

1. Hello everyone. I'm Yukiko Himeno from Sakura International, Japan. It is my great pleasure to give a talk in this session as a representative of our research team. Today, I would like to present our study on the experience of persons with locked-in syndrome.
2. Our research team consists of 3 major institutions. Sakura International is a peer support organization offering home care service for people with intractable disease such as ALS in Japan. Dr. Yumiko Kawaguchi is the present vice chairman of the organization and received her Ph.D degree from Ritsumeikan University in 2013. Prof. Tatsuya Mima, a Medical Sociologist, was a vice chair in her dissertation committee. I, Yukiko Himeno, am a physiologist collaborating with them and other young researchers at Ritsumeikan University. Prof. Mima and I visited Rovira i Virgili University (URV), in Tarragona, Spain in 2019 where Prof. Fernando Vidal and Dr. Lina Masana work. Prof. Vidal is the principal researcher for the research project "Anthropology and Phenomenology of the Locked-in Syndrome." We all collaborate in the framework of this project.
3. The aim of this study is to understand the experience of persons with locked-in syndrome, whom we call PwLIS, to understand their "happiness" in a qualitative way. The uniqueness of our study is the approach taken from the academic side and the involvement of people living with the disease. We investigate the individual and social impact of LIS, as well as the needs and expectations of PwLIS. We study their experience on the basis of what they tell us about it, as well as their comments and statements. Learning more about PwLIS will help us to figure out the social and cultural structure that underlies the living experience of PwLIS and identify aspects that might have been overlooked in the care of PwLIS, to make recommendations for professional caregivers and service providers, and to raise public awareness.
4. In February and March, this year, we conducted a survey on the PwLIS. We prepared a webpage and sent out a link to this webpage on Facebook in groups with many members who have ALS. Lina and Fernando, who conduct the research in Europe, carried out the survey using the same questionnaire in France and Spain. They prepared a short greeting video message to welcome volunteers to the survey.
5. In the survey, the respondents used various kinds of communication tools. 72.2% used line-of sight input to manipulate their computers, tablets or smartphones, like the French DJ who created music using eye navigation technology for the closing ceremony of the Tokyo Paralympics this year. 61.1% used lip reading, like Jean Dominique Bauby in the

film, *The diving bell and the butterfly*. 55.6% used a transparent alphabet board written in Japanese, and others included means like Dr. Tenbata moving his trunk to communicate.

6. In Japan, the term “LIS, locked-in syndrome”, is not so familiar, especially to PwLIS from motor neuron disease such as ALS. Indeed, a half of the respondents answered “No” to the question “do you think your physical condition is LIS?” although they all met the clinical criteria for LIS. Then, we asked what they thought about “LIS” having become the official medical term. A significant proportion 80 % of the respondents who knew the term “LIS” but did not think it applied to their own physical condition expressed misgivings and criticized the term, saying, for example:

“It is laziness, ignorance and arrogance on the part of healthcare professionals.” “I think it's inappropriate. I think being locked-in means there are physical and mental problems, but what is it that is being referred to as being locked-in?” “It is a dangerous expression that can lead to the negative misconception that all ALS patients end up with LIS.” “If the people around me can respond to something coming from my body that isn't language, I will not be locked-in.”

These responses showed that respondents with ALS who did not think their own physical condition was LIS made a point of distinguishing their own condition from LIS on the basis of the assertion that they were not actually “locked in.” In their view, being “locked in” would not occur as long as healthcare professionals and the people around them responded properly.

7. On 28th March this year, we held an International On-line Workshop titled “Locked-in state as everyday life.” In this workshop, we gave talks about the outcomes of the survey, which will be published in the near future; PwLIS also made presentations and commented on our research.
8. Mr. Takano prepared his PowerPoint slides with synthesized voice and manipulated his computer by his line-sight input computer. He made a presentation based on his participation in the study; he answered “Yes” to the question “do you know the name LIS?,” answered “No” to the question “do you think that your physical condition is LIS?,” and raised the crucial question “am I locked-in?”
9. Mr. Onda sent a copy of his comment to us beforehand to read instead in the session, but he participated in the online session on live; the caregiver said “excuse me, but Mr. Onda

wants to use lip reading. Shall I go ahead?" These two PwLIS were the invited speakers in the roundtable session.

10. Mr. Okabe also prepared a manuscript beforehand to make a comment in the roundtable session to emphasize the importance of communication for PwLIS. His caregiver read aloud on behalf of him in the discussion.

11. In the roundtable discussion, there were three non-disabled people from academic and activists in addition to the two LIS invited speakers. In that connection, we can make the following observations:

- In terms of using Information and Communication Technology, no special consideration was necessary for the PwLIS.
- On the other hand, it was necessary to secure a certain amount of time for the real-time voice remarks of PwLIS, such as the helper's lip-reading using the spoken letters or the alphabet board, the line-of-sight input, and the switch operation.
- However, in situations where strict real-time performance was not required and the time table was adequate, it was possible to proceed smoothly, and online social participation of PwLIS seems to have been realized.
- Unexpectedly, inclusion of PwLIS in the society seems to have been partially furthered as the result of avoiding 3Cs (Crowded places, Close contact, Confined spaces) in the era of the COVID-19 pandemic.

"Working from home has become commonplace and it helps me a lot"

"I realized equality because I do not meet directly"

For further contents of the workshop, access our YouTube content from this code.

12. These are the take-home notes from my presentation.

- In Japan, the negative connotation of the words "locked-in," partly at least due to the fact that PwLIS can communicate, led these persons to reject or question the medical term "LIS".
- Although the results reflect only information-rich PwLIS who can use social network system as a communication tool on a daily basis, the results suggest that PwLIS would be truly "locked-in" only if they were totally unable to communicate.
- Therefore, it may be beneficial to offer devices as public support to facilitate communication between PwLIS, their caregivers, and the larger social environment.

This is the short movie of Ms. Misao Hashimoto having communication through her specialized caregiver. If you're a PwLIS and interested in sharing your experience for the realization of an inclusive society, please join us. If you're a researcher or healthcare professional and interested in our quest to better understand the experience of PwLIS and the conditions for a happy life, please join us. Thank you very much for your attention.