

# Sexuality in people with Locked-In Syndrome (LIS)

Ana Santángelo Lázaro  
ana.santangelo@urv.cat  
Rovira i Virgili University



ESCOLA DE POSTGRAU  
i DOCTORAT  
Universitat Rovira i Virgili

# What and How

Analyze the dimension of sexuality in people with LIS and its context.

## Methodology

In-depth interviews

Observation

Qualitative questionnaires

Review of first-person narratives



# Maria and Mario

Heterosexual couple

They have been married for 25 years

He enters LIS at the age of 33

It is in an almost complete LIS

Neck movements, facial expression, index finger and thumb movements

Computer-mediated communication

Blink communication

He lives in a residence

She lives in their house

# Space

"After 9 months in hospital he came home and that was when we started with sexuality when we could stay alone [...] When he had to go into a nursing home, it became less and less frequent until today it is almost non-existent because we cannot be together" (María. Questionnaire).

"He lives in a residence where we tried it once, but the residents in the rooms next door don't come out of it, you can hear everything from one room to another and it was very uncomfortable, it was not rewarding for either of us" (Maria. Questionnaire).

"We are not well. You can hear everything" (Mario. Interview).

"More than a marriage, what currently exists is a relationship of total dependence of me on her" (Carballo, 2005, p. 72).

# Tiredness and impossibility

## Age

"Sex between us has changed because of two very important issues, age and the lack of intimacy to have sex [...] the times we travel and are together we are so tired at the end of the day that we don't even try, I imagine that age has had an influence" (María. Questionnaire).

## Physical dimension

Movements and efforts you can no longer make

## Dependency and privacy

"You've seen what it's like, I have to do the work myself" (Maria).

# Passivity-activity

"Sexual intercourse on the other hand are also quite sporadic (according to what "the specialist" told us they would be impossible), and I have always felt a kind of frustration for not being able to participate actively in them" (Carballo, 2005, p.130).

"I undervalue my sexuality because I can't move" (Mario. Interview).

"He never had erection problems, but he couldn't ejaculate, and it was important for him to be able to do so [...] I will never forget the first time he managed to ejaculate because of the happy face he made, it gave me the impression that he had taken a weight off his shoulders [...] Because he said that a man has to ejaculate" (María. Interview).

"The constitution of masculinity through bodily performance makes gender vulnerable when performance cannot be sustained, for example, as a result of physical disability" (Connell, 2003, p.86).

"Conventional patterns of masculine socialization require a bodily hexis marked by strength and power. Therefore, masculinity, like femininity, requires capacity: a body capable of normatively performing certain attitudes and practices that are themselves producers of masculinity" (Santesmases, 2023, p. 39).

# Provisional Conclusions from a Case Study

Difficulties in talking or discussing sexual desires.

Lack of information from health professionals.

The *genitalocentric* and *coitocentric* idea of sexuality.

The impossibility of being spontaneous

THANK YOU VERY MUCH

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