Living with Ambivalence

The Experiences of Japanese Hansen’s Disease Survivors and their Families in the Era of Reconciliation
Background

• The segregation policy in Japan 1907-1996

Sanatoria (as of 2013)

13 National
1 Private
The feelings of the survivors

• We are perpetrators rather than victims.

‘…… being a Hansen’s disease patient is shameful because I myself was the cause of prejudice and discriminations’

Because ......
Survivors  →  their families

From the viewpoints of survivors, they think

they ‘damaged’ their relationships with their families

Because of the segregation policy,
- their houses were disinfected
- they were separated from and could not support their families
- they lost their reproductive functions

Because of the stigma of the illness,
- families were discriminated against by others
- families were excluded by community members
- family members committed suicide
- family members were forced to get divorced  and so on.
The era of reconciliation

- 1996  the abolishment of the Leprosy Prevention Law
- 2001  the court decreed the law unconstitutional
- 2001  compensation given to survivors
- 2008  the Law on Promotion of Issues Related to Hansen’s Disease

→  the legal and institutional reconciliation process had begun
Survivors recognized that they suffered because of the segregation policy of the Japanese government.

\[ \Rightarrow \text{VICTIMS} \]

\[ \therefore \text{they externalized the cause of their sufferings from themselves to the government, especially through the process of the lawsuit (1998-2001)} \]
The result of the segregation policy revealed after the reconciliation process.
The legal and institutional reconciliation has begun.
The social reconciliation

Institutional → social: especially to their family

↓

The social workers in sanatoria work on:

• making notarial deed wills
• financial management support
• counselling for the relationships between the survivors and their family
• procedures when the survivors die, and so on
A few survivors can claim their family ties have been restored, though they want to continue to improve their relationships with their families.

They have very complicated feelings when reflecting on their past experiences.

Furthermore, they know what their families did.
Families → survivors

Because of the stigma of the illness,
- families excluded the survivors from family events:
  e.g. - did not tell them when a parent died
        - refused to contact = silence
        - moved without sharing their new address
        - did not come to see the survivors
        - deleted survivors’ records from their family registries
The narratives of a survivor’s son

• “Frankly, it was an emotional support to me that my father was alive, but at the same time, because my father was alive I was haunted by how shameful it would be if his identity was exposed.”
The narratives of a survivor’s brother

• “I considered my sister’s intent to go out of the sanatorium as a survivor reintegrated into society against the height of prejudice and discrimination in society, but there was nothing I could do about it.”

• He could not accept his sister’s intent immediately, in spite of the era of reconciliation that is taking place in the legal realms.
The narratives of a survivor’s brother

• This family member, though he was willing to speak as a panelist in a symposium on Hansen’s Disease, wore sunglasses.

• ‘24 hours a day, 365 days a year, I am terrified of the shadow I cannot see.’

The shadow he refers to is the discrimination faced by families of survivors when it is discovered a family member was treated for Hansen’s Disease.
Problems still remain

- Survivors and their families
  They continue to live between the feeling of acceptance and rejection towards each other.

- Problems of our own
  How do we face the survivors and their families?
  We have to raise awareness of the discriminative viewpoints we ourselves hold.
Conclusions

• The experiences of survivors and their families are still problematic.
• It is a mistake to believe that the problem of Hansen’s Disease has been solved in Japan.
• The reason why the survivors’ families cannot accept survivors is the existence of severe stigma in general society.
• We have to generate people who can be supportive neighbors for the survivors and their families.
Thank you for your kind attention