

REVIEW:

An ethical review of the production of human skeleton models from autopsied patients with Hansen's disease in pre-war Japan

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Abstract

On May 9, 2013, a local newspaper in Kumamoto prefecture in Kyushu, Japan reported that pathology researchers at Kumamoto Medical School had produced dozens of human skeleton models (hereafter, models) from autopsied patients who had died of Hansen's disease (HD) in the 1920s. A general meeting of the "Hansen's Disease Citizen's Association" was held in Kumamoto City immediately after the release of this news. The Association made an emergent appeal, demanding investigation into the production of these models and the ethics of medical professionals and researchers at both the Kumamoto University School of Medicine and the National Sanatorium *Kikuchi Keifuen*, where all autopsied patients had been admitted. Both former patients with HD and commentators specializing in historical issues concerning HD argued that medical professionals involved in the production of these models were discriminatory towards patients with HD and carried out unethical medical practices. The authors believe it important to examine, from the humane perspective, the factors that had allowed medical professionals to participate in these activities without condemnation from both the medical community and lay population. The paper discusses the long history of discrimination against patients with HD and the ethical fragility of medical professionals as two main factors that contributed to the production of these models. The sociopolitical circumstances of the era in which this occurred must also be considered, including the national atmosphere and the ethical immaturity of the medical community at the time. In conclusion, the authors stress the importance of preventing discrimination and ensuring robust ethical guidelines for medical professionals in order to keep history from repeating itself. It is essential to continue the endless battle against discrimination as well as serious reflection upon the past and learning from it.

Keywords: Discrimination, Hansen's disease, history, Japan, medical ethics.

Introduction

On May 9, 2013, a local newspaper in Kumamoto prefecture located in Kyushu Island, Japan reported that pathology researchers at Kumamoto Medical School had produced dozens of human skeleton models (hereafter, models) from autopsied patients who had died of Hansen's disease (HD) in the 1920s. This news spread throughout the country, renewing national attention on issues of discrimination against people suffering from various diseases and former patients with HD (Sawamoto 2013; Izumi 2013, Editorial 2013). A general meeting of the "Hansen's Disease Citizen's Association", aiming to eliminate prejudice against individuals with the disease and addressing the lessons learned from historical discrimination, was held in Kumamoto City immediately after the release of this news.

The Association made an emergent appeal, demanding investigation into the production of these models and the ethics of the medical professionals and researchers at both the Kumamoto University School of Medicine (originally Kumamoto Medical School) and the National Sanatorium *Kikuchi Keifuen*, where all autopsied patients had been admitted. Finally, the Association demanded that the Ministry of Health,

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Labour, and Welfare investigate whether or not similar activities had occurred at other institutions (Sakamoto 2013).

Both former patients with HD and commentators specializing in historical issues concerning HD argued that medical professionals involved in the production of these models were discriminatory toward patients with HD and carried out unethical medical practices. They also asserted that these practitioners were inhumane, and had violated the human rights of the patients by treating the human body as an object (Sawamoto 2013, Editorial 2013, Kyodo Tsusin 2013; Nittere News 24, 2013). On March 24, 2014, an “Investigation Committee” concerning the production of human skeleton models of patients with Hansen’s disease at Kumamoto University Graduate School of Life Sciences (hereafter, Investigation Committee) published a report on this matter, revealing the details discussed below (Investigation Committee Report 2014).

An associate professor from the Kumamoto Medical School Department of Pathology (hereafter, Department) initiated production of the models from autopsied patients with HD who had been admitted to the Kyushu Sanatorium (currently called the National Sanatorium *Kikuchi Keifuen*) between 1927 and 1929. A list of autopsied bodies was found that exclusively consisted of patients with HD and revealed that the associate professor had conducted autopsies on 43 patients with HD between November 1927 and March 1929. Models were produced from 20 of these patients and were preserved at the Department. None of these models exist today; they are thought to have been destroyed during the World War II bombing of Kumamoto City by the United States. The associate professor mentioned this incident in an article published in 1951 under the title of “*An Afterword (Batsu ni kaete)*” (Suzue 1951).

Autopsies had been conducted with due process for the majority of the 43 cases. However, no written consent was obtained from the patients or their family members to produce the models. The Investigation Committee believed that the associate professor produced these models for anthropological research aimed at proving the existence of a biological predisposition for contracting HD. The findings of this study were formally presented in 1931, under the title “*A study of the biological predisposition of Leprosy patients: the first report,*” at the Japanese Society of Pathology (Suzue and Nagase 1931). “*An Afterword,*” published in 1951 by the said associate professor, includes this statement:

“I always showed off this precious collection of human skeleton models of patients with HD to celebrities who visited Kumamoto Medical School, bragging with pride.”

The Investigation Committee argued that the acts of preserving models as a ‘research collection’ and showing them off with vaunt suggested a lack of consideration for the deceased, even if the audience had been medical researchers. Such behavior by the associate professor was judged to be problematic from a research ethics standpoint. The Investigation Committee concluded that production of the models caused harm to the affected patients and to those concerned with similar issues in a modern society. These actions were also considered to have caused psychological suffering and contributed to the distrust of physicians, medical researchers, and healthcare professionals in general. The Investigation Committee voiced deep regret and promised to prevent similar occurrences.

This paper examines what factors allowed for the production of these models without hesitation or any serious consequences at the time they were produced. The presentation of research findings based on anthropological analysis of the models was not criticized by the medical community in 1931, and it was not until 2013 that the 1951 publication of “*An Afterword*” became the target of social blame. We believe it

important to examine, from the humane perspective, the factors that allowed medical professionals to participate in these activities without condemnation from either the medical community or lay population. The sections that follow discuss the long history of discrimination against patients with HD and the ethical fragility of medical professionals as two main factors that contributed to the production of these models. We also consider circumstances of the era in which this occurred, including the national atmosphere and the ethical immaturity of the medical community at the time. We further argue the importance of preventing discrimination and ensuring robust ethical guidelines for medical professionals in order to keep history from repeating itself.

Methodology

This paper provides a critical analysis of the historical account of discrimination against patients with Hansen's disease in Japan starting from 1920, and the reasons behind it, which also resulted in the production of skeletal models from the autopsied bodies of patients who had died from this disease. The research uses historical records, newspaper accounts of this act, and the reports of the formal organizations and the Investigation Committee that was formed to investigate it. Most of these reports were in Japanese language, and therefore this paper maybe the first academic review of the production of the skeletal models that was first reported in Kumamoto, Japan in 2013.

The paper uses ethical review and analysis to discuss and shed light on the reasons for such discrimination and the implications for current practice of medicine in Japan regarding patients suffering from stigma of disease.

Findings and Discussion

The history of discrimination against patients with HD in Japan

Discrimination against patients suffering from HD, as well as those who have recovered from it, has been one of the gravest human rights violations in historical and contemporary Japan (Table 1).

Table 1. A summarized timeline of events related to the production of human skeleton models from deceased patients with HD in Japan

1907	Establishment of the <i>Leprosy Prevention Law</i> (first legal isolation of roaming patients with HD from communities)
1909	Five public sanatoriums for patients with HD were built
1915	Forced sterilization of patients with HD at Zensei Hospital
1927	Production of human skeleton models from deceased patients with HD
1930	First establishment of a national sanatorium for patients with HD
1931	Establishment of the <i>Leprosy Protection Law</i> (original legislation forcing isolation of all patients with HD); presentation of " <i>A study of biological predisposition of Leprosy patients: the first report</i> " to the Japanese Society of Pathology
1936	Initiation of the " <i>20-Year extermination plan</i> " for leprosy; spread of the " <i>No Leprosy patients in our prefecture movement (Mu rai ken undo)</i> " throughout Japan
1948	Enactment of the <i>Eugenic Protection Law</i> (legalizing the sterilization of patients with HD and abortion of fetuses carried by these patients)
1951	Publication of " <i>An afterword</i> " in the " <i>Bulletin Monograph of Dermatology</i> " of Kyoto University
1958	Enactment of the <i>Leprosy Protection Law</i> (new legislation maintaining the forced isolation policy against all patients with HD)
1996	Abolishment of the <i>Leprosy Protection Law</i>

We argue that the nationwide discrimination and prejudice towards patients with HD in Japan at the time played a significant part in the production of these models. Discrimination is defined as unfair treatment of a particular individual or group without a legitimate reason (Niimura 2008). People have discriminatory feelings or thoughts when they feel uncomfortable about and loathe, disdain, or are afraid of a person or group without a rational reason (Nakajima 2009). HD has a dreadful history of discrimination. Patients with this illness not only suffered from severe and persistent symptoms, but were also forced to leave their home or town. These individuals were compelled to wander, and were socially devastated by separation from spouses, children, parents, and other relatives (Ohtani 1993, Niimura 1998). Since ancient times, individuals with HD were forced to, metaphorically, “experience death” during their lives. They were stigmatized as being impure or criminal, and were thought to be “quasi-humans” being punished by Buddha or God. Patients with HD were thus sentenced to social death in addition to their disease-related suffering and disability (Ohtani 1993, Niimura 1998). In Europe, the prevalence of isolation institutions for patients with HD increased in the 19th and 20th centuries. In Hawaii, this malady was referred to as an ‘isolation’ disease (Dobson 2010). In Japan, HD was recognized as “Buddha's vengeance,” the disease of heaven’s judgment, the shame of entire families, or “*suji*” (a bad pedigree), since the Edo era (Ohtani 1993, Niimura 1998, Akamatsu 2005).

HD was irrationally considered both a genetic illness and an infectious disease, with current and former patients being long abhorred in local communities. Japan also maintained a national forced isolation policy, via the *Leprosy Protection Law*, that lasted 90 years keeping patients with HD in forced isolation (Dobson 2010; Hataya 2006; Kumamoto *nichinichi* 2004; Inspection Committee 2005). Although this law was repealed in 1996, serious prejudice and discrimination against recovered patients still continue. A Japanese physician, who has been involved in the care of patients with HD for decades, called the illness outstandingly extraordinary because the suffering from this disease leads to loss of one’s home and homeland (Tokunaga 1982).

Akamatsu, a Japanese anthropologist, wrote that latent discrimination against those who had a family member with HD is obvious in the context of marriage. People who believe that their children or grandchildren might marry someone with a HD pedigree have been known to tenaciously investigate multiple generations of the prospect’s familial ties to determine whether any members had HD. Even a rumor of a relative with HD can be sufficient to call off an engagement (Akamatsu 2005).

Narratives about patients with HD in sanatoriums revealed that their family members were not present when they passed away, did not attend their funerals, and did not collect their ashes after cremation. Many of these patients’ families refused to allow the patients to visit their homes while they were still alive. When they returned home, some were told by their families: “Do not come back. Keep away from this house,” “You have such a shameful disease,” and “You would keep me from looking at people in the eye” (Tokunaga 1982). One patient with HD repeatedly escaped from a sanatorium in search of freedom, but was rejected by people from his hometown, his relatives, and even his own mother. In one instance, people believed that a grandfather with HD would socially hurt his grandson (Tokunaga 1982). In November 2003, a hot springs hotel in Kumamoto, Japan, refused lodging to patients who had previously suffered from HD. This situation reminded Japanese society of the deeply-rooted and long-lasting prejudice and discrimination toward patients with HD (Hataya 2006).

In 2009, a study of the daily lives of patients who previously suffered from HD was conducted by a human rights volunteer group. Respondents reported that patrons at local public bathhouses told them not to

come; staff at local bookstores ordered them not to touch the books; and guests at their home would not eat food they served (Sankei newspaper 2009). A 2013 survey reported that 37% of laypersons would feel uncomfortable bathing with former patients with HD, and 42% would not want a marriage between their family and the children of former HD patients (Kusonoki 2013). As is evident from the above discussion, the production of models from deceased patients with HD occurred in a society that was severely discriminatory towards patients with the disease. It is thus not an overstatement that these unethical and inhumane attitudes toward, and policies against, patients with HD are partly responsible for having allowed these models to be produced.

Ethical fragility among medical professionals

Besides the severe and widespread discrimination against both current and former patients with HD, we argue that ethical fragility among medical professionals, especially physicians, contributed to the environment that allowed the production of these models. Certain characteristics shared by many medical professionals could make them ethically susceptible, leading them to do something considered unacceptable from the modern moral standpoint. For example, Colaianni suggests that the present medical culture remains relatively unchanged from the time when German doctors participated in the genocide carried out by Nazis, transforming life-saving professionals into murderers. She claimed that the culture of medicine made German doctors more morally vulnerable than laypersons at that time (Colaianni 2012).

This characteristic of moral vulnerability now and then among medical doctors has arisen from the rigid hierarchy and socialization in medical culture, a strong career ambition, and a 'license to sin' (i.e., physicians are allowed to perform actions in medical school that are taboo in other contexts, in the pursuit of scientific knowledge), all of which result in arrogance and a belief that they are above the law (Colaianni 2012; Berger 2002). It has also been suggested that physicians become accustomed to inflicting suffering, as part of their professional duties (Colaianni 2012).

Tsuneishi has recounted the actions of the '731 Unit', in which Japanese medical researchers performed cruel human experiments, human vivisection, and murders. Participants quickly became accustomed to the brutality of their acts and developed a serious lack of social awareness and individual independence, attempting to justify their barbaric actions by claiming that they had been done for the glory of the Emperor and Japan (Tsuneishi 1995).

In the "*Final Report on Hansen's Disease-Related Issues*," the Inspection Committee in 2005 reported on fetus sample records found in HD sanatoriums, stating:

"The personnel of many national sanatoriums for HD had failed to treat the residents as human beings with dignity, and completely ignored the dignity of fetuses in the past. Furthermore, they had treated resected body parts from the patients in an unethical manner. In other words, what ought to be addressed most is that the personnel, including physicians, nurses, medical technicians, and administrative officials, had all lost their awareness of medical ethics".

A scientific misconduct researcher suggested that egocentrism, contempt of others, and perceptions that one is 'above the law', the rules of society do not apply, and that one is doing what is right or highly important, can strongly contribute to research misconduct, fabrication, and falsification. It has also been argued that some professors at medical schools commit research fraud because they have developed a belief that they are different from and superior to others (Hakuraku 2011).

Those involved in the production of the models may have had similarly problematic beliefs and

perceptions of themselves, the medical profession, and other individuals. Both past and present medical cultures occasionally nurture arrogance, the tendency to justify actions in the name of science, the nation, or the Emperor, unconditional confidence in doing what is perceived to be right, and numbness to the brutality inherent in some medical practices. The national goal of exterminating HD at the time may have been used to justify the production of these models for medical research. The study was consistent with national policies at that time, and was regarded as beneficial. Research was viewed as socially significant insofar as it aimed to reveal the mechanisms involved in contracting the disease. At the time, HD was viewed as weakening the nation, and stopping its spread was seen as promoting overall health and reinforcing the physical capacities of Japanese people.

Individuals with feelings of elitism, career ambition, and clear purpose, as well as beliefs in high productivity, progress, health, and social improvement, are likely to think that human beings who are unable to contribute to social progress should be excluded from global society. It can be argued that such eugenic ideas are clearly connected with discrimination against disabled individuals, including patients with HD, and that these ideas attenuate empathy for physically and socially vulnerable persons and weaken psychological resistance to the violation of human rights. As a consequence, respect for the dignity of deceased patients with HD and courteous treatment of dead bodies is easily lost.

The “*Final Report on Issues Related to Hansen’s Disease*” published by the Inspection Committee in 2005, discussed the establishment of a lifelong isolation policy in Japan; this report posited that doctors had propagated the belief that HD was highly contagious, extremely dangerous, and should not exist in a civilized nation, as well as the belief that HD must be eliminated at any cost. The report concluded that these widespread beliefs led Japanese citizens to discriminate against both current and former patients with HD. The report also suggests that some Japanese medical professionals at the time actively discriminated against and isolated patients with the disease. Looking at all the evidence together, we propose that ethical fragility among medical professionals contributed to their willing involvement in discrimination against these patients and production of the models without consent.

National Setting

Production of the models in question occurred between 1927 and 1929. In addition to the social discrimination against these patients and the ethical fragility of medical professionals, the national setting at the time may have contributed to this shocking event. It is necessary to consider the overall environment during this era to better understand these occurrences. Two related factors that are important to consider are the pre-war nationalist policy aimed at enriching and strengthening Japan, and the immature level of research ethics at the time.

The medical society of Japan developed a system of medical ethics in the late 1880s and early 1890s. The major ethical principles governing medical practice at the time were care and consideration for patient suffering, non-maleficence and beneficence, and mercy. Physicians’ virtues were also considered essential (Goto 1999). However, Ozeki pointed out that the missions and obligations of physicians at the time could not be separated from the nationalistic awareness of the era. It was believed that medical progress would promote health and thereby enhance national productivity (Ozeki 1970). It was also believed that, in order to compete with Western countries, Japanese medicine had to enhance the physical abilities of Japanese citizens. Thus, from the beginning of modern medicine in Japan, many Japanese physicians had engaged in healthcare and medical research motivated by nationalism or enthusiasm to serve their country. Confucianism was believed to have contributed to the foundations of Japanese medicine and the

establishment of healthcare and public health systems (Ozeki 1970). We argue that the application of Japanese nationalist ideas to medicine led to the development of eugenic ideology. This nationalist ideology, which was focused on enriching and strengthening Japan, may have led Japanese physicians to discriminate against socially vulnerable people, including those with HD.

To further understand the national setting in the 1920s, it is necessary to consider what constituted research ethics at the time. To the best of our knowledge, international research ethics guidelines had not yet been established. Throughout history, medical research has taken place at the expense of condemned criminals, those with mental illnesses, slaves, minorities, and those under forced isolation (Baker & McCullough 2009). Indeed, other significant unethical human experiments were carried out soon after the 1931 presentation of the findings of the model study, including the Tuskegee syphilis study (1932-1972), the Japanese Unit 731 bioweapon experiments (1932-1945), and human experiments conducted at Nazi concentration camps (1939-1945). It was not until 1947 that the Nuremberg Code was developed. However, unethical medical research on human subjects did not disappear (Beecher 1966), and this prompted the World Medical Association to develop the first version of the Helsinki Declaration in 1964.

Production of the models occurred in a period of nationalistic and eugenic totalitarianism and immaturity of medical research ethics. It is unlikely that physicians, medical researchers, or even Japanese society, gave significant consideration to human rights and dignity. It is also unrealistic to expect that these medical researchers would have obtained informed consent, from patients or their families, to produce the models at the time, although such practices are unacceptable from a contemporary ethical standpoint.

Conclusion

What course of action is appropriate for ethically dealing with the knowledge of the production of these models, which were made from deceased patients who experienced discrimination and forcible isolation nearly 90 years ago? It would be too simplistic to respond that the practice had occurred due to the features of the era during which it occurred and the immaturity of research ethics at the time, without further reflection. It would also be fruitless to only apply retrospective ethical judgments to individuals who were directly involved in these events and condemn them. To allow for a thorough reflection, it is necessary to analyze the major contributing factors involved, and to assess human inclinations. The following passages discuss discriminatory attitudes toward patients with HD, as well as the concept of ethical fragility among medical professionals.

Discrimination must be eliminated in order to stop the harm it causes to targeted groups and its impact on their biological and social lives. As discussed in detail in the preceding sections, discrimination has caused torment throughout the lives of current and former patients with HD (Ohtani 1993; Akamatsu 2005; Hataya 2006; Kumamoto *nichinichi* 2004; Investigation Committee 2005; Tokunaga 1982; Inami 2007). We believe that health-related discrimination still persists today, and cannot be completely eliminated. Never has a utopia existed that is completely free of discrimination, and there likely never will. The only chance for full realization of human rights and ethics is through a fight against weakness, arrogance, selfishness, self-centeredness, narrow-sightedness, and the failure to recognize and appreciate the suffering of others. It would likely be an endless battle.

Discriminatory ideas and feelings reside in the dark side of the human spirit, no matter how they are developed or established. It is impossible to avoid all discomfort or unpleasant feelings towards particular

individuals or groups, and it is instinctual to fear contagious diseases that deform or destroy the body. Discriminatory thoughts, feelings, and actions are natural to humans, but discrimination against an individual or group is distinctly inhumane. It has been suggested that discriminatory thoughts and feelings are part of the basic human mentality (Akamatsu 2005). It is essential to look into human darkness in the face in order to make progress in countering discrimination.

Despite dark tendencies, humans also have empathy for others. They possess a pure, natural compassion that makes it impossible to remain indifferent in the face of another's misfortune (Jullien 2002). Solidarity is highly valued in human society, and this sentiment is pivotal for anti-discrimination education and activities. Akamatsu, a folklorist studying various types of discrimination in Japanese communities, stated that "The animal called the human being is hopeless. But, we cannot afford to give up anti-discrimination activities. There is no choice but to continue the activities with patience" (Akamatsu 2005). While we cannot present a methodological solution to eliminate discrimination against patients with HD, it is important for individuals with empathy and compassion for the suffering of others to continue to enlighten those who are less empathetic and compassionate. These individuals must also recognize that their mission will be endless, due to the strong and tenacious nature of discriminatory thoughts and feelings.

Finally, what approach is best for addressing problematic attitudes among physicians and medical researchers and helping them become ethically robust? Regrettably, arrogance is common among physicians, and violates the benevolent spirit of medicine and the quality of medical care (Jullien 2002). Physicians and medical researchers are prone to become arrogant and look down on others. They tend to overestimate the power of medicine and forget its limitations, and are at risk of developing a eugenic worldview. They may also have a big power, which can be a double-edged sword. It is very difficult to entirely remove discriminatory ideas from the mind, and everyone should be aware of them. We argue that physicians with eugenic beliefs, who are eager to conduct medical research and feel that they are above the law, could end up repeating such barbaric acts of human rights violations. Therefore, it is important to reflect upon the past and learn from it. Only by doing so will it be possible to prevent similar tragedies in the future.

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