



Special Article



Modern History of Hansen's Disease in Korea

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ABSTRACT

Modern history of Hansen's Disease (HD) in Korea begins with nationwide use of the chemotherapeutic agent Diamino Diphenyl Sulphone for the patients in 1955. Definition of the case was different from time to time. Based on World Health Organization (WHO) criteria, Ministry of Health and Welfare (MOHW) reported 4,393 registered patients and same number 4,393 as new cases in 1977. This is the turning point they accepted patient reporting system of WHO, but total number of registered and managed as leprosy patients was 28,029 in 1977, which means the people who needs HD service from government at that time. The number of new cases decreased from 4,393 in 1977, 39 in 1996 to 4 in 2017. Regarding to new cases, it takes 40 years to accomplish from thousands level to below 10. Now we have 166 active cases (registered patients) and reported them as patients to the WHO. Korea Civil Assistance Command invited Dr. RG Cochrane who visited Korea for six weeks to make blue print for eradication of HD in Korea. With his advice and MOHW set HD project and plan for manpower to solve HD problems in 1955. Dr. Joon Lew and his colleagues founded Korean Leprosy Prevention Association in 1947 to combat leprosy, enlighten the public, and solve social problems caused by HD. The Korean Leprosy Prevention Association led by him changed its name to the Korean Leprosy Association in 1956, and grew into the current Korean Hansen Welfare Association. This organization is now playing a leading role in the eradication and management of HD in Korea.

Keywords: Hansen's disease; Leprosy; Diamino Diphenyl Sulphone; Multi-drug therapy; Joon Lew

DOMESTIC OUTBREAKS AND EPIDEMICS

The World Health Organization (WHO) collects information on the epidemiology of Hansen's Disease, such as details of outbreaks, newly detected patients, pediatric patients, and the extent of treatment worldwide, and includes information on the Weekly Epidemiological Record (WER, <http://www.who.int/wer>). The statistics for the past 54 years in Korea, which belongs to the Western Pacific Regional Office as per the WHO, shown in the **Table 1**. Statistics for 2006 - 2014 are part of WER, Data from 2017, 1996, and 1977 were extracted from the Status of Hansen Disease Report by the Korea Hansen Welfare Association and the Health and Social Indicators on the Leprosy project [1]. The source of the year 1953

Table 1. Leprosy (Hansen's disease) outbreaks in Korea (1953 - 2017)

	2017	2014	2011	2006	1996	1977 ^a	1953 ^b
Number of registered patients	166	199	283	420	1,072 (0.24/10,000) ^c	4,393 (1.21/10,000)	17,188
Newly detected patients	4	6	6	15	39 (0.1/100,000) ^d	4,393 (1.21/10,000)	
Multibacillary leprosy patients among new patients	3	5	6	15			
Women among new patients	2	2	2	9			
Children among new patients	0	0	0	1			
Deformity of grade 2 or higher among new patients	1	2	2	4			
Relapsed patients	0	1	7	5			
Paucibacillary leprosy cure rate	100		100		100		
Multibacillary leprosy cure rate	100		100		100		

Units: persons, %.

Number of registered patients: Registered prevalence, the number of leprosy patients currently undergoing multidrug therapy for leprosy.

Newly detected patients: New patients discovered that year.

Multibacillary leprosy: If leprosy is found via microscopic examination, the infection rate is higher than that of paucibacillary leprosy.

Women among new patients: Leprosy is relatively difficult to find in women compared to men.

Children among new patients: new patients under 14 years of age.

Deformity of grade 2 or higher among new patients: Patients with grade 2 disabilities are hard to identify, and the chances of transmission are higher.

^aStarting 1977, leprosy patients under the World Health Organization (WHO) criteria (positive patients and those who tested negative for bacteria among new patients under WHO criteria for the last three years) have been reported.

^bStatistics prepared by the Ministry of Health and Social Affairs in December 1953.

^cPrevalence rate, prevalence per 10,000 persons.

^dRate of newly detected patients, detection rate per 100,000 persons.

statistics is the Ministry of Health and Social Affairs. By randomly classifying the era, we examined the occurrence and prevalence of leprosy after the Liberation (1945) in terms of the occurrence of newly detected patients and registered patients.

1. After liberation to 1976 (Registered cases contains symptomatic patients and patients with medical history)

Although somewhat different by era, from before Liberation to 1976, leprosy cases included both symptomatic patients and cured patients with medical history. The number of patients with leprosy announced by the Ministry of Health and Social Affairs in 1953 was 17,188, meaning that the number of patients registered and managed by the central office were 17,188. Patients with leprosy did not recover from the deformity of the eyes, hands, and feet caused by nerve damage; however, since cured patients who had completed treatment for active symptoms also considered as patients at that time, the actual number of new patients is unclear.

2. 1977 - 2017 (Registered patients, symptomatic patients, registered prevalence)

According to the WHO statistics, the number of registered patients in Korea has declined rapidly for 40 years (1977 - 2017). Epidemiological studies on symptomatic patients and new patients was done according to WHO standards starting in 1977. Since 1977 was the first year that the information collected according to the WHO standards, there were 4,393 symptomatic patients, that was consistent with new patients. At this time, the total number of registered and managed as leprosy patients (in general terms) was 28,092. Based on the WHO criteria, the number of registered (= symptomatic) leprosy patients significantly decreased from 4,393 in 1997, to 166 in 2017.

The number of new cases decreased from 39 in 1996 to 4 in 2017. Looking at the 20-year changes from 1977 to 1996, the prevalence rate (number of patients/10,000 people), which was used as an indicator in the past, decreased from 1.21/10,000 to 0.24/10,000. If the number of multibacillary (MB) cases increases among new patients, the likelihood of

transmission also increases. Additionally, the presence of children under the age of 15 among the new cases implies a deficiency in the measures to control leprosy.

3. Target of the Hansen's disease project

According to the data published by the Korea Hansen Welfare Association (2017), the targets of the leprosy project in Korea included all people with a history of leprosy. Since December 13, 1999, the National Assembly of Korea decided to use the word Hansen's Disease and patients with Hansen's disease, rather than leprosy and lepers, since using the term leprosy can be considered as discrimination against human rights. Targets of the Hansen's Disease project were designated as patients with medical history (10,402) who have lost the ability to work due to nerve damage and functional disorders in eyes, hands, and feet; they were divided into patients needing 'regular treatment' to treat leprosy and related sequelae (5,997), and 'Hansen's disease service recipients' that needed rehabilitation services and recurrence management (4,405). The 166 patients with active disease were registered cases and reported to the WHO.

4. Estimation of the number of patients

One of the urgent problems that needed to be addressed by the United States of America (US) military government in Korea and the health and sanitation officers of United Nations Civil Assistance Command Korea (UNCACK) was the presence of patients in the streets, looking for food in the midst of the turbulent period of the Korean War. In 1960, the president of the Korean Academy of Medical Sciences stated that there were 45,000 leprosy patients nationwide [2], of which 21,200 placed in 32 national, public, and private sanatoriums.

After the Korean War, the Korea Civil Assistance Command (KCAC) supported the health, welfare, and hygiene projects of the Korean government, decided to invite a foreign expert for solving resolution against the leprosy problem in Korea. In 1955, Dr. Robert Greenhill Cochrane, an advisor to the American Leprosy Mission and a world-renowned authority, visited Korea to analyze and solve leprosy problems in Korea. He reviewed the status of the leprosy patients, sanatoriums, and hospitals across the country for six weeks. In *Leprosy in Korea* [3], he outlined a plan to eradicate leprosy in Korea, and estimated that the number of leprosy patients surveyed by the Ministry of Health and Social Affairs, which was 17,188, needed to be multiplied by tenfold, and the number of patients was 170,000. This estimation was based on the fact that more than 60% of the patients are MB, and that India had estimated the number of leprosy patients to be more than 10 times the actual number [3]. At that time, Korean doctors who were engaged in the project proposed the opinion that the number was overestimated. The prevalence of the first sample survey conducted in the Yeongnam region and Wolseong-gun, Gyeongsangbuk-do, was 2.6/1,000 people on average, suggesting that the number of leprosy patients nationwide was 70,000 - 80,000 [4].

DISEASE PATTERNS IN KOREA

1. Hansen's disease, a medical disease

Hansen's disease is a chronic disease caused by infection with *Mycobacterium leprae*, but depending on the state of immunity against *M. leprae*, there can be tuberculoid leprosy with less than five skin lesions, and lepromatous leprosy with more than six skin lesions and numerous nodules. In addition, various mixed manifestations are observed, such as borderline leprosy. During training junior doctors and students are taught to observe the

following precept: "If the patient does not have neurological symptoms, do not diagnose the patient as having leprosy". These patients need to be evaluated for autonomic, sensory, and motor nerve damage. Many patients were reported to have suffered, because they were unable to recover from nerve damage and deformities such as clawed hands, hand/foot drop, and lagophthalmos for the rest of their lives. Chemotherapy using sulphone treatment for leprosy in Korea started from the 1950s. Previously, patients suffered from leprosy and neuritis, a common sequela of leprosy.

2. Hansen's disease, a cultural-psychological-social illness

Patients who suffered from leprosy (Hansen's disease) in the past often described their illness experience as "three years because I did not know, three years because I knew, and three years because I was rotting". Here, "three years because I did not know" is consistent with the findings of modern medicine that the incubation period is about 3 - 5 years; "three years because I knew" refers to a period when the patient was diagnosed with leprosy due to symptoms, but suffered because there was no proper treatment, and because they were ostracized by people around them. Even after patients were diagnosed as Hansen's Disease, there was no known treatment. Until the early 1950s, patients were treated with chaulmoogra oil, but the side effects due to the injection and ingestion of the oil include occurrence of ulcers, abscesses on the buttocks at the site of injection, and vomiting and nausea after ingestion. Moreover, people who insisted they were cured by chaulmoogra oil, relapsed soon after. The US Public Health Services in charge of the leprosy problem in the country officially declared in 1947 that chaulmoogra oil would no longer be used as a treatment for leprosy. The phrase "three years because I was rotting" referred to the period when the nerve damage of the eyes, hands, and feet became severe, and the deformities led to inability to work.

Ha-Un Han (1920 - 1975), a leprosy patient and a famous poet, tells the sad story of forced to hide in a small room, in his autobiography, "My Sad Half-Life" [5], the book describes the situations faced by leprosy patients. If the neighborhood or community found out about a leprosy case nearby, the patient's household was ostracized, and the family of the patient went for an Exorcist performances to expel evil wind from him, relocation of an ancestor's grave, or panaceas, and exhausted all their money. Eventually, when the disease progressed, the leprosy patient often became a heavy burden for the well-being and happiness of the family, and they left their home. Leprosy is a stigma which causes the patient to be ostracized by family and society, and is the patient is considered an outcast. Leprosy can be seen both as a medical disease, the other hand as a cultural-psychological-social illness. The general public accepted the scientific fact that 99% of the infectious power of the organism was lost with a single dose of 600 mg of rifampicin.

The patient sometimes changed their name in the clinic, or registered two social security numbers or without family names. In the past, the director of the National Sorokdo Hospital, Dr. Changwon Cho, has created a new family name called Cho (a new family name, origin place is Sorokdo) following his family name 'Cho' to register inpatients without family name on resident registration of Government. national legal registry.

3. Leprosy cure

WHO estimates that it takes 12 months for MB leprosy, and six months for paucibacillary leprosy to be cured, and suggests a basic guideline for deregistering patients who are registered. The policy is that 1 in 1,000 people with recurrences can be treated again, and even if the bacterial index is positive, if the morphology index is 0, the patient is deemed not

contagious, and is deemed as cured. When the patient being treated is told that the treatment will end in 12 months, they usually say “I still have a disease, why do you say I am cured?” In particular, if a patient has a deformity of grade 2 or more, they question, “I still have a disease in my hands and my feet, how can you say I am cured?” In other words, there is a gap between the WHO, which judges that the patient is healed when the active lesion is resolved, and the patient, who wishes to go back to the state before they were physically ill. Therefore, efforts must be made so that medical (physical), psychological, spiritual, social, and economic healing can be achieved. Korea's policy on Hansen's disease aims to care active patients, to prevent further complications, and also to provide ‘Hansen's disease services’, and minimum living security, which enable the patient to achieve such healing as soon as possible.

PREVENTION AND MANAGEMENT

1. The role of the US Military Government in Korea and KCAC

The US military government decided that the leprosy problem in Korea was serious, and invited medical missionaries Robert Manton Wilson (1880 - 1963) and Archibald Grey Fletcher (1882 - 1970), who were presidents of Yeosu Aeyangwon and Aerakwon at Daegu; Wilson came to Korea in February 1946, As a leprosy advisor to the Military Sanitation Bureau, Wilson stayed in the Sorokdo sanatorium, and reviewed the option of merging Yeosu Aeyangwon and Sorokdo. Lieutenant General Lerch, the then military secretary, had the opportunity to look into the leprosy problem in Hawaii before coming to Korea. Wilson sought a way to solve the leprosy problem in Korea with Victor Heiser, who was in charge of leprosy problems at the Public Health Service, and had founded the Culsion sanatorium in Philippines. The military government had plans to expand the Sorokdo sanatorium to a capacity of 8,000 - 9,000 people. They want to introduce latest chemotherapy and democratic system to Sorokdo patient community. Director Hyongtae Kim accepted the systems to patients at Sorokdo resulted in reduction of number of managers from 350 people during Japanese Colonial Period to 100 people with this new system. At the time, the establishment of a democratic and autonomous system in Sorokdo, the world's largest sanatorium with 5,716 people, was of great significance.

Minok Kim, who was elected as the Mayor of self-governing society of patient, sent a letter to then Lieutenant General Lerch, and expressed sincere appreciation on behalf of the patients for sending relief supplies, chaulmoogra oil, and other medicines to Sorokdo Hospital. Military General Lerch was surprised, and praised the democratic procedure of the Sorokdo sanitarium and the election of the Mayor, and saw it as the starting point of democratization in Korea; this news was published in the Farmers Daily in 1947 [6].

The US military government began to help treat leprosy in Korea by supplying large quantities of Promin (the first chemotherapeutic agent) and Dison (a diamino diphenyl sulphone [DDS] derivative). After this act by the military administration, the KCAC supplied these products made from Japan. According to the annual report of the National Nursing Home Rehabilitation Center (Sorokdo), the use of these drugs has resulted in phenomenal treatment benefits that were not found in chaulmoogra oil treatment. In other words, remarkable effects were such as reduction and eradication of bacteria, absorption of bare nodules, reduction or loss of perceptual paralysis, removal of spots, and regeneration of hair.

As part of the strategy to solve the leprosy problem in Korea, the KCAC invited Robert Greenhill Cochrane to the country. He traveled all over Korea for six weeks, established fundamental measures to resolve leprosy through actual medical treatment and visits to sanatoriums, and made recommendations to the Ministry of Health and Social Affairs and the KCAC. As part of these measures, he proposed that the public health doctors who will be in charge of dealing with leprosy should be given domestic and overseas training; additionally countermeasures for the prevention of leprosy infections in children, and administration of BCG vaccinations were also proposed. Dr. Cochrane treated patients, shook hands with them, and picked his nose with his bare hand; this was a shock to Korean patients, because Korean doctors at the time covered their whole body and wore gloves when treating patients.

2. Beginning of the Korean Leprosy Prevention Association (Korean Hansen Welfare Association), the establishment of the Leprosy Society, and the achievements of Joon Lew

Dr. Joon Lew and his colleagues Mr. Daehyun Kang, Soowon Bang, and others founded Korean Leprosy Prevention Association founded in 1947 to combat leprosy, enlighten the public, and solve social problems caused by leprosy. It was enrolled by Ministry of Health and Welfare as a government recognized corporation in 1948. Dr. Lew (1916 - 2015) graduated from Kyungshung Medical College in 1941, spent 10 months at Sorokdo Rehabilitation Center, majored in microbiology at Graduate School of Kyushu Medical school, and obtained a doctorate degree in 1945. During the Korean War, he studied at University of California, Los Angeles, and received a doctorate for his thesis on *M. leprae*. As a pacemaker of Korea's relief of leprosy project, a leading figure in leprosy research, a professor of microbiology, and a businessman who presented the model of a settlement village, he made great contributions to Korea. The Korean Leprosy Prevention Association led by him changed its name to the Korean Leprosy Association in 1956, and grew into the current Korean Hansen Welfare Association. This organization is now playing a leading role in the eradication and management of Hansen's disease in Korea, under the command of the Korea Disease Control and Prevention Agency.

Dr. Lew, as a professor of Yonsei University College of Medicine, conducted an epidemiological study on leprosy patients living in groups across the country with his students. He found that there were about 40,000 patients, and that 73% of them were able to work like normal individuals. In other words, he provided a way for the patients to earn a living by working on their own, and persuaded them to be engaged in jobs such as poultry and livestock farming, and agriculture, and encouraged them to support themselves. Representatives of each settlement village formed a congregational assembly (now Korean Federation of Hansen Associations) in 1948 to regain their rights and interests, and to strive for economic and social rehabilitation.

The Korean Leprosy Society founded during the 1958 General Assembly of the Korean Academy of Medical Sciences with 10 people including the head of the Ministry of Health and Social Affairs, people in charge of leprosy in the chronic diseases department, and the medical doctors of the mobile clinics. That year, an inaugural general meeting and lectures on leprosy were held at the Sorokdo rehabilitation center from August 11th to 13th. The list of the members in the first issue of Leprosy Bulletin in Korea showed 44 full members. They are Joon Lew, Ikjin Jang, Min Jeong, Daegyeong Choi, Seungcheol Gal, Kangsoo Lee, and Jeonggu Yoon of the Department of Microbiology at Yonsei University College of Medicine, Sangtae Kim (previous Sorokdo hospital director, Busan University Medical School), Siryong

Choi, Gyehan Kim, Buho An (Catholic Medical College), Doil Kim, Yongma Ha, Yoongeun Cha, Jaeju Seo, Yuseon Yoon (Chief, Ministry of Health & Social Welfare), Seokwoo Yoon, PS Crane (Jeonju Jesus Hospital), Soonbong Seo (Department of Dermatology, Kyungbook Medical University), Seonghwan Kim (Department of Dermatology, Seoul National Medical University), Jinbok Kim, Miyoung Song, Sook Bang (USOM-K Health Bureau), Heeyoung Jung (Central Prevention Research Institute), and 24 associate members such as Father Swneey, Head of the Catholic Leprosy Service and Rev. Lloyd CM (Daegu Leprosy Service). About 40 people attended the inaugural general meeting, and the founding society elected Lew Joon as the president, Sangtae Kim as the vice president, Seokwoo Yoon as the secretary general, and Buho Ahn as the academic chair. These individuals contributed greatly to resolve the leprosy problem.

3. Opening of a leprosy clinic in Seoul City Medical School

Special Skin Clinic for leprosy patients founded in 1955 by Dr. Lew. The opening of the Leprosy Clinic near the Severance Medical School, thanks to his efforts and persuasion of the neighboring professors and hospitals, was the result of overcoming indescribable difficulties. In 1959, a four-story building built near the Severance Hospital in front of Seoul Station, and a leprosy-specialized clinic founded in Korea's medical school hospital for the first time, with a sign informing that it was a special skin clinic. In 1956, the Catholic Leprosy Service (CLS), located on the premises of Seongshin Medical College (now College of Medicine, The Catholic University of Korea) St. Mary's Hospital, was in charge of mobile medical treatment and the treatment of St. Lazarus Village. In 1961, it renamed as the Institute for Chronic Diseases, and today, it is engaged in research and treatment under the name "Institute of Hansen's Disease".

4. Support from foreign organizations

CLS received supplies and financial support from the Catholic Relief Society (Monsignor Carrol) supported by religious groups, especially the US Conference of Catholic Bishops; in particular, food support received, such as corn, was enough to cover the entire area of Korea to a height of 5 cm. The mobile clinic Korea got support from the American-Korean Foundation, OEC, and Centre International Development de Rural from France. With the growth and economic revival of the Korean government, mobile clinics were transferred to the Korean Leprosy Control Association.

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