

Chapter 8

Cultural Rehabilitation: Hansen's Disease, Gender and Disability in Korea

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On 11 October 2004 in Seoul, the Korean Bar Association hosted the Human Rights Reports Forum of People with Hansen's Disease (leprosy). The media reported this as the first collective public appearance of *Hansenin* (people with Hansen's Disease). More than 400 people with disabilities who were cured from Hansen's Disease gathered, voiced their experiences, and called for special legislation to redress the extreme segregation and stigmatization they had experienced. These unprecedented collective voices of *Hansenin*, in a public space, attracted social attention to the violence perpetrated against them throughout the twentieth century. This forum points to the human rights of *Hansenin* emerging as an important socio-legal issue in the beginning of the twenty-first century in South Korea.

Leprosy in Korean history was more than just a disease; it was also a classifier of people, creating a kin called *mundungi* (lepers). Japanese colonial authority (1910–1945) and later South Korean public health documents (1954–1999) used the term, *nahwanja* (leprosy patients), which had medical overtones, but the cultural legacy of the *mundungi* maintained the image of the fearsome vagabond. The repulsion against contagion of the disease came to coexist with the fear generated by the imagined grotesque behaviors of the people with leprosy during the second half of the twentieth century.

Nabyŏng and *mundungbyŏng* both mean leprosy, and people who are associated with the disease detest these terms because of stigma that comes with them. They have now been replaced with the term *Hansenbyŏng* (Hansen's Disease) by human rights advocates and policy makers in Korea.¹ The derived term, *Hansenin* indicates people with Hansen's Disease as a kind of social identity. *Hansenin* does not necessarily mean that a person has the disease currently, but instead connotes a group created from historical and social responses to the disease. In a broader sense, *Hansenin* also includes the children, or the second generation, of leprosy patients. Due to the second generation's genetic association with a parent who had the disease, the children have been also ostracized in Korean history, labeled as *migama* (uninfected children) that falsely implies the latency of the disease. In this essay, I use the term lepers or leprosy not to subscribe to the stigma the term invokes but to engage with the discourse of the time. I use *Hansenin* and Hansen's Disease as well in order to reflect the changing atmosphere in contemporary Korea. These term changes illustrate that the disease and its imaging process are in culturally contested terrain.

This essay pays specific attention to leprosy, which often results in impairments. The disease alters a person's social destiny apart from its biological consequences. I make a case for leprosy as a layered historical and cultural construction that forwarded family as an uninhabitable space for disabled people. The contemporary strategy of raising consciousness of

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¹ In 2000, the Contagious Disease Prevention Law was amended to change the designation of leprosy to Hansen's Disease in South Korea.

the stigmatized populations displays the tendency for seeking cultural rehabilitation, which refers to cultural representation that reinforces gender, heterosexuality, and reproduction as a way to reincorporate the excluded people. Leprosy also offers a case study of how disease and disability in a colonized nation were used to demonstrate the necessity of the colonizer's intervention.

People with leprosy were the first population medically institutionalized in Korean modern history, a practice initialized by western missionaries and the colonial government. Leprosy also provides an illustrative explanation for how a postcolonial modern nation inherited medical imprisonments disguised as preservation of public health. The essay looks at the conception of nation and the process of alienation that emerged in the gendered domestic spaces of cultural representation. I also address the systemic discrimination experienced by *Hansenin* and connect it to the wider rubric of disability discrimination, other diseases such as AIDS, and gender politics within marginalized communities.

The Political Movement of *Hansenin* in the Twenty-First Century.

The public gathering of *Hansenin* in 2004 can be related to a broader social reform movement. Pro-democracy movements grew throughout the 1980s, and the success of the 1987 struggle, which achieved open presidential elections, marked a significant transition for social movements in Korea. Subsequently in the 1990s, the more specified interests of minorities emerged in Korean society after the rapid growth of pro-democracy movements, the radical women's movement, and the labor movement. Recent pluralized minority movements include those of foreign laborers, sexual minorities, inter-racial people, disabled people, political prisoners, and sex workers. These emerging groups challenged previous social movements that focused on normalizing democracy and addressed only the majorities' oppression under the state regime (Cho, 2004).

However, after the overthrow of the military regime, the normalized democratic nation revealed itself to be under the influence of neo-liberalist globalization, which nurtured nationalism and Korean-based global corporations. The 1997 economic crisis resulted in an International Monetary Fund intervention, which demanded the structural adjustment of the labor force and the privatization of the public sectors. This global intervention caused massive lay offs and job insecurity that rattled labor movements. People who participated in the pro-democracy and labor movements found themselves in a secure position advocating for a relatively privileged labor class.

Relatively sizable women's organizations, such as Korean Women Workers Association, were credited with playing a major role in the pro-democracy movement in the 1980s (Enloe, 2004, p. 48). Now, partly state-supported organizations, realizing the differences among women, face criticism from women whose interests were excluded from or intentionally avoided by "general" women's advocacy. At the same time, disabled people began asserting human rights actively and the movement became more visible in the 1990s, empowered by a series of international efforts addressing disability, such as the International Year for Disabled People in 1981. Despite the growth of the disability rights movement in Korea, the communities of people with diseases or disabilities remained within the purview of religious or private social service organizations run by Christian churches, which focused on relief, cure, volunteerism, and philanthropy. Even among the minority movements using human rights discourse over the last decade, leprosy issues had not emerged in political efforts until after the arrival of the new millennium.

What then motivated the political emergence of people who had been segregated on the basis of the disease to come forward in public forums about human rights violations and

discrimination? A well-publicized Japanese court case on leprosy provides a clear explanation of this apparently sudden public emergence of *Hansenin*'s advocacy. On 11 May 2001, the Kumamoto court of Japan ruled that the Leprosy Prevention Law was unconstitutional and ordered the government to compensate the 127 plaintiffs who were institutionalized in Japan. This landmark ruling called for an exploration of leprosy history in Korea and Japan alike. The Japanese Prime Minister, Junichiro Koizumi, publicly apologized for the policies of forced institutionalization and sterilization enacted by the previous government, which were based on incorrect scientific beliefs. The apology was welcomed as a victory made possible by the persistent movements begun in the 1960s. The movements led to the abolishment in 1996 of the notorious Leprosy Prevention Law, which had enforced segregation since 1930.

The Japanese Health Ministry decided on 16 August 2001 that a law should be made to compensate former lepers taken to isolated sanatoriums in Japan. Japanese parliament approved a compensation bill worth up to 14 million yen to each of the hundreds of people who suffered decades of systematic civil rights violations by the state. The lawyers had to emphasize that the lawsuit was not about a war issue but about damages caused by the Leprosy Prevention Law that had enforced lifetime segregation as a national policy even after the disease was proven to be curable by multidrug therapy in the 1960s. Only after the turn of the century, when people finally started to be recognized as victims of violence in modern history, could this kind of restitution be possible.

Subsequent to the legal success in Japan, 117 Koreans who were institutionalized during the colonial period in the Sorokdo institution in Korea requested compensation in 2003 and 2004. However, the Japanese government rejected this request saying that they were not eligible and that the compensation was only for the people who were segregated forcibly in the sanatorium in Japan. It is important to recognize that unified efforts of people with a history of leprosy and their allies in Korea and Japan, in their collective search for justice and public acknowledgement of the crimes of Japanese imperialism, set the tone for a rhetoric concerning the human rights of *Hansenin* beyond their nationality. This transnational legal movement fostered social advocacy in Korean society, which was exemplified in the Human Rights Report Forum. Later in October 2005, a Japanese court rejected the appeal for the denial of compensation of 117 Koreans but a different court ruled in favor of 25 Taiwanese plaintiffs who were institutionalized by the colonial government. After the persistent efforts, Japanese government started approving Korean *Hansenin*'s requests of compensation in 2006.

This alliance between Japan and Korea against Japanese policy should not overshadow the continued post-colonial controls and human rights violations exerted by the Korean government. Fortunately, what is notable and effective in this event is that the lawsuit is framed in neither an anti-Japanese nor a nationalist discourse. Apart from legal activism, there are a few problems in the media's efforts toward raising public awareness in relation to the history and human rights discourse around leprosy. Recent journalism focuses on eradicating the prejudice against *Hansenin* by disproving the scientific theories of heredity and communicability of the disease that originally justified institutionalization and sterilization. The understanding of the process of stigmatization against certain diseases practiced in the past can lead us to identify current discrimination against people with certain biological conditions. Because the human rights of *Hansenin* discourse is based strongly on the fact that leprosy is not highly contagious nor hereditary, questions are left unanswered regarding what forces and knowledge were used to implement the isolation of *Hansenin*, a process that continued even after the development of the cure.

What are the political ramifications of the corrected contemporary discourse premised on the fact that leprosy is curable and not hereditary? If people diagnosed with leprosy deserve

human rights because the disease is found to be treatable and not contagious, how can human rights be achieved for people who are not curable and may even be contagious? For example, how can the movement make some connections to the human rights of people with AIDS as a stigmatizing disease in the contemporary era? These questions invite a more comprehensive understanding of the nature of the *Hansenin's* oppression in relation to other disabilities in history.

Family and Motherhood: “Oksimi” and “Pawi”.

Leprosy frequently appears in Korean modern literature written during the 1930s when the institutionalization of people with the disease was strictly enforced. Kim Chŏnghan’s short story “Oksimi” (1936) provides a way to view the complicated interactions within a patrilineal family structure in the midst of the existence of a disabling disease, the emergence of modern femininity, and the changes in the socio-economic configuration. The presence of leprosy in the male head of the family, Ch’ŏnsu, reveals what power structure the family is founded upon and that family’s resulting choice for survival in the community. By choosing a nondisabled wife, Oksim, as a protagonist, the narrative allows us a rare chance to look at how the dynamic changes when the gender hierarchy in a patriarchal family context is renegotiated by a state-targeted disease.

Kim Chŏnghan’s works, in general, combine realist descriptions with socialist critiques of a changing Korea. His works disclose the hardships of peasants under colonial rule and manifest his resistance against Japanese exploitation even when censorship increased greatly. “Oksimi” did not draw the same kind of attention from critics in terms of its reflection of Korean society, as did the author’s other works. “Oksimi” does not make it immediately clear what Kim Chŏnghan intends to highlight at first glance. The lack of critics’ interests in this story is due to the ambivalent nature of the power structure between a nondisabled woman who starts to be influenced by a more liberatory atmosphere and a disabled man who is suffering because of his waning authority in the family. Kim Chŏnghan tells us that the old values and social order are subject to change as modernity and different economic relations arrive in the village.

The story starts with Oksim’s unnamed feeling surfacing in spring while working in the fields within sight of laboring men. After the day’s labor, Oksim comes home to yet another labor: feeding her in-law’s family, including a sick mother-in-law, two young sisters-in-law, and her son Subok. The father-in-law appears to be kind and gentle while trying to cure his son, who is now living in a hut apart from their house. The spatial placement of lepers in a separate hut is a common practice revealed in the literature of the colonial period. Some depictions of this treatment are more related to hiding the presence of the patient and protecting a family’s reputation than endorsing confinement as a method of preventing infection. “Oksimi” also provides some explanation: “given the time’s situation, when the disease came to be known to the neighborhood, he couldn’t help but moving into a hut” (C. Kim, [1936] 1975, p.34).²

The story evolves into a love affair that Oksim has with An-Sipchang (Manager An), whom she used to like as a girl. An-Sipchang convinces her to run away with him considering her husband’s disease and the outdated value of chastity. Although “Oksimi” does not mention the colonial situation and new policing system for institutionalizing lepers, it serves as a general backdrop. Loosening traditional values, including neo-Confucian principles of chastity and filial piety in a transitioning society and the fear of the disease open up Oksim’s pursuit of sexual

² Translations of the texts are made by me unless otherwise noted.

pleasure and other life options. However, Oksim cannot make up her mind out of concern for her son.

When “Oksimi” first appeared in *Chosŏn Ilbo* (Chosŏn Daily), the original title was “P’aedŏknyŏ” which means “immoral woman” (C. Kim, 1978, p. 76). The newspaper changed the title to “Oksimi” prior to its serialization. Even though the original title “P’aedŏknyŏ” seems to criticize feminine immorality—lost virtue of chastity—in the changing society, the story itself does not display a judgmental gaze on Oksim’s choice of having an affair. As Oksim starts working in construction labor as a contractor, she continues her affair with An-Sipchang which her husband Ch’ŏnsu ends up witnessing. Chasing them, Ch’ŏnsu makes an important connection between the construction of modern landscape and the changes in women’s lives: “I knew what that bitch wanted from the beginning. Did she ever go to the construction of the new road because she wanted to work? She got horny so she went to pave her path and herself” (C. Kim, 1975, p. 38). Upon disclosure, she runs away with An-Sipchang in the night without her belongings. After Oksim’s departure, Ch’ŏnsu’s family declines even further economically, and the sicknesses that he and his mother experience worsen. Ch’ŏnsu’s father alone works for other tenants as he is now deprived of his own tenancy.

Out of the blue, Oksim comes back one day and hugs her son Subok like a “hungry animal” (C. Kim, 1975, p. 39). Her return is described as being based on maternal yearning for the son she left behind. This motherhood effectively reveals her pursuit of an exiled sexual life as a selfish one. The return is followed by brutal violence at the hands of Ch’ŏnsu. The father-in-law, however, accepts Oksim back and instead chases his son away to the Sorokdo institution, while the mother-in-law remains furious at Oksim, reflecting the moral judgment imposed upon women’s sexuality at the time. Shortly after, Ch’ŏnsu’s hut, which served as a tentative solution between the family and the institution, is set on fire. The unsympathetic attitude of the author to the violence of Ch’ŏnsu works to justify the family’s choice of Oksim over him. Signifying the important shift from the Confucian teaching about disability in family and (nondisabled) women’s duty to provide care to the family members, the narrative’s emphasis moves toward the removal of the disabled person from the family while problematically justifying institutionalization. Upon the father-in-law’s support, Oksim promises her loyalty to him and to the family.

The key to understanding Oksim’s return is to think of it as a compensatory movement of the narrative toward the destroyed family suffering economic hardship. The disease itself does not cause disruption of the family, but rather Ch’ŏnsu’s destructive behavior because of his frustration with his loss of power. Consequently, the narrative shows that Oksim and Ch’ŏnsu are not compatible in the same space. On the contrary, it is the kind and caring patriarch, the father-in-law, who accepts the “blasphemous” daughter-in-law. The existence of disease in the family solely poses a threat to its survival economically and sexually since it causes the depletion of the finances and seems to lead the wife astray. However, this disruption of the family is compensated and resolved by Oksim’s return to her reinforced role as a daughter-in-law and a mother. In this narrative structure, the Sorokdo institution—a rather sudden alternative—appears to be the ultimate solution for the family crisis. The exit of Ch’ŏnsu from the family and his eventual destination suggests that the maintenance of the family is dependent on the existence of institution.

At this juncture, the transformation of family in modern economic changes accompanies women’s reinforced traditional role of serving and the additional economic laboring when the male-head is forced to be institutionalized. What was it about disability that threatened the survival of the family so much that the person with disability or disease had to be exiled? The father-in-law’s acceptance of Oksim, his grief at watching his son depart for Sorokdo, the

existence of the institution, and the colonial state's surveillance of the illness altogether identify family as an unsuitable space for a disabled person. In this narrative structure, the Sorokdo institution, where nearly 6,000 patients were incarcerated by the colonial hygiene police system during the late 1930s appears to be the solution. The modern transformation of the rural community accidentally and momentarily opens an emancipatory space for women to pursue sexual engagements; however, Oksim does not successfully merge into modern life free from the responsibility toward the extended family. The motherhood of Oksim serves as an unchanging default value. Whereas Ch'önsu never displays any affection to his son, Oksim's motherly affection toward Subok functions as a naturalization of motherhood.

In the same year "Oksimi" was published, Kim Tongni published a short story entitled "Pawi" (The Rock, T. Kim, 1936). In 1935, the colonial authority systematically forced the institutionalization of lepers, and the asylum came to have full jurisdiction over their patients' behaviors. "Pawi" reflects this historical background of heightened institutionalization. The story begins in the fall. As the weather gets colder and colder everyday the homeless people—including "cripples, beggars and lepers"—gather under the train bridge near the village. The cooling weather also echoes the increasingly hostile atmosphere against sick people under the Japanese medical policing system. The latest arrival is a *yöin* (meaning a woman) with leprosy who ends up joining the group after leaving her hut. The first publication of the story delivers more lengthy conversations among the outcasts under the bridge expressing their growing worries about the hygiene police which was ordered by the state to take all sick people away and shoot them "with a gun" (T. Kim, 1936, p.325). *Yöin* denies the possibility of such events by repeating, "surely not" (*sölma*), based on her belief that they are innocent people.

The optimistic expectation of "surely not" is soon overwhelmed by the heavy anxiety shared in the silence of the group. The first edition reads, "They believed that their 'surely not' was based on the absolute authority of something like sky [heaven]. But their intelligence was not high enough to articulate what that authority was" (T. Kim, 1936, p.325). This is a moment of recognition that there is a shared feeling of inherent injustice in taking sick people, treating them like criminals, and killing them. However, people under the bridge cannot put this feeling into words. This depiction shows that the systemic discourse of prevention of the disease and the nationalist rhetoric of eugenics have not reached the individuals. The feeling of injustice when people hear the possibility of incarceration because of an illness delivers the subjectivity of people who are already located at the outskirts of the community and the fear of further endangerment.

Following the scene under the bridge, the author steers the story's direction toward *Yöin*'s motherhood as her main source of frustration and suffering using her retrospective tale. Her son Suri is an important figure by virtue of his absence in the narrative. Given that sons were believed to be the future and carriers of the family lineage, the author describes how his future is transformed by his mother's disease and therefore so is the family's future. *Yöin* is not just expelled from the family but she is also portrayed as the one who breaks it apart. The costs of medication lead to financial crisis for the son and his loss of hope. In despair for his life, Suri disappears because of the loss of his savings related to his mother's medical expenses. His disappearance signifies the discontinuation of the family lineage and plays a significant role in the narrative leading directly to the husband's pursuit of abusive behaviors toward *Yöin*. After Suri disappears, it becomes harder to hide her existence as the surveillance by neighbors heightens.

The husband decides to force her to commit suicide by bringing rice cakes with poison in them. The growing communal antagonism against lepers as kidnappers serves as an important impetus for her decision to eat the poisoned cake. At the time of the story's publication, the

image of lepers as kidnappers was substantiated by alleged crime reports in the newspapers, and nearly every engagement with lepers in the village by others was perceived to be to an attack. In the narrative spaces of “Oksimi,” and “Pawi,” families with lepers try to hide the existence of the patients to protect them from being taken away to institutions. However, the flesh-eater image of lepers creates hostility in village communities toward these people. Eventually the family and community spaces become uninhabitable for lepers.

Yöin eats the poisonous rice cakes knowing that she will die. But the narrative goes on, “Death wouldn’t come easily. Eventually she just had to go somewhere and they say, she left the rice-cake thrown up all over the hut” (T. Kim, 1975, Trans. O’Rourke p.54). Running away from her husband, Yöin makes her own hut near the railroad bridge waiting for a chance to run into her son. This is because the Rock of Blessings is near for her to pray on, “believing that by rubbing the rock she would get to meet her beloved son” (T. Kim, 1975, Trans. O’Rourke, p.54). The bridge signifies the periphery of the village but it shifts into a center because of the location of the religious symbol. Like a dream, she briefly encounters her son and he leaves with the promise to visit her again. She keeps rubbing the Rock of Blessing eager to meet Suri again but only after dark to avoid people.

However, villagers find her, drag her off of the rock, and beat her until she loses consciousness. A workman from the local village office washes off the rock as if the rock is tainted by Yöin. One day she overhears people talking about her son who “was sentenced six months” and “he would be released for good soon,” signifying that he had turned into a criminal and was in jail. Her son is the basis of her existence in the story and her despair over her son’s destiny makes her fall down on the ground. Simultaneously, her hut is set on fire by villagers. Shown as a final signal of the village’s uninhabitability, the flame destroys her as it does the hut. The following day she is found dead on the rock. A comment by the villager captures the depth of the rejection of Yöin: “The dirty thing would have to die here” (T. Kim, 1975, Trans. O’Rourke, p. 56).

“Pawi” relates the process of how the physical and relational aspects of family become a space of antagonism toward disability: one forced by the social demonization of people with certain conditions and the community’s participation in that enforcement. On the other hand, like “Oksimi,” “Pawi” allows the interpretation that the adversity of the disease is more of a social consequence. Rather than the danger and suffering of the disease itself, the depletion of finances and the communities’ violence make survival impossible for the affected people. However, in both stories, women are assumed to be the keepers of family but with different conclusions. One family survives by the return of the nondisabled female, Oksim, while the other is disintegrated by the diseased woman. The woman’s motherhood in “Pawi” is exalted as similar to the rock’s supernatural power, but the villagers’ violence does not allow her to fulfill her role. In the following section, social contexts around the disease will be examined more closely.

The Image of Lepers as Child-Eaters.

There was a popular saying told to babies until the 1960s: “If you don’t stop crying, lepers will take you.” This saying reflects and contributes to leprophobia—the very real fear of lepers circulated by the media with its accusations of lepers as kidnappers for the purpose of using the human body as a cure. The social alienation of monstrous lepers emerged in the 1910s after Western missionaries established their existence as a social problem. The public media further facilitated the negative image of *mundungi* under Japanese Cultural Policy in the 1920s (Jung, 1997a, p.13). The disciplinary warning citing lepers was popular until 1960, according to Jung, along with tigers, and Japanese police officers (1997a, p.11). Jung suggests that this kind of

repulsion against leprosy began around the same time as the plantation and expansion of Christianity because Christianity brought with it the conceptualization of leprosy as “divine punishment” (1997a, p.13). He argues that even though leprosy existed before the twentieth century in Korea, it was not treated as a social issue by Koreans. Western missionaries “rediscovered” leprosy around 1886 and made it a social agenda in 1910 (Jung, 1997a, p.6).

However, the image of the flesh eater and its association with leprosy were not invented in the beginning of the modern era. In *The Annals of the Chosŏn Dynasty (Chosŏn Wangjo Silok)*, there are several entries regarding the use of human flesh to cure diseases such as epilepsy and leprosy. For instance, the chronicle of the King Sŏngjong, “Sŏngjong Silok,” records that there was a woman, Tŭlbi, who cut off her finger, dried, powdered, and fed it to her husband upon hearing that flesh was good for curing sickness. As a result of her actions, her husband’s leprosy was cured (“Sŏngjong Sillok” 29 February 1472).

In the King Sŏnjo period, the chronicle records that there were vagabonds who stole gallbladders by kidnapping and attacking people in order to sell the organs to lepers seeking cures. Sŏnjo ordered the arrest of these organ snatchers (“Sŏnjo Sillok” 26 June 1576). Although these anecdotal reports tie lepers to cannibalism, they hardly represent lepers as a group of anti-social attackers. Instead, human organs were sold by nonlepers as a source of medicine to the lepers who were seeking cures. The wife’s sacrifice of her finger for curing the husband was recorded as an exemplar of her loyalty to her husband. The association between leprosy and the use of human body as medicine was somehow twisted into the image of lepers who sacrifice the lives of other people for cures.

While this image of lepers as child-eating vagabonds was dispersed through the newly available printed public media, the discourse of infection and the hereditary nature of the disease started to emerge in the propaganda supporting the sterilization and institutionalization of lepers after the 1930s. This fear seems to have advanced and later coexisted with the fear of leprosy infection, but it has not been replaced. Between 1920 and 1931, there were 21 articles in *Tonga Ilbo* (East Asia Daily), one of the popular Korean newspapers after 1920, about lepers allegedly attacking, kidnapping, and killing women and children, and eating the organs of the dead bodies. By contrast, there are only four entries about seeing a leper’s presence in restaurants or public baths as a threat to public health. There is no mention of infection and only one entry mentioning male sterilization as a way of stopping the genetic transference and eradicating leprosy. It is likely that even if sterilization was publicized in 1927 as a method for suppressing the disease (Jung, 1997b, p. 231), it was not common knowledge until the late 1930s.

In the beginning of the 1930s, a growing body of entries began to appear regarding charity toward lepers after they were released from the institutions. The superstitious fear was combined with the social problem of lepers’ presence in the communities. The infection theory of leprosy became more dominant than hereditary theory around the 1960s. In the next section, I illustrate how this history is reexamined from the contemporary human rights perspective.

A Documentary, *Ah! Sorokdo*, Part One.

The political emergence of *Hansenin* today provides a way to reflect on the achievements of previous movements of human rights for minority groups in Korea, especially in relation to other identity categories, including gender. The disease as a gendered embodiment and the social reaction create a sense of crisis in family structures. While the modern family has been made incompatible with members with Hansen’s Disease subjected to the state’s control, contemporary activisms of biosocial communities reinforce the family as a rehabilitating place for men made possible by their union with nondisabled women. In this political partnership between marriage

and human rights, disabled women and their alternative forms of concurrent families are neglected. This move gears toward domesticating people while ignoring the problems they face in regards to their public participation through education and employment.

As a cultural response to the Japanese court case of 2001, which determined that the Leprosy Prevention Law was unconstitutional, Munhwa Broadcasting Corporation (MBC) aired a two-part documentary, *Ah! Sorokdo*, produced by Kwangju MBC (dir. Kim Hui and Kim Myōngkon, 2001) on national primetime television. Part one is titled “People Standing at the End of the World,” and part two is titled “Beyond Prejudice and Segregation.” The first title literally describes the location of the island Sorokdo at the south end of the peninsula and figuratively describes the status of the people living there who were expelled to the margins of society. Since the Japanese colonial authority built a hospital to confine Koreans with leprosy—which became the Korean national leprosy hospital after Korea’s liberation from Japan in 1945—the island’s name came to carry the same stigma as the disease did throughout the previous century. Although there have been several other hospitals built by missionaries and there are former patients now living dispersed beyond the island, Sorokdo became the metonymic representation of outcast lepers’ spaces.

The documentary’s structure and content touch upon key points of contemporary leprosy—and further disability—representation, especially when it is made from a human rights and awareness perspective. Part one, “People Standing at the End of the World,” starts with recent social events. The film opens up with scenes of researchers excavating a site where a massacre of lepers occurred during the 1945 interregnum after sudden independence from Japan. The survivors surrounding the site deliver the testimony of the atrocious massacre. Leaving the audience puzzled about the specifics of the event untaught in Korean history, the film moves on to the vivid scenes in Japan when formerly segregated people hear the announcement of the victory in their legal battle against the government. These scenes set up the subject of leprosy with historical and political magnitude. Interviews with people who have been living in Sorokdo since the colonial period testify to the discrimination they faced with acts of punitive sterilization and forced labor.

The film then inserts a brief interview with the then-director of the U.S. National Hansen’s Disease Research Programs, “L. K. James” [sic] (James L. Krahenbuhl), who suggests that the castration of lepers was “barbaric” and has “no basis in modern thinking.” Although the documentary touches upon Nazi eugenics, Japanese colonial policy, and the continuation of sterilization of disabled people from eugenic reason as the historical background of such violence, this interview demonstrates the Western point of view as enlightened and modern. This point raises critical questions. If the mistreatment of *Hansenin* is understood as barbaric and premodern, how do we account for the promotion of leprosy management and institutionalization by the colonial authority and Korean government as a symbol of a modern nation? The testimony of the American authority on the barbarism in Asian history exemplifies the West’s erasure of its own violence and its attempt to project leprosy onto the Oriental world, a projection that Japan tried to overcome. In the next section, I briefly look into the history of the internationalization of leprosy and resume the analysis of the documentary.

The Problematization of Hansen’s Disease in International Politics.

Hansen’s Disease was named after the Norwegian scientist Gerhard Armauer Hansen who discovered the causative agent, Leprosy Bacillus, in 1873. In Europe, medical practitioners in his time started to use Hansen’s Disease as the professional term, but the term has never replaced leprosy in general international discussion (for example, World Health Organization currently

uses leprosy as its term). Earlier, I mentioned that attempts have been made to replace the term “leprosy” with the term Hansen’s Disease in Korea since the last decade of the twentieth century. This renaming seeks to associate the condition with a more scientific and medical connotation in order to break away from the stigma attached to the terms *nabyōng* (leprosy) and *mundungi* (lepers). Ironically, despite the progressive attitude that the name Hansen’s Disease is intended, Hansen supported a policy of confinement for people with leprosy without proving whether the disease was highly contagious.

In his memoir, Hansen claimed that he was deeply influenced by Darwin, and encouraged the compulsory segregation of lepers and circulated the fear of contagion in order to make the policy effective in Norway. He had eugenic interests, believing that his country would join “advanced nations such as Germany” as long as his people were capable of fighting the disease (Hansen, 1976, p. 108). Hansen put forward reforms to existing laws forbidding lepers from being placed in regular hospital wards. He actively engaged in a legislative movement to advocate for the segregation of leprosy patients.

However, because of the common Norwegian understanding of leprosy as God’s will, his policy invoked anger and strong opposition. Facing this opposition, he brought the problem down to a matter of protection for the people themselves and tied it into patriotism. Hansen promoted a division between “the sick” and “the healthy” that urged “the healthy” people to exercise power largely on behalf of the nation. In his memoir, Hansen displays his nationalist fervor and equates national advancement with leprosy treatment. His strategy shows how leprosy is a classifier for dichotomous segments of the population: “the healthy” and “the sick.” Assigning nonaffected people to enforce a patriotic mission—finding and isolating leprosy patients, worked effectively in expanding legislative power. His efforts were considered very successful in suppressing the disease in Norway and were recognized internationally through the first International Leprosy Conference in Berlin in 1897.

Shubhada S. Pandya (2003) examines the first attempt to internationalize the problem of leprosy in the last decade of the nineteenth century by the civilized countries of the West who feared the invasion of leprosy into their nations via immigrants and returning expatriates from ex-colonies. Pandya argues that the politicization of leprosy as an international problem in Asia and Africa was generated from an imperialist enterprise (2003, p.162). The first International Leprosy Conference made a move toward endorsing leper segregation, promoted by the British in their interests in India. The support was followed by the approval of a proposal to prevent and deny entry of “alien” lepers at the Third International Leprosy Conference in Strasbourg in 1923 (Pandya, 2003). By developing scientific discourse, the international problematization of leprosy as threat to Western world in that period differentiated itself from superstitious beliefs about the disease of prior moments.

How then was leprosy used as the rationale for cultural inferiority and as the symbolic site of intervention for international control and national betterment? In *Leprosy, Racism and Public Health*, historian Zachary Gussow (1989) argues that leprosy reemerged in the non-Western world as a result of the political activities that situated leprosy as “a disease of ‘inferior people,’ a designation which invited international intervention in Asia and Africa by Europeans and Americans” (p. 19). Gussow’s argument can be understood in light of Foucault’s claim in *Madness and Civilization* that “[a]t the end of the Middle Ages, leprosy disappeared from the Western world” (p. 3). Foucault suggests that “lepers” and “leprosy” in Middle Ages are concepts that rose and fell with the church’s power and that this disappearance did not necessarily represent the actual decline of prevalence in the West.

By making connections to social Darwinism and the flourishing of eugenics in the United States, Gussow (1989) argues that germ theory heightened fears that contact with “inferior”

peoples would threaten the safety and future of the “superior” race in the last decade of nineteenth century, thus the modern stigma of leprosy is characterized by racism. According to him, the “backward” and “uncivilized” worlds’ bodies were perceived as “degenerate, their minds primitive, and their diseases loathsome” (p. 20). Gussow further argues that the reemergence of leprosy in the late nineteenth century coincided with the expansion of colonialism.

This argument provides a background for understanding the modern development of leprosy management in Western missionaries’ roles in Korea. Furthermore, leprosy serves as a key subject to explore, in that its heavily politicized interpretations and practices circulated around how concepts of nations, Orientalism, reproduction, and disability interact. How did Japan attempt to prove their enhancement by employing a strong surveillance of leprosy in its own territory and the colonies? Jung Keun-Sik (2002) suggests that modern leprosy relief projects were initiated by Western missionaries in East Asia. Such efforts also became battlefields of hegemonic struggles between Western and Japanese imperialism.

Around 1907, missionaries reached their peak expansion in Korea, and in 1909 R. M. Wilson established the first leprosy hospital in Kwangju. Jung (1997a) explains the social alienation of people with leprosy in relation to the implantation of Christian churches by Western missionaries around the turn of the century (pp. 15–16). Concerned with the expansion of Christian influence, and under the direct result of the First International Leprosy Conference in Berlin, Japan actively sought to catch up to the Western missionaries’ management of leprosy in East Asia. Finally in 1916, the Japanese Government General, Chosŏn Ch’ongdokbu, joined this field by establishing the hospital *Chahye Pyŏngwŏn* (Mercy Hospital) as a predecessor to the Sorokdo institution. Jung (1997a) explains that the establishment of the hospital was international propaganda for justifying colonial occupation rather than for a relief of patients (1997a, p. 16). Until the mid 1930s, leprosy relief was dominated by missionaries; however, the colonial government started to gain overall dominance in leprosy management when the Chosŏn Leprosy Prevention Act was enacted in 1935.

The colonial government attempted to monopolize the management of leprosy rather than collaborate with Korean professionals. The colonists imported their own brand of leprosy control as a means to assert their superiority over the Korean nation and the Western missionaries who were simultaneously attempting to expand their influence on Korean society through leprosy treatment as well. Consequently, a dual form of domination by colonists and missionaries came into play over the management of lepers. Jung makes an important argument that leprosy asylums (also called homes, colonies, or leprosaria) mark a new social system of modern institutions that never existed before (1997a, pp. 22–23).

Given this historical background, the human rights discourse of *Hansenin*, exemplified in the documentary *Ah! Sorokdo*, invests in delivering the unknown history of the island and the people who were under control of colonial medical power. While colonial history calls for the political understanding of *Hansenin* as Koreans who were oppressed by the Japanese, the Korean government’s exploitation of the labors of the Sorokdo residents, the continued violence toward them, and the continued incarceration extends the leprosy problem beyond simplified Japanese versus Korean conflict and brings in contemporary contexts of body politics within the nation.

Cultural Rehabilitation through Marriage in *Ah! Sorokdo* and *Your Paradise*.

Part two of the documentary *Ah! Sorokdo*, “Beyond Prejudice and Segregation,” uses a literary narrative as a historical account of the Sorokdo Island during the 1970s. It introduces Yi Ch’ongjun’s novel, *Tangsendŭl ūi Ch’ŏnguk* (1976, *Your Paradise*, 2004), which is one of the most well-known novels on the topic of leprosy. It is based on the real historical events of Sorokdo after decolonization. Until very recently, *Your Paradise* has been predominantly read as a political allegory by critics, which uses Sorokdo Island and the hospital’s sovereignty over the island as a way to describe the Pak Chŏng Hŭi (Park Chung Hee) regime. The author himself has commented over the course of time in his various writings and interviews that the novel aimed to allegorize the military regime.

In the novel, the hospital’s new director, Colonel Cho Paekhŏn (a character based on the real previous director Cho Ch’angwŏn), arrives on the island wearing a military uniform, signifying Pak Chŏng Hŭi after the 1972 coup-d’etat. His status as a medical doctor and a military colonel reflects that the island is ruled by the hospital’s authority, a synthesis of medical and political power. The novel was praised by critics in its brilliant description of Korea’s political situation under a military regime through its metaphorization of the institutionalized lepers as Korean people under the dictatorship. However, despite this intended political allegory and the dominant reading, the novel has not been contained within that allegory; rather it became an effective narrative delivering the people’s history of the island, which was adopted by *Ah! Sorokdo* as the *Hansenin* movement emerged.

The novel deals with Director Cho’s effort to build a real paradise for lepers in the wake of their distrust and skepticism about such efforts by previous directors. All previous efforts have ended up elevating the status of the “reformers” themselves, which is seen in the statue of the previous Japanese director. The elder Hwang, who articulates this distrust, later turns to support Director Cho’s Omado Island reclamation project. In contrast, Yi Sangguk, a *migama* (uninfected child of leper parents) working at the hospital, remains skeptical about the project and escapes the island. By escaping, Yi Sangguk disavows the establishment of such a “paradise” and its medico-militarized control. The author maintains ambivalence towards Director Cho’s character. Director Cho’s reclamation project in reality is one part of the history needing proper tribunal resolution. The project, intended to grant land to residents so they can live independently, is unsuccessful in spite of the cooperation and the sacrifice of residents and their years of labor. The village people in the nearby area do not want the lepers’ land to be connected to the peninsula by reclamation so the government ends the project and distributes the reclaimed land to the people on the mainland.

After introducing the history of the Omado Island reclamation project and the government’s betrayal, the documentary attempts to provide some resolutions. The narrative shifts from a cultural space into medical and Western professional perspectives under the subheading of “Is leprosy hereditary or contagious?” The employment of medical and Western rhetoric is a common strategy for informative documentaries about disability in Korea. By showing a medical doctor’s statement that Hansen Disease is neither hereditary nor contagious, the documentary enacts a radical transition from the socio-historical dimension of the problem to a medical one. Inevitably, this move fails to show the fact that the prejudice or misinformation that has made segregation and sterilization possible in the past was formulated under a combination of political, imperial, and medical forces. In the documentary, the problem is positioned within the binaries of ignorance versus enlightenment, premodern versus modern, and culture versus science. The second provides solutions for the first.

Built on the scientific ground of safety for noninfected people from the disease, *Ah! Sorokdo* part two finds budding social changes connecting the divided worlds of the *Hansenin* and “healthy” people and providing for a hopeful future. In the subsection entitled “People

Dreaming Reconciliation with the World,” changes are evidenced by two marriages between disabled men and nondisabled women. This part of the documentary seems to be adopted from the novel, *Your Paradise* ([1976] 2004) in that it ends with the marriage of a disabled man cured from leprosy and a nondisabled woman.

The first marriage in the documentary is between a female nurse, Pyön Hyemin, and Yi Seyong, a man who had been institutionalized in Sorokdo. Unexpectedly, a nurse’s choice of marriage itself disproves prevalent myths about leprosy confirming the medical knowledge introduced. The science discourse is supported by the social arrangement of marriage and the cultural image created around it. The assumption is that marriage here is possible when contagious and hereditary threats of disease are proven unfounded. In its logic, marriage resides in the nondiseased world because marriage only achieves symbolic value through the absence of disease. The existence of marriage proves leprosy to be curable, noncontagious, and nonhereditary, which are all simulated as preconditions for human rights.

The second marriage in the documentary is between a couple living in the settlement village. The documentary valorizes the couple’s effort to change prejudice toward people with leprosy, especially the husband’s effort to enlighten people through the Christian songs he composes. As in the first marriage depicted in the film, the second marriage is presented as a way of resolving discrimination and prejudice. However, the nondisabled wife testifies that she faced many objections when she got married. Additionally, she had to face the same kind of stigma because she associated with a person with leprosy and lived in a leprosy community. The fact that the wife had to go into the husband’s settlement village—instead of the husband moving out of the segregated community into integrated society—suggests that the function of marriage as a bridge between lepers and the healthy works only at a superficial level not at the level of their material living conditions. Moreover, these marriages are one of many gendered formulations in which lepers are represented only by men.

Meanwhile, marriage as symbolic integration assigns gender to disability and able-bodied worlds in disability representations: specifically the nondisabled world as female and disabled world as male. Yet, as in Kim Tongni’s “Pawi,” a disabled woman appears to deconstruct rather than suture this divide. On the other hand, women are constructed to represent able-bodiedness in which disabled men are easily integrated with nondisabled women without threatening the mainstream. Female—rendered nondisabled subjects—work as gateways of integration. However, this project does not succeed completely, for nondisabled women are often absorbed into disabled men’s space. Consequently, both of them are prohibited from entering the male dominated able-bodied world. What is notable in this process is that a disabled women’s space does not open up in any dimension.

In *Your Paradise* ([1976] 2004), when Director Cho returns to the island as a civilian after the failure of building a bridge to the mainland, the author implies that there is an alternative project to be launched following the political failure. The last section of the novel includes a significant theme relating to marriage as the symbolic solution of the narrative. The author relates the marriage between Haewön, a former male leper, and Miyön, a nonleper female. Director Cho encourages the two to get married. He is later visited by a reporter, Chöngt’ae, coming from the mainland who is deeply interested in writing about such an unusual marriage. Chöngt’ae creates a political rhetoric around the marriage through his writing. However, Chöngt’ae finds out that the nonleper status of the bride is forged by Cho who intentionally hides the fact that she is a *migama*, a daughter of lepers, which would grant her the same status of lepers. This information is unknown to the husband-to-be. The author says, “Even to this day, he thinks that Miyön is a normal healthy person, unaware that her parents were lepers” (Trans. Lee and Tangherlini, 2004, p. 502).

The director told Chōngt'ae that he and Miyōn had agreed to keep her past a secret in order for Haewōn to overcome his belief that only patients were able to live together. It was necessary if he was to gain more self-confidence... "...Please let Haewōn and the islanders think this marriage is between a former patient and a non-patient" (2004, p. 503).

The marriage becomes an evident cultural rehabilitation tool for the man as shown in the dialogue. Cho aims to change Haewōn's internalized leper identity through his marriage to a woman who belongs to the dominant group. Cho practices the speech before the ceremony on the wedding day. He reveals his political intention to use the marriage to thwart his failed geographical and material unification project. Instead of his failed project of territorial connection through the reclamation, Cho tries to find a symbolic integration across the remaining divide.

Looking at this situation, we might come to the conclusion that a union of hearts is much more important than the material connection of muddy embankments. In that sense, the marriage of Yun Haewōn and Yi Miyōn is a meaningful union of two people from two very different stations in life. The embankments, which were built by rock and soil and only exist as physical entities, are only today being truly connected before our eyes. (2004, 508)

The author Yi Ch'ōngjun articulates, thirty years after the novel's publication, that Sangguk, who overhears the monologue speech, is the figure who challenges and suspects the integrity of Cho in terms of his ambition (Wu, 2003, p. 271). The fact that the speech is never heard in the wedding ceremony, because Cho is so involved in his speech that he misses the wedding, signifies that Cho's political intention to compensate for the historical injustice of taking away the reclaimed land never comes true. The author says in the interview, "I intended to distrust and suspect the character with political belief. That's why I ended the novel with the speech. There is no more political person than a speech maker" (Wu 271). The interviewer, Wu Ch'anje, asks Yi if he wanted to depict Miyōn as a "pure healthy person." Yi responds that he would have done so if he were an activist not a novelist with critical eyes. He believed that the marriage between a leper and a healthy person was too naïve, too romantic, and too surreal a conclusion considering the social situation of the times. The author also continued that he wanted to be on the side of lepers, not on the side of a ruler, no matter how noble the ruler's intentions and goals because real paradise cannot possibly be based on segregation.

One key critique of the novel cautions against dictatorships, implying that true paradise cannot be built by one person's sovereignty and power, however humane and well planned; another focuses on the possibility of altruistic intentions not swayed by the corruption of power. However, critics did not see Sangguk's role as the author's disclaimer of the politicization of the forged marriage as the symbolic solution of segregation between the lepers and the personnel at the hospital, between the island and the peninsula, and furthermore between lepers and nonlepers. Marriage is a disguised integration with political overtones.

Although the author of the novel intended to reveal the problematic nature of this arrangement, it was nevertheless appropriated by the television documentary, *Ah! Sorokdo*, without challenging the normality of marriage, which is constructed by excluding disabled people while reinforcing unequal gender relations. The documentary abruptly suggests that such a marriage would cure the historical trauma in the collective memory of *Hansenin*. This award-winning documentary engages in the cultural rehabilitation of the image of people with leprosy in a gendered form. Marriages between disabled men and nondisabled women became a symbolic bridge between the segregated space of "lepers" and the "healthy": one that could reunite the nation. Such representational efforts at cultural rehabilitation ultimately reinforce the

normative power of heterosexual marriage and leave disabled women's experience out of the picture all together.

Conclusion: Hansen's Disease in the Twenty-First Century.

The total number of people institutionalized in leprosariums and leprosy hospitals has decreased since the 1963 amendment to the Contagious Disease Prevention Law. 735 *Hansenins* are living in the institutions in 2005 (Y. Pyön et al 2005). However, until 22 October 2002, Sorokdo National Hospital maintained an internal regulation, that prohibited marriage unless the infected person was sterilized. *Hansenins* report many occasions in which they were not allowed to enter restaurants, hospitals, or use public transportation. Similarly, in Japan, in spite of the radical advancement of legal compensation, discrimination continued. For example, in 2003, Kurokawa Onsen Hotel in Kumamoto refused to allow twenty-two residents of a nearby sanitarium taking part in the ritual of soaking in steaming tubs of spring water to stay overnight (McCurry, 2004, p. 544).

While narrative analyses show the process of how the family was gradually constructed as an uninhabitable space because of the creation of institutions by hygienic police systems, contemporary activism resorts to moving people—who have been deprived of family and reproduction—into creating heterosexual families. The political formulation of marriage between disabled males and nondisabled females exemplified in works such as *Ah! Sorokdo*, shows a different affirmation of the cultural order. However, these alternative relations also depend on affirming a patriarchal gendered configuration as a way to compensate for continued segregation and to culturally rehabilitate stigmatized people. This becomes problematic when it forwards the gender of disability and disease as male and reinforces unions with nondisabled females as the only symbolic gateway to illusionary integration.

In 2003, a qualitative research project by Eriko Sase, Masamine Jimba, and Susumu Wakai (2004) on why disabled Koreans still stay in leprosariums indicates, "Most people diagnosed with leprosy are still disconnected from their families and society even after being cured and the abolishment of the isolation policy in 1963" (2004, p. 1396). From this account, it is evident that a long history of segregation cannot be fixed by sudden intervention of relocating them without their own agency in planning of transition. Subsequently, it is easy to ignore that the current lives of people either in the institutions, settlement villages, or in the communities form various kinds of familial relations. Making marriage between male *Hansenin* and a nondisabled woman a symbol of integration is limited in its attempt to erase the stigma of unmarriageability. The symbolized marriage clears the suspicion of contagiousness, thus leaving questions about people with contagious disease and their endangered rights.

The history and narratives of Hansen's Disease dramatically reveal the making of the family as a nondisabled unit of society during modernization. In this, public policy infiltrated the family while providing a faulty problematization of disabled people and forwarding a solution of institutionalization as inevitable, effectively preventative, and naturalizing their erasure from the public domain. We have witnessed the growing visibility of resistance and pluralized activisms among minorities in Korea. Activism focuses on revealing and reconstructing the humanity of marginalized people and their human rights. In the care of Hansen's Disease, cultural rehabilitation mainly occurs by enforcing marriage, which problematically does not include female *Hansenin* in the representation.

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