

1. Thank you for attending the workshop today. Due to the time difference, the event is held late in the evening in Japan time, but we appreciate you taking the time to participate despite your busy schedules. In Fernando's opening remarks, he introduced our international project and explained the purpose of the workshop. In my presentation, I will share my approach with you, explain the background of the research, and talk about the results we have obtained so far and the direction this research is aiming for. The title of my presentation is "Perceptions of interpersonal relationships among people with locked-in syndrome."
2. First, the background and the purpose of the study. We aim to understand the lived experiences of people with locked-in syndrome in a qualitative way, using the first-person narratives of people with locked-in syndrome as the most important primary source. In particular, we would like to focus on and analyze the perception of relationships among people with locked-in syndrome, who are unable to avoid building close physical and psychological relationships with others in their daily lives due to their total paralysis. What kind of people are referred to as having locked-in syndrome? I think many people are unfamiliar with the term, so I will explain it in the next slide.
3. Locked-in syndrome refers to people who cannot move their arms, legs, or mouth, and cannot speak. They may have a tracheotomy and be put on an artificial ventilator, or a gastrostomy tube to eat. Their eyes, ears, senses, consciousness, and intellectual abilities are usually preserved, so they communicate with others through blinking and eye movements. There are two main causes of locked-in syndrome: neurodegenerative diseases such as amyotrophic lateral sclerosis (ALS) and cerebrovascular disease. In my presentation, I will report on a survey of people with locked-in syndrome mostly because of advanced ALS.
4. Next is the method. The subjects of the online survey were people with locked-in syndrome. Participants were recruited using snowball sampling on social media such as Facebook, and 18 people responded. Most of the locked-in syndrome subjects in this study had neurodegenerative diseases (ALS), with one patient suffering from Guillain-Barré syndrome and two suffering from head trauma. Data analysis consisted of 47 questions about their experiences and 50 items of personal data. A qualitative descriptive analysis was conducted on the responses to the open-ended questions.
5. The subjects' attributes are as follows. They were relatively young, ranging in age from 30 to 63 years old, with 14 men and 4 women. In terms of classification of locked-in syndrome, 10 had classic LIS, in which only the upper cranial nerve area was preserved, and 7 had incomplete LIS, in which other parts of the body were also mobile. LIS had cerebrovascular causes in 2 patients, and non-cerebrovascular causes in the rest. Of these, 15 patients had ALS and 1 had Guillain-Barré syndrome.
6. There are five questions regarding the interpersonal perceptions of people with locked-in syndrome .
  - Q.1 What are the most important things in your life now?
  - Q.2 What has helped you the most in living with LIS?
  - Q.3 If and how have your relationships changed after LIS?
  - Q.4 Do you think there are differences between care by a family member or someone close to you and care by others?
7. The first question was: What is the most important thing in your life now? The most

common answer was " Everyday life as usual " at 28%. 24% said that family was important, and 16% said that social relationships were important. More than half of the respondents, 56%, mentioned interpersonal matters in their lives.

8. The second question was, " What has helped you the most in living with LIS?" What impressed me here was the way the respondents' used words. For example, 31% answered that **the presence of a helper, a trusted person, or a caregiver** was important. 19% answered that support from people around them, family, or supporters,

and 13% answered that relationships with friends, caregivers, family, and supporters were important. For example, if someone's presence is helpful, it may be assumed that there is a strong trust that the person will help if they are there. If someone's support is helpful, I imagine that the person is in a position to decide for themselves whether or not to provide support. Also, if it is expressed that a relationship with someone is helpful, there may be a possibility that that person will not help you depending on that relationship. And it can be understood that the s Visiting Care for Persons with Severe Disabilities plays an important role as a mechanism for establishing relationships with support providers and ensuring the presence of trusted health professionals.

9. The next question was, "How have your relationships with people close to you changed since you developed locked-in syndrome?" 24%, or about a quarter, answered that they hadn't changed much. The next most common answer was that the relationship had become more intense. "All that's left is my family." "Family is now more important to me than before. I don't see the friends I had before I got the disease." "I have grown become apart from friends who look at me with pity."
10. "Compared to before, my love for my wife, children, and mother has been rebuilt and we have built closer relationships. ( ... ) On the other hand, my relationships with friends and former colleagues ( ... ) tend to be weak. I think this **is due to the difficulty of communication as well as excessive consideration for severely disabled people, including people with LIS (Locked-In Syndrome).**" From what we've seen so far, it may seem at first glance that family becomes more important than friends after developing LIS. However, once this excessive consideration was overcome, ... respondents said, "Friends and acquaintances started coming to see me" and "All my friends have become caregivers," we learned that it is possible to build new relationships with friends and acquaintances.
11. The last question. When asked if there are differences between care by a family member or someone close to you and care by others, 72% of respondents answered that there is a difference. When asked further whether they would prefer to be cared for by family members, 77% of those who answered that there is a difference, 67% of those who answered that there is no difference, and 82% of all respondents answered that they would prefer not to be cared for by family members.
12. When we asked why they did not want to be cared for by family members, the most common answer was not wanting to burden their family, with half of the respondents giving this answer. It seemed that many of the opinions were based on real experiences, such as being irritated and mentally exhausted through the experience of caring for family members, becoming emotional, getting into arguments, and feeling more comfortable with someone else. On the other hand, there were two people who wanted to be cared for by family members, and the reasons given were "...I would be able to have time in a completely private room," and "There are times, such as major earthquakes or the spread of infectious diseases, when it is difficult to have a helper accompany me."
13. This is the last slide, but rather than showing a conclusion, I would like to end by sharing with you the challenges that have become apparent through the narratives of people with locked-in syndrome. First, what are the conditions for a system that supports the daily life of people with LIS including carers to be established as a form of life, a unit? To answer this question, we need to clarify how the boundaries of the individuals are, how they communicate with each other, and what kind of interactions the relationships that connect them bring about. We realized that we must discuss the legislation, and its application based on this understanding. This interdisciplinary research has only just begun, and I hope to explore this new field with you all.

That's all. Thank you for your attention.

