

“AM I LOCKED-IN?” ILLNESS TRAJECTORIES AND THE EXPERIENCE OF LOCKED-IN SYNDROME IN JAPAN AND EUROPE

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GENERAL GOAL: To understand the lived experience of persons with locked-in syndrome (PwLIS) in a qualitative and cross-cultural perspective.

REPORTED HERE: Do PwLIS recognize themselves in the official name of the diagnosis and in the image of PwLIS as a “mind trapped in a body”?

Methods



Japan: Open-ended on-line questionnaires. Participants were recruited using the snowball sampling method through SNS such as Facebook.



France: Testimonies by members of the French Locked-in Syndrome Association ([ALIS](#))



Spain: Testimonies by participants in the project [Anthropology and Phenomenology of the Locked-in Syndrome](#).



[Introductory movie](#)
[YouTube content of the Workshop on PwLIS](#)

Participants

		Japan(n=18)	France(11)	Spain(5)
Age (Average±SD)		47.9±9.7	52.1±10.0	61.2±11.1
	Answered	17	10	5
	No answer	1	1	0
Gender	Male	14	6	3
	Female	4	5	2
LIS category	Classical	10	2	-
	Incomplete	7	9	-
	Complete	0	0	-
	Recovered	1	0	1
Cause of LIS	Vascular	2	9	-
	Non-vascular	16	2	-

Recognition of the term “locked-in syndrome (LIS)” in Japan

		Vascular(n=2)	Non-vascular(n=16)
Did you know the name “locked-in syndrome (LIS)”?	Yes	2	10
	No	0	5
	No answer	0	1
Do you think your physical condition is LIS?	Yes	2	5
	No	0	9
	No answer	0	2
What do you think about the official name of the diagnosis (Locked-In Syndrome)?		(n=2)	(n=15)
	No objection	2	4
	Discomfort	0	10
	No answer	0	1

CONCLUSIONS

- In contrast to European PwLIS (due to stroke), Japanese PwLIS (due to ALS) tend not to recognize themselves as “locked-in syndrome.”
- European PwLIS considered “LIS” as an adequate name for their condition, and recognized themselves more in the image of PwLIS as “minds trapped in a body.”
- Although we could not engage in cross-cultural comparison, the divergence corresponded to a crucial difference in participants’ illness trajectories: sudden vs gradual entrance in the locked-in state, respectively for PwLIS due to stroke and PwLIS due to ALS.

Funding: The Society-with-Coronavirus Research Program of Ritsumeikan University and JSPS KAKENHI JP19K21620 to T.M. Grant PID2019-106723GB-I00 of the Spanish Ministry of Science and Innovation to F.V.

Some examples

“What do you think about the official name of the diagnosis (Locked-In Syndrome)?”



Communication using mouth alphabet.

- I think it’s good to be defined [by medical professionals] as a case. However, I also want [them] to spread the fact that it is possible to keep persons in an unlocked situation by using technology.
- I feel that this name was given thinking only about the negative aspects. But if I were healthy, I wouldn’t feel uncomfortable about this name.

- It is a dangerous expression that can lead to the negative misconception that all ALS patients become LIS.
- It is laziness, ignorance and arrogance on the part of healthcare professionals.

- I don't care, it's just a name
- Corresponds well to the difficulties
- Defines reality fairly well.
- It sums up the reality of what we go through.
- It's a good name, even if having a means of communication means you're not so locked in...
- This name is adapted to the disability, but only for the first few years.



“Sometimes people with LIS are described as ‘a mind trapped in a body.’ What do you think about it? Why?”



- Even if I can’t speak, I can communicate my intentions through mouth alphabet [a system akin to the alphabet board used in combination with blinking] and communication devices, so I don’t think my mind is trapped in my body.
- 100% accurate. The moment I have the communication software on the PC, I escape from captivity.
- [agree] because having a perfect head and a paralyzed body makes you feel like that, like a caged lion.
- [during the first four months, was “a prisoner” of his body] but from the moment I started to move (minimally) my toes, I felt that everything was going to change. Little by little, I stopped being a prisoner.



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