1. **Presentation**

Hello everyone,

I am Ana Santángelo, anthropologist. I am currently doing my PhD studies at the Rovira i Virgili University, in the Anthropology and Communication programme. In Catalonia, Spain. The thesis is part of the project "Anthropology and Phenomenology of the Locked-in Syndrome". Within this project, I study the experience of sexuality in people with LIS and their partners.

2. **Theme and methodology**

As I said, the main theme of the thesis is to analyse the experience of sexuality in people with Locked-in Syndrome. I am currently conducting three case studies.

The methodology used is in-depth interviews, observation, qualitative questionnaires and the analysis of first-person narratives written by people with LIS.

What I present here today is the progress of one of the case studies. It is about a couple living in Spain. The fieldwork consisted of several visits to their place of residence, interviews, questionnaires, observation of their daily dynamics and the analysis of a first-person narrative written by him.

3. **Case study**

Heterosexual couple. They have been married for 25 years. She is 53 and he is 57. He lives with LIS. They met when she was 17 and he was 22. In 1999, Mario ends up in LIS as a result of two strokes when he was 33. Two and a half months after they got married. He was in hospital for 9 months. Afterwards, he returned to the house where he had previously lived with his wife. After a year and a half, almost two years, he decided, voluntarily, to go into a residence.

She visits him almost every day. When she visits him, they usually leave the residence, go out to eat, have a drink or watch a game. They are both sports fans, especially handball and rugby. They also share several groups of friends. With one of them they used to go on a few trips. This has decreased over time.

As far as sexuality is concerned, I will focus on three fundamental and interrelated themes. These themes are the ones that have been most present in the fieldwork process.

4. Main themes

4.1. Physical space

Physical space is related to intimacy and privacy. According to them, the possibility of "being alone together": * I'm not going to read all the quotes as a matter of time, if that's OK.

> "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).

Physical space is a handicap for both. Neither of them feels comfortable having sex in the residence where Mario lives:

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

I consider Goffman's (1961) idea of **"total institutions"**, spaces with their own rules and values, to be appropriate. Like prisons, psychiatric hospitals or the army, hospitals and residential homes could also be considered as such: "they are spaces governed by standardised rules of behaviour and use of space, of **regulation of intimacy**" (Santesmases, 2023, p. 116). In this case, Mario and Maria do not have a space where they can develop their intimacy. The visits imply that they are outside the residence. Therefore, their sexual interactions become almost non-existent.

Despite this situation, they have created **codes and strategies** to communicate their intentions regarding sexuality. Strategies that sometimes involve incorporating the complicity of other actors, such as the social and health care staff in the residence. This also shows that, even if they are not entirely comfortable, there are situations in which they can overlook this discomfort.

Finally, there is a **tension between dependency and intimacy**. When Mario returned home after the 9 months at the hospital, they reactivated his sexual activity by being able to

"be alone together". However, when he was admitted to the residence, sexual activity decreased due to the lack of intimacy. In other words, the greater the intimacy (being alone together), the greater the dependence of the person who is in a situation of physical disability. The fact that Mario is in the residence means that Maria is not in the role of carer.

This gives them both autonomy. In fact, Mario names it in his narrative:

> "In order for me to be able to stay at home, it was necessary to get at least one more person for my parents and Maria to try to live as normal a life as possible. When I was finally convinced that this would not be feasible then I **took the decision to go into a residence**, and although I suppose that the visits I have here almost every day from my relatives will also influence their way of life, at least I want to believe that they have more free time" (Carballo, 2005, p.29).

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

Therefore, the further apart they are physically, the more autonomy they gain and, in turn, the more they lose the possibility of enjoying sexual relations in comfort and intimacy. This point is directly related to the next one: tiredness and impossibility.

4.2. Tiredness and impossibility

Within the impossibility Maria mentions her age as an important element. However, although it is not an element they both share in the same way, it conditions them:

> "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).

The age factor generates **tiredness and impossibility**. It is an element that shows how sexuality has evolved within the LIS experience. In this quote, she also mentions traveling. During the interviews, she also named holidays as special times when they slept together, as Mario leaves the residence and goes to the house. Then they could be intimate and even have sex.

However, these situations have diminished over time. Maria relates this to the physical effort involved in caring for Mario. Similarly, in the residence, she talks about the physical impossibilities that exist due to the space and the furniture. It is increasingly difficult for her:

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

This is also related to sexuality. That is, she has to do the "work" for the sexual intercourse to exist. The idea of "work" in sexual intercourse is something I am exploring and which comes up in other interviews. This brings me directly to the next point.

4.3. **Passivity-activity**

In the narrative written in the first person by Mario in 2005, he says:

> "Sexual relations on the other hand are also quite sporadic ("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 would like to focus on two aspects of this quote. On the one hand, the idea of active participation. Mario is referring to movement. When he talks about not being able to participate actively, he is referring to the fact that he would like not to be in the immobile situation he is in. It generates a lot of frustration and resignation.

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

On the other hand, he talks about sexual intercourse as an equivalent of ejaculation. Mario's possibilities to ejaculate take a central place in the sexual life of both of them:

> "He never had erection problems but he could not 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 put on, it gave me the impression that he had taken a weight off his shoulders" (María. Questionnaire).
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> "Because he said that a man has to ejaculate" (Maria. Interview).

Considering Maria's answer, I am thinking about whether it is a gender issue: How is masculinity constructed? What behaviours is it associated with? How is masculinity called into question when the body cannot respond to these behaviours?

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

> *"Conventional patterns of masculine socialisation require a bodily disposition 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).

Therefore, Santesmases continues, if femininity implies restraining the body's own impulses, it could be said that masculinity is its expansion, its capacity to occupy physical and symbolic space. Penetration would be the symbolic demonstration of this masculinity. Hence the traumatic experience of many men with functional diversity (and many others) when they experience erectile dysfunction, anorgasmia or inability to ejaculate.

5. Conclusions

It is too early to conclude anything in a generic way because I am studying the experience of sexuality in three cases. It is true that some of the issues that emerge, even in individual terms, show general issues. For example, the difficulties in talking or discussing sexual desires or the lack of information from health professionals. Also the genitalocentric idea of sexuality. In relation to this, I find temporality interesting. The lack of spontaneity in sexual relations is a recurring theme in the interviews and is an example of the need to broaden our conceptions of sexuality away from an ableism perspective.