Globethics Repository



Punishing paternalism

This page was generated automatically upon download from the Globethics Repository. More information on Globethics see https://www.globethics.net. Data and content policy of Globethics Repository see https://repository.globethics.net/pages/policy.

Item Type	Article
Authors	Miyasaka, Michio
Publisher	EUBIOS ETHICS INSTITUTE
Rights	With permission of the license/copyright holder
Download date	2026-11-19 01:15:30
Link to Item	http://hdl.handle.net/20.500.12424/176467

DeGrazia, David. (2008) Single Payer Meets Managed Competition: The Case for Public Funding and Private Delivery, *Hastings Center Report* 38: 23-33.
Dunn, John. (1994) *Democracy: the unfinished journey 508 B.C.-1993 AD*, Oxford University Press.
Emanuel, Ezekiel J and Victor R. Fuchs, (2005) *Health Care Vouchers-A proposal for Universal Coverage*, New England Journal Medicine 352: 1255-1260.
Gottleib, S. (2000) Medical Bills Account for Forty Percent of Bankruptcies, *British Medical Journal* 320: 1295.
Hollenbach, D. (1979) *Claims in Conflict: Retrieving and Renewing the Catholic Human Rights Tradition*. New York: Paulist Press.
Iltis, Ana Smith and Mark J. Cherry (2008) First Do No Harm: Critical Analyses of Roads to Health Care Reform, *Journal of Medicine and Philosophy*, 33; 403-415.
Jacobs, Lawrence (1994) All Over Again? Public Opinion and Health Care, *New England Journal Medicine* 358: 1881-1883.
Kunz, J.L. The United Nations Declaration of Human Rights, *American Journal International Law*. 43: 316-322.
Lebacqz, K. (1987).*Justice in an Unjust World*. Minneapolis, Augsburg, Press.
…….(1986) *Six Theories of Justice: Perspectives from Philosophical and Theological Ethics*. Minneapolis: Augsburg Press.
Lovin, R.W. (1995) *Reinhold Niebuhr and Christian Realism*. Cambridge: Cambridge University Press.
Maritain, J. (1941) *The Rights of Man and Natural Law*. Trans. D.C. Anson. New York: Charles Scribner's Sons.
Menzel, Paul and Donald W. Light (2006). A Conservative Case for Universal Access to Health Care, *Hastings Center Report* 36: 36-45.
Morgan James J and Thomas H. Lee, (2005). Do we Really Want Broad Access to Health Care? New England Journal Medicine 352: 120-1263.
National SCHIP Policy Overview, U.S. Department of Health and Human Services 13 Dec 2007 http://www.cms.hhs.gov/nationalschippolicy.
Sade, Robert M., (2008) Foundational Ethics of the Health Care System: The Moral and Practical Superiority of Free Market Reforms, *Journal of Medicine and Philosophy* 33: 461-497.
Taylor, James Stacey, (2008) Market Incentives and Health Care Reform, *Journal of Medicine and Philosophy* 33; 498-514.
United Nations Declaration of Human Rights, http://www.un.org/en/documents/udhr/, accessed 17 May 2009.

Punishing Paternalism: An Ethical Analysis of Japan's Leprosy Control Policy

Michio Miyasaka, Ph.D.
School of Health Sciences, Niigata University
Asahimachi-dori 2-746, Niigata City 951-8518, Japan
Email: miyasaka@clg.niigata-u.ac.jp

Abstract

Leprosy (Hansen's disease) has been associated with a deep stigma that dates back to ancient history. Japan's leprosy control policy exemplifies the ethical questions this disease evokes in the context of human rights in modern medicine. This paper explores the history of Japanese leprosy control policy which started during its rapid modernization in the late 19th century and continued until 1996. I argue that the responsibility of the medical profession for development of the overall control policy which resulted a mass human rights violation. Japanese leprosy control policy can be interpreted as four powers given to the medical profession: 1) forced isolation, 2) sterilization, 3) forced labor, and 4) arbitrary punishment. Japanese leprologists considered forced isolation necessary, even after sulfone drugs became widely available and the international medical community suggested that forced isolation should be abolished. Male patients who wished to marry had to undergo vasectomy, and pregnant female patients were forced to have abortions. Patients with milder symptoms were assigned heavy labor, which may have exacerbated their condition. Leprosarium directors were empowered to arrest and punish disobedient patients without court order. Records show that 22 of 92 persons imprisoned in Jukambo, a special leprosarium facility for the most severe punishments, died in confinement. In the landmark Kumamoto judgment in 2001, the court ruled that forced isolation was not justifiable after it became medically unnecessary, since at least the 1960s. However, the other three troubling aspects of the control program were left unquestioned, even though those would be much more difficult to justify. Furthermore, the lawsuit was filed against the country, and no individual responsible for the establishment and continuation of the policy was prosecuted.

1. Introduction

Leprosy, or Hansen's disease, has been associated with a deep stigma that dates back to ancient history. In many parts of the world, patients were ostracized by their communities and families based on religious or popular beliefs that often described leprosy as a result of sins or wrongdoings. It was described as a divine punishment for immorality in the Old Testament, and hundreds of leprosy patients were considered to be killed because of rumors that some of them poisoned wells and fountains in medieval Europe.[1)] In Japan, there was a Buddhism-rooted belief that explained leprosy as an outcome of wrongdoings in the patient's previous lives. Japanese folklore tells of leprosy

patients cast away in valleys or on mountains.[2] However, the leprosy control policy in modernized Japan exemplifies a situation that has evoked serious ethical questions in the scientific period of modern medicine and public health. In the second section of this paper, I will explore the history of Japanese leprosy control policy from a *paternalism* point of view in which four powers were given to the medical profession. The third section briefly sketches how the control policy ended.

2. Leprosy Control Policy In Japan

Japan's leprosy control policy started during its rapid modernization in the late 19th century when the country opened its ports and started introducing Western socio-legal systems and medicine. Leprosy patients of the day gathered and formed colonies around shrines, temples, and hot springs. Some Westerners observed them leading miserable lives on the streets as outcasts or beggars,[3] and some missionaries established private leprosaria. In 1889, the French Catholic missionary Germain Léger Testevuide opened the first private leprosarium, Koyama Fukusei Hospital in Shizuoka Prefecture. The establishment of private leprosaria by several other foreign missionaries followed. Their activities were welcomed by patients, but stimulated a rivalry from Japanese leaders who wished to make Japan "a first-class nation" with a modernized public health system.[4]

From an ethical point of view, Japanese leprosy control policy can be interpreted as four powers given to the medical profession which resulted a mass human rights violation: 1) forced isolation, 2) sterilization, 3) forced labor, and 4) arbitrary punishment.

1) Forced isolation

The first International Leprosy Conference was held in Berlin in 1897, in which two Japanese physicians participated. The conference acknowledged leprosy as a contagion caused by *Mycobacterium leprae*, as described by a Norwegian physician, Armauer Hansen, in 1873. There were differing views among the attendees regarding the containment of leprosy by isolation,[5] but the conference eventually concluded that patient isolation was necessary as part of the disease control strategy. This conclusion inspired Japanese leaders and physicians to support patient isolation[6] In 1900, the Japanese Ministry of Home Affairs conducted a national survey and reported 30,359 leprosy patients.[4] In 1907, the Leprosy Prevention Law (LPL) was enacted, under which physicians were required to report all leprosy patients they found, and political officers were empowered to order these patients admitted to leprosaria. In 1909, five public leprosaria opened in Aomori, Tokyo, Osaka, Kagawa, and Kumamoto. Additional leprosaria were added later to total 13 national leprosaria that covered most of the country.

During the 20th century, international and Japanese health care professionals gradually diverged in their views of forced isolation of leprosy patients. The International Leprosy Association (ILA) increasingly emphasized voluntary and limited isolation. After sulfone drugs were found effective in the 1940s and their use increased in the 1950s and 1960s, the ILA and other international medical organizations recommended that enforced isolation be avoided as much as possible.[6] In Japan, on the other hand, leprologists continued to believe that patient isolation was effective and necessary. Furthermore, they repeatedly requested expansion of the capacity of leprosaria and more intensive isolation. There was only minor argument among Japanese leprologists that forced isolation may not be necessary. In 1931, leprologist Noboru Ogasawara of Kyoto University insisted that the disease was not incurable, not heritable, and not highly contagious,[7] but his claim was ignored and attacked by other leprologists. In 1935, the government adopted a program to eradicate leprosy within 20 years, and local governments launched a nationwide campaign in 1938 named Muraiken Undo (literally, "campaign to clean up leprosy in every prefecture") through which they encouraged local residents to identify leprosy patients in their neighborhood and inform officials in order to send them to leprosaria.

After WWII, Japanese society was drastically democratized under US occupation; however, the policy of forced isolation of leprosy patients survived. The new Constitution proclaimed fundamental human rights for all nationals, including freedom of political activity. In 1951, the National Leprosaria Patients' Association was established. Although this association demanded the abolition of forced isolation, leprologists were successful in maintaining it. In the same year, three leprosarium directors, Kensuke Mitsuda, Yoshinobu Hayashi, and Matsuki Miyazaki, recommended that the Diet maintain and reinforce the isolation policy. The LPL was revised in 1953 in accordance with the leprologists' opinions: it upheld compulsory isolation, prohibition of leave without permission, and punishment of disobedient patients. As the law defined no discharge codes, patients had to be isolated for life. Meanwhile, the nationwide campaign Muraiken Undo had resulted in almost complete isolation of patients. The number of those hospitalized in leprosaria reached 11,057 in 1955, which was estimated to be 91% of all leprosy patients in the country.[8] Therefore, in the 1950s, almost all leprosy patients in Japan had been isolated in leprosaria and were destined to live out their lives there, even after they were treated with sulfone drugs and proven not to have bacilli.

2) Sterilization

The notion that leprosy patients should be prevented from having children had been accepted, not only by Japanese leprologists, but also by foreign missionaries involved in the care of leprosy patients. However, they adopted very different approaches. Hanna Riddell, an English missionary who opened a private leprosarium, Kaishun Hospital in Kumamoto, insisted on *sex segregation*, the idea of hospitalizing female and male patients separately. However, Kensuke Mitsuda, a leading leprologist, argued against her approach, pointing out that sex segregation was unrealistic. He wrote, "It will be natural for desperate persons to live only for the pleasure of the moment. But the only pleasures they can obtain in leprosaria are gambling or adultery. ... Here, a moral anarchy has emerged that resulted in more than a dozen babies that should not

have been born." [9] Mitsuda concluded that sex segregation was impracticable in national leprosaria, and that *sterilization* of patients was more realistic and would contribute to patient welfare by permitting them to marry. Furthermore, he believed that sterilization would contribute to a peaceful atmosphere in leprosaria, because physicians could allow patients to marry without letting them have children.

In 1915, Mitsuda began to vasectomize male patients who wished to cohabit with female patients. In the book he published in 1950, Mitsuda wrote that the first vasectomy was performed on a voluntary patient,[10] but many patients later claimed that sterilization was conducted against their wishes and that it severely impaired their dignity. Furthermore, pregnant female patients were often forced to have abortions. Former patient Shige Tamashiro regretfully described an enforced abortion, or rather, the infanticide. She clearly remembers the infant waving its hands and legs on a surgical plate, before a nurse covered the nose and the mouth of the infant with a piece of gauze to terminate its breathing, saying to Tamashiro, "It is a cute girl, and looks very much like you."[11]

During Japanese colonization of the Korean peninsula, officials of Shorokuto Kousei-en, a Japanese-run leprosarium on Sorokdo Island near the southwestern tip of the peninsula, performed patient sterilization as a *punishment*. A former Korean patient testified in a lawsuit against the Japanese government in 2004 that he was vasectomized when he refused to worship at a Japanese Shinto shrine in the leprosarium. He was placed in the confinement room, and forced to undergo sterilization without being given any explanation. Vasectomies and abortions had been conducted on leprosy patients without legal basis, but both were legalized by the Eugenic Law (*Yusei Hogo Hou*) enacted in 1948.

3) Forced labor

Former patients have claimed that living conditions in national leprosaria were far from appropriate. They were assigned many types of labour, because doctors in leprosaria "encouraged patients towards mutual aid."[12] Patients with milder conditions were assigned to nurse invalid patients, bury dead patients, wash bandages and gauze for reuse, collect night soil, and repair buildings and roads. For example, During WWII, patients of Kuryu Rakusen-en, a national leprosarium in Gumma located on a hillside at an altitude of 1200 meters, were ordered to walk down to markets about 10 kilometers (6.3 miles) away to buy charcoal and firewood in order to save gasoline. They had to walk on mountain trails back to the leprosarium carrying heavy loads of charcoal and firewood.[13] It is presumed that heavy labour exacerbated their condition, because the disease renders victims insensitive to wounds and pain. Former patient Yuji Kodama of Kuryu Rakusen-en related that when he and other patients were gathering firewood in a steep valley, he noticed that bunches of firewood passed from one patient to another were stained with blood.

4) Arbitrary punishment

Leprologist Mitsuda wrote that some patients in leprosaria committed assault and battery, theft, adultery, and incited riots, but "there was no way to control disorderliness."[14] He also pointed out that if a leprosy patient who was not institutionalized committed a crime and was arrested, he or she would be sent to a leprosarium instead of a prison because prisons would not accept leprosy patients. In 1916, the government accepted their request for police power by revising the LPL so that leprosarium directors were empowered to arrest and punish disobedient patients. Accordingly, confinement facilities were built in all national leprosaria. The director could imprison patients for up to one month and reduce their meals to twice a day without a court order. However, leprologists of the day regarded confinement as nothing but a mild "house arrest" which "seldom had any effect on the brutal ones who could repeat their crimes."[15] Directors of national leprosaria decided to build a special facility in which they could give more severe punishments. The special facility was constructed in Kuryu Rakusen-en in 1938 and officially named Tokubetsu Byoshitsu ("special sickroom"), but was called Jukambo ("maximum confinement facility") by patients. In fact, it was a place of deadly confinement composed of eight cells. A post-WWII investigation of Jukambo unveiled one of the darkest aspects of Japanese leprosy control policy. Records showed that 22 of 92 persons imprisoned died during their imprisonment or within a few months after their release. The dates of their deaths in Jukambo were concentrated between November and March, when the air temperature of the region dropped to -16°C (-3.2°F) or below. Jukambo cells had no heating apparatus, and the building was on a low foundation, probably to prevent patients from escaping through the floor. Furthermore, patients were usually imprisoned much longer than the ordained period. The average length of confinement was more than 130 days. The longest imprisonment was over 500 days.

In 1947, media coverage made Jukambo a scandal and officials of the Ministry of Health and Welfare (MHW) commented at the Diet that they would abolish it. However, the power given to leprosarium directors to arrest and punish patients remained in effect, and a "leper's prison" was established in Kikuchi Keifu-en, a national leprosarium in Kumamoto, in 1953.

3. End of The Policy

The Japanese leprosy control policy remained unchanged for a long time. It survived the 1950s when post-WWII reform democratized Japanese socio-legal systems, the 1960s when sulfone drugs became widely available and studies showed that leprosy was rarely contagious,[16] and the 1970s and 1980s when Japanese scholars introduced bioethics and its concepts (i.e., patients' rights and informed consent). Its crucial last moments came as late as the 1990s, when all residents in leprosaria had become "former patients" who were bacteriologically negative and had spent most of their lives there.

1) Patients' rights movement

It should be noted that patients' activities to abolish the control policy started early. Since the 1920s, patients' associations were organized in each leprosarium to improve living conditions. Their activities were suppressed during wartime, and they were terrorized by arbitrary punishment, especially confinement in Jukambo. However, the suppressed energy burst out once the Constitution of Japan guaranteed fundamental human rights, including freedom of assembly and speech, and the Jukambo was abolished. As mentioned above, the National Leprosaria Patients' Association was established in 1951, and demanded abolition of the above-mentioned questionable powers. Some patients went on hunger strikes at their leprosaria, and a few hundred went on a sit-down strike in front of the MHW and Diet Building. However, their movement came up against public ignorance. There had seldom been media coverage about the patients' movement, and Japanese media generally approved of the isolation policies until around the 1980s.

2) Abolishment of LPL

Admittedly, at least in the 1980s, patients' unions and medical professionals began to cooperate to change the situation. Fujio Otani, a medical official of MHW, is regarded as a key player in the partnership between medical professionals and former patients who were now old and afraid of being discharged from leprosaria by force. Furthermore, due to sterilization, they had no children who could support them when they went back into society. The powers given to medical professionals over patients were now applied mildly. Former patients were almost free to leave their leprosaria and were released from heavy labor (which had gradually been assigned to the leprosarium staff). [17] Otani expressed his opinion that the LPL should be repealed and replaced by a new law to guarantee their livelihood and welfare at the 1994 meeting of the Japanese Leprosy Association and at the 1995 Government-organized LPL Review Committee. In accordance with the Committee's report, the Diet passed the Act to Abolish the Leprosy Prevention Law in 1996.

3) Lawsuit against the country

On May 11, 2001, the Kumamoto District Court declared that the isolation policy had violated the fundamental human rights guaranteed in the Constitution of Japan. The court associated the isolation policy with an "absolute isolation" and "extinction" of leprosy patients. It held the MHW responsible for failing to seek an early reversal of the LPL, and the Diet responsible for inaction in repealing it, ordering compensation and an apology from the government.[18] The point at issue in the Kumamoto judgment was the forced isolation of leprosy patients, which the court ruled to be unjustifiable after it became medically unnecessary, since at least the 1960s. However, the other three questionable aspects of the leprosy control policy that I have considered here were left unexamined, even though those would be even more difficult to justify. Furthermore, the lawsuit was filed against the country, and no individual responsible for the establishment and continuation of the policy was prosecuted.

Conclusion

The history of Japanese leprosy control policy described here suggests that the responsibility of medical professionals for development of the overall control policy was significant. Most aspects of the control policy were proposed by leading leprologists, and the policy can be considered as their strong paternalism being realized as extreme powers to accomplish 1) forced isolation, 2) sterilization, 3) forced labor, and 4) arbitrary punishment. On the other hand, the history also shows that there was a patients' rights movement in its own right - a half century before academic bioethics introduced Western concept of patients' rights to the country. However, the movement found the society less supportive in pre-bioethics Japan in which overwhelming power was given to the physician. The patient's only choices were to obey or to offer a hopeless resistance at the risk of punishment.

Acknowledgment

This manuscript was supported by a grant-in-aid for Scientific Research (project number: 15652001) from the Japan Society for the Promotion of Science.

References

1) Boiteau, P. et al. Rôle éventuel de la malnutrition dans l'épidémiologie de la lépre. Exemple de la France du moyen âge et de la Renaissance. *Bulletin de Philologie et d'Histoire, année* 1968, 1971;1:9-18.
2) Yamamoto, Y. and Kato, S. *Goza no yugichi-hi*. Gumma. Goza no yukuchi-hi kanko kyoryoku iinkai, 1972. (in Japanese)
3) Ashmead, A.S. *Suppression and Prevention of Leprosy*, Norristown, PA: Herald Printing and Binding Rooms, 1897, 80-85.
4) Fujino, Y. *Inochi no kindaishi,* Kyoto. Kamogawa Shuppan, 2001. (in Japanese)
5) Pandya, S.S. The First International Leprosy Conference, Berlin, 1897: The Politics of Segregation. História, Ciências, Saúde – Manguinhos. 2003;10 (supplement 1):161-177.
6) Balina, L.M. and Valdez, R.P. Reflections on the International Leprosy Congress and Other Events in Research, Epidemiology, and Elimination of Leprosy. *International Journal of Leprosy* 1994;62:412-27.
7) Ogasawara, N. (1931) Rai ni kansuru mittsu no meishin*. Shindan to chiryo* 1931;18. (in Japanese)
8) Tofu Kyokai. Mitsuda Kensuke and leprosy prevention in Japan. Tokyo. Tofu Kyokai, 1958. (in Japanese)
9) Mitsuda, K. *Kaishun byoshitsu.* Tokyo, *Asahi Shimbun*, 1950, 204-205. (in Japanese)
10) Ibid., 54.
11) Chugoku Shimbun. *Yatto taiyo gatetta.* Anonymous article on May 12, 2001. (in Japanese)
12) Mitsuda, op. cit., 210-211.
13) Kuryu Rakusen-en Kanja Jichikai (ed). *Fusetsu no mon (Fifty-year History of Patients of Kuryu Rakusen-en)*. Gumma. Kuryu Rakusen-en Kanja Jichikai, 1982, 205-214.