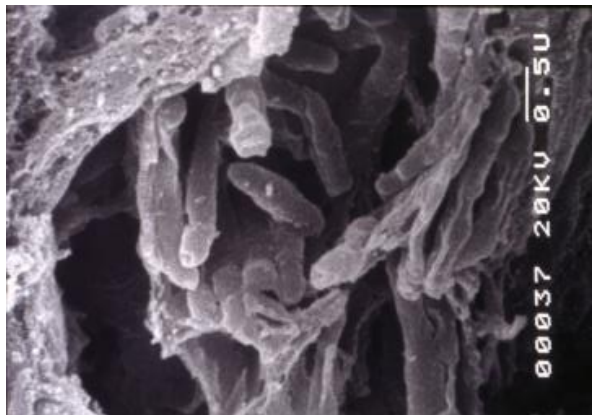


What is Hansen's disease?

It is a chronic granulomatous inflammatory condition caused by the leprosy bacillus (*Mycobacterium leprae*).



Armauer Hansen discovered the leprosy bacillus in 1873



Leprosy bacillus imaged using a scanning electron microscope from the footpad of a nude mouse (Image source: Dr. Masanori Matsuoka of the Leprosy Research Center at the National Institute of Infectious Diseases)

Characteristics of infection with the leprosy bacillus (*Mycobacterium leprae*) (1)

◇ The optimum temperature for *M. leprae* is 30-33°C (lower than body temperature)

It proliferates in the peripheral nerves and mucosa near the surface (ends of the hands and feet, head, face, nose, eyes, and ears).

* Since the core temperature of the body is higher at the vital organs necessary for maintaining life (liver, kidneys, pancreas, etc.), they do not proliferate there. Thus, deaths due to organ failure are rare (excluding acute aggravation from the leprosy reaction, weakness around the time of the Pacific War, and the like)

- The parts of the body that are most visible are affected by lesions
- Affected individuals must continue to live through their changes in appearance.

■ Makiko KONDO: Biography

Dr. Makiko Kondo obtained Bachelor of Education and Registered Nurse degrees from Tokushima University in 1989, a Master of Science in Nursing degree from Chiba University in 2000, and a Doctor of Philosophy in Nursing from Osaka Prefecture University at 2007. Currently, she is an associate professor at the Graduate School of Health Sciences in Okayama University. She teaches doctor's course, master's course (Oncology Certified Nurse Specialist), and undergraduate. Her field of expertise is qualitative studies and building of new principles and theory, and her research themes involve bioethics and life review of Hansen's disease survivor had experienced extreme state, care for parents with cancer and their children, nurses' grief care, and conceptualization of clinical nursing competency.

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ISBN 978-1-943484-20-1



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