



International Workshop

“Still the same: personal continuity in narratives of Locked-in Syndrome”

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My research

- Understand the experience of the body and its relationship to the personal or subjective expression of individuals with LIS from a first-person perspective.
- Testimonies and narratives published by people who have experienced LIS, mainly as a result from a brainstem stroke.
- Spain, France, the United States, and Canada.

Methodology:

- First-person perspective: **Expertise of those living with the condition on a daily basis**, helping us understand "what is at stake" (Kleinman & Kleinman, 1991).
- Expand our understandings of how we can live and experience our bodies and selves.
- LIS challenges one-dimensional view of the individual that dominates Western imaginary.



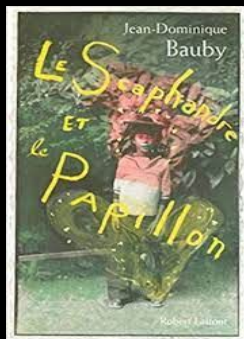
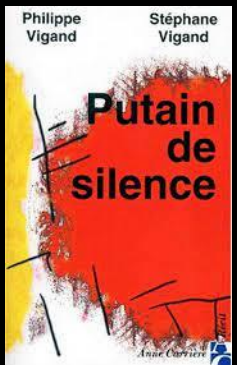
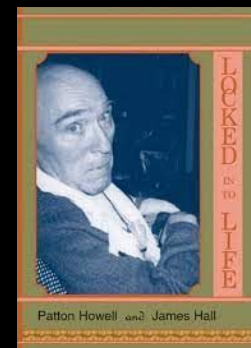
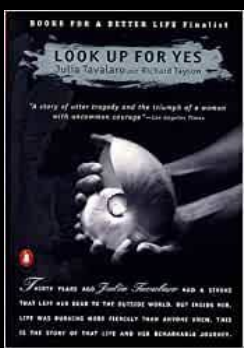
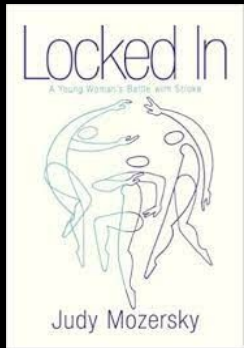
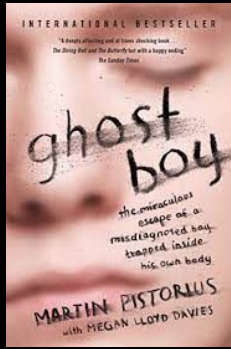
Working with the narratives:

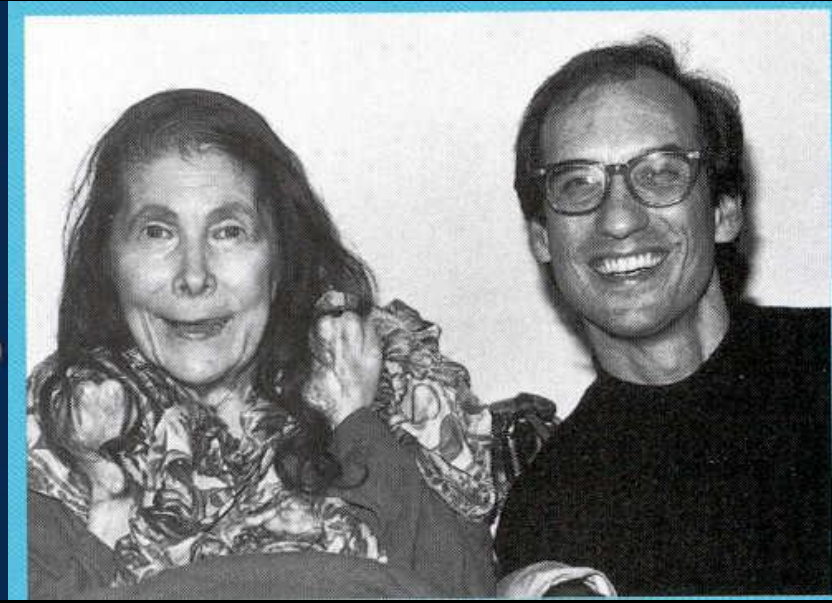
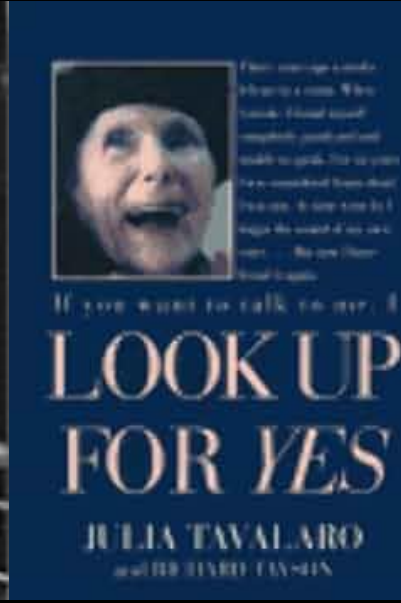
Many published accounts haven't been systematically studied and compared.

Rich descriptions of daily life with LIS, care relationships, available resources, and personal reflections.

Subgroup with the resources and opportunity to share their stories, still remains a "silent majority" (Vidal, 2020).

Sample: 12 cases; diverse and heterogenic in terms of age, gender, class, and other relevant factors.





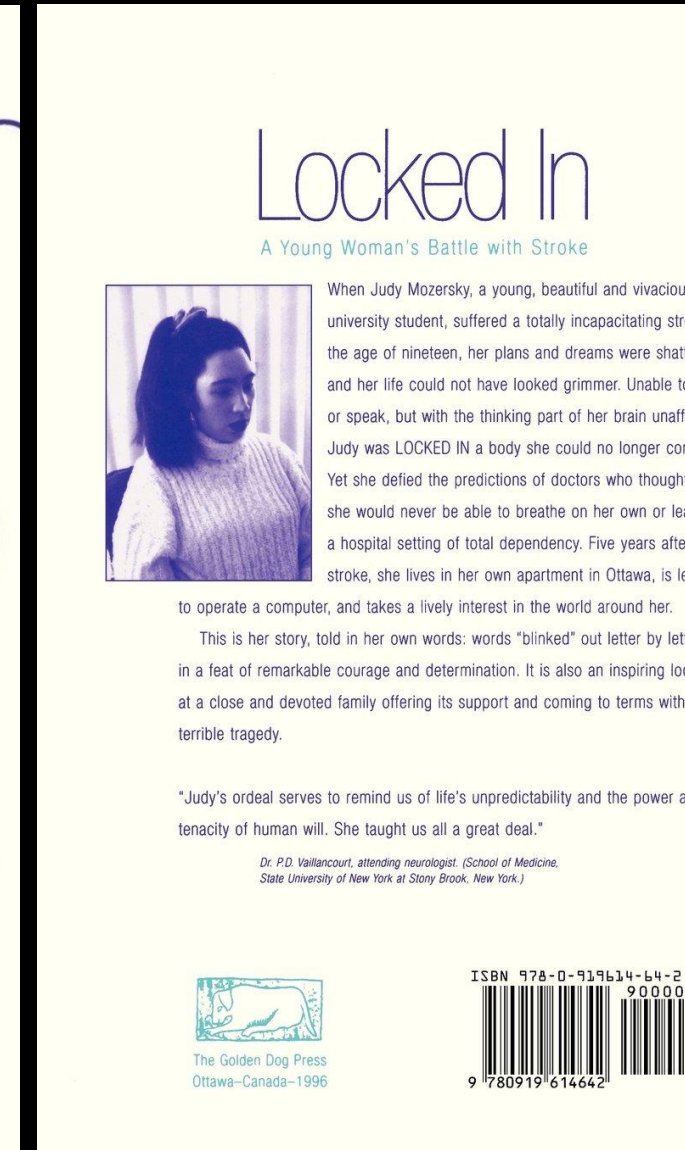
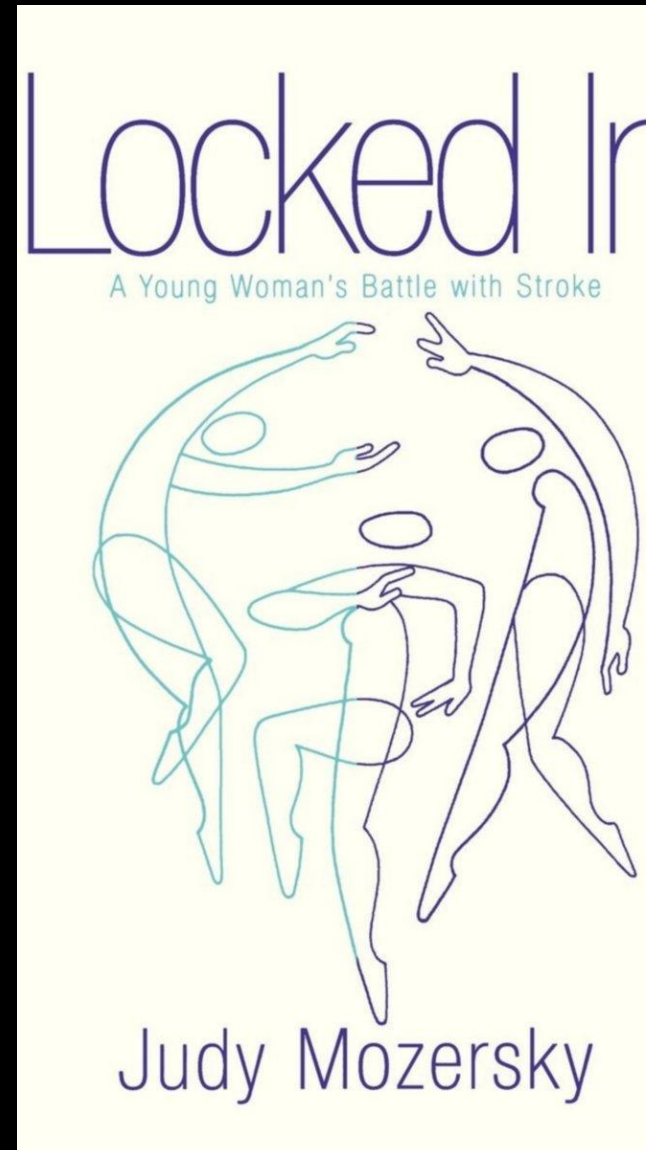
Jean Dominique Bauby y Claude Mendibil, 1996

Julia Tavalaro y Richard Tyson, 1997

(Co)autobiographical narratives

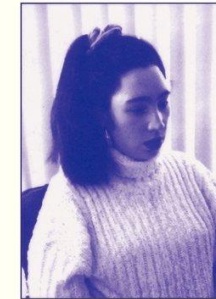
"Still the same":
Personal continuity in
locked-in syndrome

- Published in 1996, five years since Judy's stroke in June 1990.
- Blinking for writing.
- Multiple testimonies.



Locked In

A Young Woman's Battle with Stroke



When Judy Mozersky, a young, beautiful and vivacious university student, suffered a totally incapacitating stroke at the age of nineteen, her plans and dreams were shattered and her life could not have looked grimmer. Unable to move or speak, but with the thinking part of her brain unaffected, Judy was LOCKED IN a body she could no longer control. Yet she defied the predictions of doctors who thought she would never be able to breathe on her own or leave a hospital setting of total dependency. Five years after the stroke, she lives in her own apartment in Ottawa, is le

to operate a computer, and takes a lively interest in the world around her.

This is her story, told in her own words: words "blinked" out letter by letter in a feat of remarkable courage and determination. It is also an inspiring look at a close and devoted family offering its support and coming to terms with a terrible tragedy.

"Judy's ordeal serves to remind us of life's unpredictability and the power and tenacity of human will. She taught us all a great deal."

Dr. P.D. Vaillancourt, attending neurologist. (School of Medicine, State University of New York at Stony Brook, New York.)



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Judy and LIS:

•“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”.

The essential Judy

*“**Through all this siege of illness, the essential Judy has not changed.**”
(Dr. Fred Plum, doctor)*

*“We didn’t yet know exactly what was wrong, We did know that Judy was very sick, I remember Anne wondering aloud **how much of our little girl we were going to get back.**” (Judy’s father)*

Make her as real and vibrant as possible

*“When she came out of her coma on Saturday morning, her eyes suddenly looked quite different—they were **the old Judy eyes**.” (Judy’s mother)*

*“He had obviously not been adequately prepared for **the shocking transformation I had undergone**. My mother had taught David to communicate with me, but I still somehow sensed that he feared me”. (Judy on her little brother)*

*“How would they know what Judy liked and didn’t? We had to tell all the nurses and therapists everything Judy liked and liked to do. We **had to make her as real and vibrant to them as possible**.” (Judy’s mother)*

Foreign amidst all those needles and tubes

*“...she was shocked by my appearance. I was surrounded by tubing and 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.**” (Judy)*

*“**I was not cognitively able to understand the situation that presented itself to me at that moment. (...) The tubes and wires that surrounded Judy were very foreign to me. I could hardly believe that this was the same person I’d known for years.**” (Lisa T, friend)*

The same warm eyes of the new Judy

*“Entering the second floor of the hospital, we met Judy. **The new Judy**. At first glance, she was hardly recognizable physically. (...) Her long braid was tied to a neck support at the back of the wheelchair to hold her head up. **But her eyes were the same**. Though not as clear and steady as they had been in the past, they were **still the same warm eyes**”.*
(Gabrielle, friend)

Impersonal spaces and objects for personal continuity

*“I had **personalized my hospital room as much as possible. I wanted it to reflect the real me. I wanted people to see me as real and vivid. I put photographs all over. I put Cassatt and Degas posters on my ceiling and walls.**”
(Judy)*



What's at stake? Some provisional reflections...

- Restoration of communication becomes urgent and vital for basic interaction and also for maintaining a sense of personal continuity.
- Tension between recognizing the person as "the same" and "different" due to the physical changes.
- The experience of "still being oneself" is relational, involving interactions with people and objects that help sustain a sense of continuity.
- Medical technology plays a part in making the appearance "foreign": Rebuilding familiarity is key.
- Personal continuity extends beyond the individual, not as individual trait but relational and dynamic.
- Still a lot of work to be done! ☺

Muchas gracias!