

PERCEPTIONS OF THE RELATIONSHIP DESCRIBED IN THE NARRATIVES BY PERSONS WITH LOCKED-IN SYNDROME

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THE AIM OF THE STUDY

- To understand lived experiences of the persons with locked-in syndrome (PwLIS) in a qualitative way.
- Analyze perceptions of the interpersonal relationship of PwLIS as they inevitably develop close relationships with others.

“What is locked-in syndrome (LIS)?”

PWLIS: PERSONS WITH LOCKED-IN SYNDROME

- They neither move their limbs nor mouth and cannot speak.
- In some cases, they may use a respirator or need a gastric fistula for nutritional support.
- Their audiovisual or sensory senses, consciousness and intellectual ability are usually maintained.
- They can communicate by blinks or eye movements.
- There are major two types of origins; neurodegenerative disease (such as amyotrophic lateral sclerosis, ALS) and cerebrovascular event.

MATERIALS AND METHODS

- Subjects of the survey
 - We conducted an online questionnaire from February 3rd to March 7th, 2021. We recruited participants using the snowball sampling method on social media (amyotrophic lateral sclerosis (ALS) Facebook groups, etc.). Eighteen out of twenty thought they met the criteria and answered the questionnaire.
 - Most of the LIS subjects in the present study were caused by neurodegenerative diseases (ALS), and a few were from Guillain-Barré syndrome and head trauma.
- Data analysis

There were 47 questions; some were Yes/No or multiple-choice questions, but most of them were open-ended questions related to their experience. 50 other questions were asked to obtain demographic data. (Ethics Review Committee for Research Involving Human Subjects at Ritsumeikan University [Approval number: Kinugasa-Human-2020-34]) Qualitative analyses were conducted on the responses to the open-ended questions.

RESULTS

Table 1 Attributes of the Participants

		Japan(n=18)
Age (years old)	Range	30–63
	Answered	17
	Did not answer	1
Gender	Male	14
	Female	4
Locked-in syndrome (LIS) category	Classical	10
	Incomplete	7
	Complete	0
	Recovered	1
Cause of LIS	Vascular	2
	Non-vascular	16

FIVE QUESTIONS ABOUT THE PERSPECTIVES OF THE INTERPERSONAL RELATIONSHIP OF PWLIS

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 with people close to you 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?

Q. 1 WHAT ARE THE MOST IMPORTANT THINGS IN YOUR LIFE NOW?

1. Everyday life as usual (5/18, 28%)

2. Family (4/18, 24%)

3. Social relationship (3/18, 16%)

To live / Not to die

4. Keep or increase the number of carers (2/18, 11%)

Keep challenging and live with no regrets

Work

5. Enjoy (1/18, 6%)

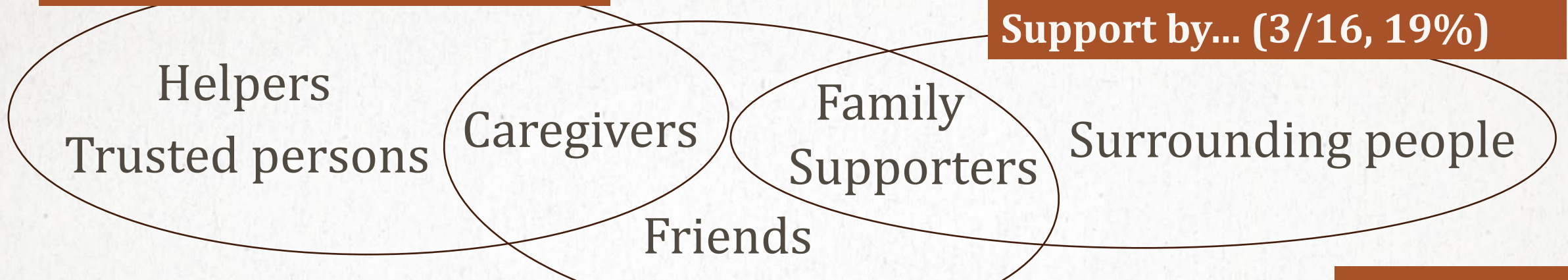
Time with privacy

➤ More than a half of the respondents (10/18, 56%) referred to the **interpersonal matters** in their lives.

Q. 2 WHAT HAS HELPED YOU THE MOST IN LIVING WITH LIS?

Existence of... (5/16, 31%)

Support by... (3/16, 19%)



Relationship with... (2/16, 13%)

(2/16, 13%)

Visiting Care for Persons with Severe Disabilities

(1/16, 6%)

Sound, Music

(1/16, 6%)

Texts written by myself

(1/16, 6%)

Tact

Q. 3 IF AND HOW HAVE YOUR RELATIONSHIPS WITH PEOPLE CLOSE TO YOU CHANGED AFTER LIS?

- Not much has changed (4/17, 24%)
- Became more intense (3/17, 18%)
- “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 disease.”
- “I have become apart from friends who look at me with pity.”

- “Compared to the past, the family love between my wife, children, and mother has been rebuilt and is more intense. ... On the other hand, the relationship with friends and former colleagues ... tends to become weak. I think this is due to the difficulty of communication as well as excessive consideration for people with severe disabilities, including LIS.”

➤ At first glance, it appeared that they came to think family became more important than friends after LIS.

→ However, once the excessive consideration is overcome...

- “Friends and acquaintances started coming to see me”
- “All friends became caregivers”

Q. 4-1 DO YOU THINK THERE ARE DIFFERENCES BETWEEN CARE BY A FAMILY MEMBER OR SOMEONE CLOSE TO YOU AND CARE BY OTHERS?

NO: 17%

YES: 72%

Both YES or both NO : 11%

Q. 4-2 WOULD YOU LIKE TO BE CARED FOR BY A FAMILY MEMBER?

33%

15%

67%

77%

50%

YES: 18%

NO: 82%

Q. 4-3 FOR WHAT REASON, YOU WOULD OR WOULD NOT LIKE TO BE CARED FOR BY A FAMILY MEMBER OR SOMEONE CLOSE TO YOU?

NO: 82%

- Reasons for NOT wanting to receive family care

Do not want to be a burden. Don't want to take away their time, effort and life (50%, 7/14)

- 'I had a lot of trouble with family care until I became independent'
- 'It's a source of quarrels and disputes.'
- 'I don't mind being taken care for occasionally, but for every day, it will be a source of mutual frustration and mental illness.'
- 'I can't help getting emotional, so it's easier for me to be cared for by someone else.'

- Reasons for wanting to receive family care

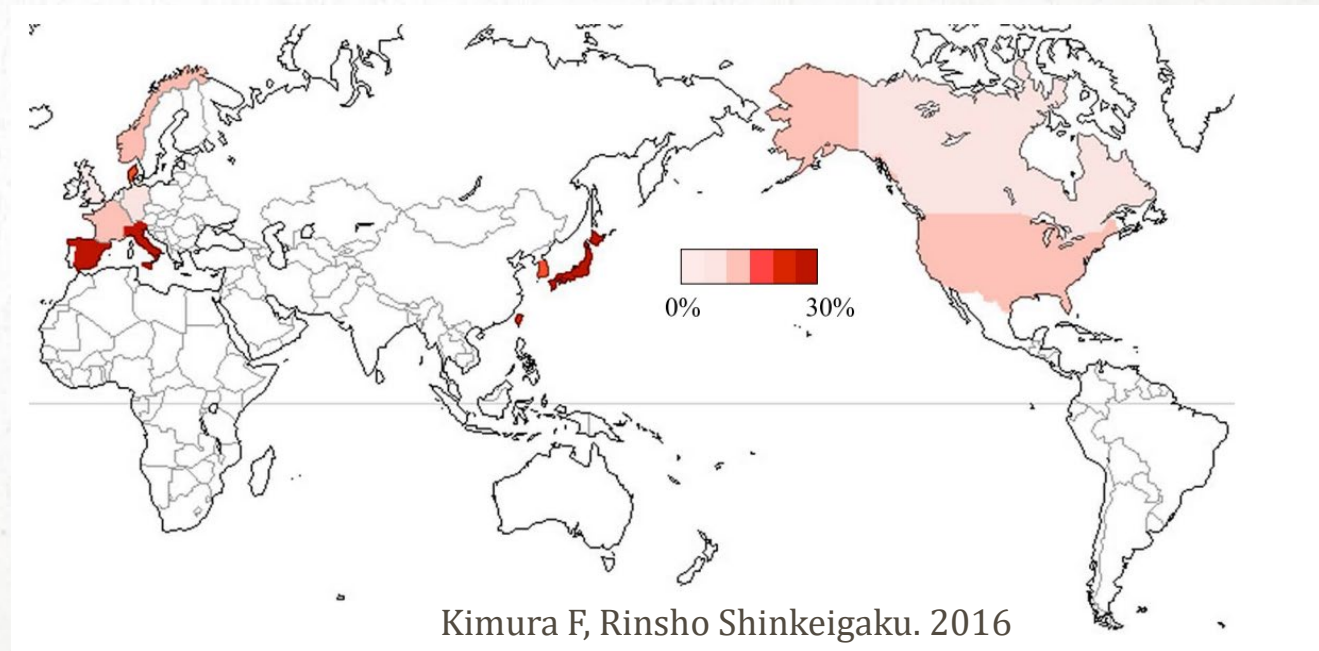
Easier to communicate (67%, 2/3)

YES: 18%

- '...can get time in a fully private room.'
- '...difficult to be accompanied by a helper, e.g. in the event of an earthquake or an outbreak of infectious disease...'

CHALLENGES ON INTERPERSONAL RELATIONSHIP RAISED BY THE NARRATIVES OF PERSONS WITH LIS

- Conditions for the establishment of a system that includes carers and supports the life of people with locked-in syndrome as a unit of life.
- The nature of personal boundaries and communication
- Networking and interaction
- Legislation and operation



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