

D1

Hello everyone. Good morning or good evening, depending on the time zone from which you are joining this workshop.

I would like to begin by thanking Yukiko Himeno and Fernando Vidal for the invitation, and especially to Yukiko for her work on translating the texts, as well as for her generosity in providing feedback for this presentation, alongside Fernando.

My name is Lucía Denegri Méndez, I am currently in the fourth year of my doctoral research, which is part of the project previously presented by Fernando.

D2

I would like to briefly contextualize the subject of my doctoral research before presenting the specific topic I have chosen for this workshop. This topic arises from the ongoing analysis I am conducting and, in my opinion, is an important aspect of the experience of individuals with Locked-in Syndrome (LIS). Please note that this is still a work in progress so in advance I thank you for your time and hope that your valuable comments will help me illuminate my future work.

The main objective of my doctoral thesis is to understand the experience of the body and its relationship to the personal or subjective expression of individuals with LIS from a first-person perspective. In other words, as we already know, since locked-in syndrome severely affects the capacity for articulate speech and motor control, my aim is to explore how these physical and bodily changes impact the way individuals perceive themselves and express their subjectivity.

To achieve this, I primarily analyze the testimonies and narratives published by people who have experienced LIS, mainly as a result from a cerebrovascular accident, a stroke. I analyze accounts of individuals affected in Spain, France, the United States, and Canada.

D3

In terms of "how" I am conducting my research, I use a phenomenological approach.

- Lived experience and first-person perspective is crucial for balancing and emphasizing the expertise of those living with the condition on a day-to-day basis. This helps us better understand what is truly at stake for those affected. Since much remains to be explored in this área.
- This aims to broaden our understanding of how we can live in and experience our bodies and ourselves. Life with LIS represents another form of being in the world, challenging and expanding the typically unidirectional thinking about the individual that dominates the Western imaginary.

D4

I also focus mainly on published narratives because:

- There is a considerable amount of them published that haven't been systematically compared yet. So it is important to recognize and value the amount of work and effort, physical and emotional put in them, and to examine it with depth and care. By comparing them, we can uncover both similarities and unique aspects of these experiences.
- Also, as I said before, they contain really rich descriptions of the process of living with LIS in terms of the day to day living, care relationships, material resources available, daily practices involved, and also personal reflections.

Of course, we have to take into account that:

- In the case of LIS, the narratives belong to a subgroup that had the desire, possibility, and material resources to produce them, unlike a still "silent majority" (Vidal, 2020). Therefore, their value lies not in making generalizations but in being able to read them for the richness of their details, their nuances, and the contextualization of the experiences.

For my research I work with a selection of 12 cases from the previously mentioned countries, all of individuals who entered a LIS as a result of a stroke. The selection of the cases has been intentional selecting the ones that provide the most detailed descriptions. I have selected a heterogeneous sample, reflecting variations in factors such as age, gender, class, and other relevant aspects.

D5

Also, an important aspect of these narratives that I would like to highlight is that, while they recount the individual experiences of those affected, most have been co-written with others. This highlights the significance of the interpersonal dimension in their creation.

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Now, let's move on to the topic of this presentation. Today, I would like to focus on an important aspect: the concept of personal continuity in LIS, which is prevalent in many narratives. By personal continuity, I mean the need expressed in these narratives to affirm that one "remains oneself" or is still the same person as before the physical and bodily changes experienced. This theme is evident not only in the accounts of individuals with LIS but also in the perspectives of those around them.

Given our limited time, I will illustrate this aspect through a specific case: that of Judy Mozerky. I chose her story because her book reflects not only her singular perspective but also incorporates the testimonies of her parents and other family members, friends, caregivers, medical professionals, social worker and other close to her. I hope to demonstrate that while personal continuity may initially seem like an

issue concerning the affected individual, in the case of LIS, is more effectively addressed in the context of relationships with others, persons and objects.

Judy's story takes place in Ottawa, Canada, where on June 14, 1990, at the age of 19 and as a junior at Cornell University studying psychology, she suddenly developed a severe headache. Although she had previously experienced intense migraines with neurological symptoms, nothing compared to the sensation of that day.

Within minutes, Judy became unable to walk. In the days that followed, she lapsed in and out of consciousness, eventually awakening to find she had lost the ability to move and speak. Fortunately, her bodily sensations returned, along with her sense of smell, taste, and cognitive abilities.

By the time she published her book in 1996, Judy was living in her own apartment and had regained some voluntary neck movements, but primarily communicated by blinking. This method was crucial for writing her story. In her book, Judy and others recount her experience with locked-in syndrome (LIS), raise awareness about the condition, discuss the risks of using birth control pills in individuals with migraines, and emphasize the importance of independent living, which Judy achieved after a long struggle with the support of her family.

D7

In her own words, about LIS she writes:

"Being paralyzed is very strange. I wake up every single day and notice that I can't move or speak. I don't think I'll ever get so used to being in this condition that I come to expect it. I look down at my arms and I will them to budge, but they remain still. Sometimes people think that I can't move because I don't try hard enough, but they are wrong".

D8

Let's look at how Dr. Fred Plum, who coined the term "Locked-in Syndrome," describes Judy's situation. Despite the overwhelming illness, he emphasizes that "the essential Judy has not changed." Similarly, in an account from her parents, when her condition was still unclear, they wondered, "*How much of our daughter are we going to get back?*"

In Judy's story, personal continuity is conveyed through this idea of an "essential Judy"—something fundamental about her that can either endure or be lost in the face of the drastic changes brought on by the stroke.

D9

Judy's mother recalls recognizing her daughter in those early days after the stroke through her gaze. Comparing her eyes while in the state of coma and after, Judy's eyes provided a sense of continuity. At the same time we can see how in the encounter with her Little brother Judy acknowledges the "shocking transformation" that had occurred.

As her mother explains, at that point the role of Judy's parents were to be *"her interpreters, and felt that had to be there all the time to help her"*. I quote *"How would they know what Judy liked or didn't like? We had to tell all the nurses and therapists everything about her to make her as real and vibrant to them as possible."*

So, as we can see, it is not only urgent for close relatives to establish as soon as possible that contact which makes the sense of personal continuity possible, but also to maintain it. This implies not only a particular disposition and attention toward the loved one, but also represents a "work" to ensure that this continuity is carried out through them, as Judy's parents express when they refer to themselves as Judy's "interpreters" or "ombudsman."

D10

An essential factor in this process is the role of medical technology. While life-saving, the "machines" made Judy appear "foreign" to those who knew her, amplifying the sense of change. Judy recalls a visit from a close friend: *"I could tell she was shocked by my appearance. I was surrounded by tubing, i.v. poles, and machinery. I wanted so desperately to tell Julie that although I looked decidedly foreign amidst all those needles and tubes, I was still the same Judy, her Judums"*.

Lisa, another longtime friend, describes her initial shock: *"I couldn't cognitively process the situation in front of me. The tubes and wires were so foreign. I could hardly believe this was the same person I'd known for years and had just seen a few months before."*

D11

Gabrielle, another friend, reflects on her first visit: *"We met Judy. The new Judy."* While it was difficult to recognize her physically, Gabrielle shares that her eyes were still the same—*"the same warm eyes of Judy."*

Here, we see how crucial the process of recognition is after the stroke, not just for Judy herself, but through the interactions with those who care for her, as the physical appearance change has been sudden.

D12

Another form of continuity that presents in most of the narratives, is also in Judy's account. As Judy explains, she had her room personalized, because -I quote "wanted it to reflect the real me". A former dancer, she filled her room with Cassatt and Degas posters. In this way, as in other narratives, personal items - whether clothes or objects- take on a very specific weight in the role of projecting the individual's identity into the surrounding space.

D13

So to finish this presentation, some provisional reflections and ideas that I'm still working on...

After the physical changes from the stroke, the restoration of communication becomes urgent and vital not only for basic interaction but also for maintaining a sense of personal continuity.

As both the individual with LIS and their loved ones navigate the tension between recognizing the person as "the same" and, at the same time, "different", where a feeling of disconnection between personal identity and physical appearance appears, it is an experience that is most intense in the early stages but can shift over time.

The notion of "still being oneself" is highly relational. It involves a complex network of interactions with people and objects that actively support the continuity of identity.

Especially in the early days following the stroke, much of the experience revolves around "rebuilding familiarity," not only due to physical changes but also because the medical equipment—"tubes and machines," as Judy describes—though essential for survival, can initially make the person feel foreign to themselves and others.

Personal continuity extends beyond the individual, encompassing the relationships and environment around them, making it a relational and dynamic process closer to a "practice", something that is made, than just an internal trait.

There is still a lot of work to be done as further work remains in comparing and exploring how these experiences are narrated in different personal accounts.

Gracias!

Thank you!