

# Removing the Invisible Barrier to Medical Resources for Individuals with Leprous Histories: Report from a Community-based Clinic in Japan

**Namisato M<sup>1\*</sup>, Shirai T<sup>2</sup>, Yana Y<sup>3</sup> and Ogawa H<sup>4</sup>**

<sup>1</sup>Department of Dermatology, Auen Poly-Clinic, Japan

<sup>2</sup>Department of Internal Medicine, Auen Poly-Clinic, Japan

<sup>3</sup>Department of Plastic Surgery, Auen Poly-Clinic, Japan

<sup>4</sup>Chief Director of Juntendo University, Japan

## Case Report

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**\*Corresponding author:** Masako Namisato, Director of Auen Poly-Clinic, 1037-1 Nakatomi Tokorozawa-city, Saitama-prefecture, 359-0002 Japan, Tel: +81-4-2990-5818; Fax: +81-4-2990-5828; Email: namima@auen.jp

## Abstract

Japan has long had a Leprosy Prevention Law. The experience of compulsory segregation often damaged patients' self-esteem, causing most to break off their family relations. Even after their disease was cured, individuals with a history of leprosy were made to live in a restricted society. When sick, these individuals often don't want to visit a clinic because they fear disclosure of their leprosy history. We set up our clinic to serve as a gateway to medical resources for these individuals, through collaboration with medical social workers. We have several medical specialists, one of whom has many years of experience in working with patients with leprosy. Our clinic actively manages 54 patients, with 2 deaths to date. The average age of the 52 living patients is 78.4 (62–99) years old. Majority of the patients had lepromatous leprosy (LL), followed by borderline leprosy. The disability rates for upper- and lower-extremities and lateral part of the eyes are very high. Patient's biggest complaints tend to focus on problems caused by their anesthetic skin and physical deformities. Other concerns center around the possibility of leprosy relapses and refractory neuralgia. Our patients exhibit various diseases that are found in elderly people. Three cases presented with active signs of leprosy, and one with relapsed LL. We should always consider the possibility of leprosy recurrence. Most of our patients are now entering the final stages of their lives. Thus, our focus should be on creating better surroundings for these individuals while welcoming them back into the community and removing their fears of societal rejection. The cooperation of medical institute where we refer our patients has accelerated our activities. In addition, we appreciate the cooperation and understanding we have received from the community.

**Keywords:** Leprosy; Social integration; Community-based clinic

## Preface

In many countries, leprosy (Hansen's disease) patients have led harsh lives. In Japan, after the 1970s, the incidence of leprosy was virtually zero. However, the Leprosy Prevention Law was active until 1996. Individuals once affected by leprosy, although cured, were subject to a prolonged segregation policy which caused serious damages to their lives as the members of society. In an effort to re-integrate these people, we set up a clinic near Tokyo in 2005, named the Auen Poly-Clinic. This report describes the activities at our clinic.

## A Concise History of Leprosy Control in Japan

Act No. 11 was a law targeting so-called "homeless lepers" and was enacted in 1907. In 1931, the Leprosy Prevention Law was passed. This law required all people who developed leprosy to be segregated in sanatoria. At the point of internment, most patients changed their names to protect their families' reputations. After World War II, leprosy became a curable disease with the introduction of Promin (glucosulfone sodium). In 1951, the predecessor of the current All-Japan Association of Hansen's Disease Patients, a nation-wide organization, was formed. Their campaigns advocated for abolition of the compulsory segregation law. However, their efforts were defeated in 1953 [1].

In the 1960s and 1970s, some patients were released from the sanatoria through the partial rescinding of the law. These individuals were labeled "community inhabitants." However, their status was informal and there was no infrastructure to support their lives in, or reintegration to, society. For the most part, treatments for leprosy and most leprosy-related diseases were available only in sanatoria. Thus, the "community inhabitants" had a difficult time living in society while simultaneously attempting to conceal their past.

In 1996, the Leprosy Prevention Law was finally abolished. This marked the end of the 89-year segregation policy. In 1998, a Government Liability Lawsuit on the Unconstitutionality of the Leprosy Prevention Law was filed and on May 11, 2001, the district court delivered a decision in favor of the plaintiffs. Accordingly, the Hansen' Disease Compensation Act was passed in the National Diet.

Under the compulsory segregation policy, many patients with leprosy experienced damage to their self-

image and grew to fear disclosure of their past medical histories. Even after the segregation law was abolished and medical care was incorporated into public health measures, only a few visit community clinics.

## What our Clinic is Aiming

Most "community inhabitants" don't want to visit their local clinic, instead opting to hide their past histories. Our clinic seeks to be a gateway for "community inhabitants" to access any medical resources. There are 3 departments, including internal medicine, dermatology, and plastic surgery. Each is staffed with specialists, including one dermatologist with an extensive history treating patients with clinical leprosy. Out of all the patients we treat every day, 1 or 2 generally have leprosy histories. When they need other medical resources, we refer them to referral hospitals, which collaborate with medical social workers (MSWs). These MSWs are reliable mediators between the patients and the referral hospitals. They explain the patient's unique and delicate situation and history to medical personnel and provide comfort and reassurance to the patients themselves.

## Medical Conditions Exhibited by Outpatients with Leprous Histories

Our clinic has served 54 "community inhabitants," with 2 deaths to date. The average age of the 52 living patients is 78.4 (62–99) at present (April 2019). Most cases have medical histories that are significant for lepromatous leprosy (LL), followed by borderline leprosy (borderline lepromatous, mid-borderline, and borderline tuberculoid). Two patients have history of tuberculoid leprosy. The disability rates for upper- and lower- limbs and the lateral part of the eyes are very high, as shown in Tables 1 and 2. Their most common complaints relate to their anesthetic skin (sensory nerve dysfunction) and physical deformities, which frequently cause keratosis ulcer, burn, phlegmon, etc. Another concern involves the likelihood of relapsed leprosy. Refractory neuralgia is also common complaint. As these patients age, like other seniors, spinal or joint pains often occur. Sometimes, patients worry that these age-related pains are suggestive of leprosy relapse.

Cases of exposure keratitis and uveitis are not rare because of their high disability rates for the lateral part of eyes and the severity of past leprosy in these patients. Regular ophthalmological examinations are therefore conducted in cooperation with 2 ophthalmologists. To

protect the anterior part of eyeball, our surgeons play an active part in reconstructive surgical efforts.

Other diseases that are common in elderly people and our patients are summarized in Table 3. Four of these patients developed cancers and 3 were referred to specialty hospitals, in coordination with the MSWs. Three cases presented with some active signs of leprosy, as shown below.

a) Weakness of muscle power along with increasing *Mycobacterium leprae* specific Phenolic Glycolipid-I antibody (PGL-I) [2]. This patient's skin smear was negative. Quiet onset and progress of neuroparalysis is sometimes observed in patients previously cured of leprosy. The pathogenesis is unknown.

b) One patient presented with a high titer of PGL-I and no other active signs. This patient has been under close observation.

c) One patient experienced relapsed LL [3]. The bacilli obtained presented with resistance-related mutations to 3 drugs; diaphenylsulfone, rifampicin, new quinolone. This patient was cured in 4 years. We must always consider the possibility of relapse in our patients.

M/F	33/19
Age	62–99: average 78.4
Leprosy status	LL: 32, B-group:18, T: 2
Disability status of limbs	G2:43 (82.7%), G1:7(13.5%)

Table 1: Breakdown of the 52 active patients.

LL: lepromatous leprosy, B-group: borderline leprosy, T: tuberculoid leprosy

G2: visible impairment/deformity because of muscular atrophy

G1: impaired sensation but no visible impairment

(WHO disability grading)

<b>Lagophthalmos</b>	16	29 (55.8%)
<b>Madarosis</b>	13	

Table 2: Disability of the lateral part of the eyes.

Orthopedic diseases	Osteoporosis, Osteoarthritis, spinal canal stenosis
Metabolic syndrome	HPT, DM, Fat liver, Hyperglycemia
Others	Asthma, RA, Dementia, Mental depression
Cancer	Lung, Prostate, Colon, Breast, BCC

Table 3: Diseases not directly related to leprosy.

HPT: hypertension, DM: diabetes mellitus, RA: rheumatoid arthritis, BCC : basal cell carcinoma

## Leprosy Phobia

There were some cases of leprosy phobia.

1. This was a male in his 60s. His father had leprosy and died in a sanatorium. He believed he contracted leprosy and, although he had no signs of leprosy, he repeatedly demanded a leprosy examination.
2. One female in her 60s previously worked in a sanatorium and worried that her limb pain might be caused by leprosy. For this patient we recommended an orthopedic examination.
3. Another elderly male and female worried that their symptoms might be caused by a strange (fearful) disease like leprosy.
4. One patient presented with hereditary neuropathy, a rare disease and appeared confident that she had leprosy. It took considerable time to explain to her that her disease was not leprosy.

These experiences have led us to understand that the long-lasting segregation policy has produced reinforcement of old social stigmas related to leprosy.

## Conclusion

This is a report from a local clinic that is open to anybody, regardless of medical history. This clinic has been modeled as a gateway for individuals having a history of leprosy to access medical resources through close collaboration with MSWs.

Most “community inhabitants” are entering their final years of life and many are alone, having broken off their family relationships. We should improve living conditions for them and remove their fear of not being welcomed by society. The overall goal of leprosy management is

complete normalization of these patients' lives alongside full community integration.

The authors would like to thank all the medical personnel and organizations to which we have referred our patients. Their cooperation has accelerated our growth and clinical offerings. But most of all, we would like to thank the other outpatients and local citizens who have welcomed this clinic and the patients it serves. Without their understanding, we could not persist in our goal to improve the lives of these patients.

### Postscript

We occasionally have friendly get-togethers at our clinic. These gatherings feature local people and ex-patients with leprosy and involve fellowship, eating and drinking, and participation in cultural activities such as music or the arts. University students and teachers come to these get-togethers to learn about leprosy and subsequently become acquainted with ex-patients and hear their life stories. They are influenced by former patients' determination to live in society during that hard time under the segregation policy.

In our community, the process of real integration is ongoing. At the same time, these "community inhabitants" are getting older and currently need or soon will need

various services to maintain their daily life activities. Some patients are categorized into the nursing-care insurance system, allowing for integration with the patient the community as a whole. We will persist in our efforts to abolish old stigmas related to this vulnerable population. We are also concerned about other "community residents". About 1500 of "community residents" are suspected as existing in Japan. All of them should be able to access appropriate medical care, and they should live in their community without fear of their history.

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