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The Certain Uncertainty of Living with Locked-in Syndrome

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Introduction

When I first began to familiarize myself with the phenomenon of locked-in syndrome (LIS), through written and audiovisual materials about people's experiences with the condition, I was surprised to learn that very few completely recovered their previous healthy functioning, and others never recovered at all. In between are different degrees of recovery, varying greatly from case to case. I wondered why this was, what sort of "luck" it is that makes it happen one way or another. The answer to this question falls primarily into the medical domain, as I will explain below. However, from an anthropological perspective, I wondered how people with LIS perceive the fact that some recover completely and others not at all. Are they (made) aware of it? How much information do they have about recovery? What do health professionals tell them? What are their thoughts, expectations, wishes, hopes, or fears regarding recovery?

In this chapter, I will elaborate some provisional answers to those questions with the aim of shedding light on the paradox of what I call the *certain uncertainty* of living with LIS. First, I will explain the particularities of the syndrome from a medical point of view, what types of LIS exist, and the clinical classification of degrees of recovery. Then I will describe the illness trajectory for people with LIS and their perceptions and experiences regarding recovery. Finally, in this chapter I intend to show how "fighting" for recovery is a controversial notion for cases of LIS, because it starts from a medically created certainty grounded on uncertainty: scarce and random possibilities, misinformation or lack of information, and, sometimes, misleading or unrealistic expectations.

Locked-in syndrome

Locked-in syndrome (a term coined by Plum and Posner 1966) is a rare condition usually resulting from a stroke in the brainstem (53 percent of cases are of vascular origin; this is predominantly the kind I will analyse in this chapter) or appearing in the advanced stage of a neurodegenerative disease such as amyotrophic lateral sclerosis. A few cases have been reported due to trauma (e.g., accident or concussion) or infection (e.g., listeria or meningitis). People with LIS cannot move (quadriplegia) or speak (anarthria), but they are conscious and cognitively able, can see and hear, and retain bodily sensation (e.g., touch, temperature, pain, pleasure). Interpersonal communication is laborious. Persons with LIS communicate by multimodal means: through vertical eye movements or blinking or spelling using an alphabet board or technological system (a tablet or computer). Some can only communicate through an interpreter (family member or professional), others manage to do it also autonomously (see the issue of communication for persons with LIS in Masana and Vidal in press; n.d.).

There are three forms of LIS according to the medical classification (Bauer, Gerstenbrand and Rumpl 1979): in *classic LIS* vertical eye movement or blinking is preserved; in *incomplete LIS*, aside from eye and eyelid movement, the individual can voluntarily move a part of their body (e.g., finger, neck, head, mouth) enabling them, for example, to manoeuvre an electric wheelchair or communicate autonomously using technological devices (tablet, computer), e.g., by using a joystick or an adapted gadget. *Complete or total LIS* entails full immobility (including eye mobility). In all cases, “the course and prognosis vary widely, even among patients with pontine [brainstem] stroke” (Bernat 2020: 231).

Five stages of motor or functional recovery have been clinically described in patients with LIS (Patterson and Grabois 1986: 761), based on the absence or presence of motor return and degree of dependence on caregiving for daily living. *No recovery* refers to patients with no motor return and total dependence on care; *minimum recovery* refers to those with minimal voluntary motor return (e.g., finger, mouth, neck) but still complete dependence on care; *moderate recovery* entails significant motor return which allow patients independence in some but not all their daily activities; *full recovery* refers to patients who gain independence in all daily activities but still have some minimal neurological deficit; and *no neurological deficit* refers to patients who recover completely, without residual neurological deficit.

The few existing longitudinal medical studies of the evolution of motor recovery for patients with LIS show significantly varying rates. For instance, a study by Patterson and Grabois (1986) finds full recovery rates of 7 percent while Casanova et al. (2023) find 34 percent. These data cannot be explained: not why, how, or to what extent some recover moderately or fully, and others minimally or not at all. What these studies agree on is the importance of intensive early rehabilitation (from one month after the stroke) as this, it is believed, reduces mortality and increases the chance of recovery. This is now the protocol in most hospitals and rehabilitation centres for persons with severe disabilities after stroke.

It is worth mentioning that LIS is not a disease but a severe disabling condition, a physical state that entails physical and functional disability, but not sensory, cognitive, or intellectual disability. People with LIS do not die from the condition itself, but usually from respiratory complications (35 percent of deaths according to Patterson and Grabois 1986). They have long life expectancy: studies find that 83 percent live ten years and 40 percent live 20 years, and others live for decades (Bruno et al. 2008; Doble et al. 2003; Halan et al. 2021; Hocker and Wijdicks 2015; Rousseau et al. 2015; Smith and Delargy 2005). Living with LIS, therefore, can be a lengthy journey, as is recovery.

The illness trajectory of LIS

The illness trajectory for people with LIS of vascular origin in Spain or France (the settings of our research) usually follows a pattern. After the stroke, they spend one or two months in an induced coma in an intensive care unit (ICU). This is a crucial period in which death may occur: 87 percent of deaths occur within the first four months after the stroke (Casanova et al. 2003; Patterson and Grabois 1986; Rousseau et al. 2015). After coming out of the coma, they are sent to a neurology unit at the hospital where an initial assessment is carried out to discern whether they have LIS or are in a vegetative state. From then on, a physiotherapist comes daily to carry out basic respiratory physiotherapy (most have a tracheostomy) and to move the individual with LIS to avoid pressure sores and limb deformities, and to ensure that the joints do not stiffen. In certain hospitals a post-intensive-care rehabilitation team will take over to provide early rehabilitation care for patients suffering from serious neurological conditions. This is a bridge between intensive care and the rehabilitation centre.

After patients have spent about six months (on average) in the neurology unit, they are transferred to a rehabilitation centre or a long-term hospital with a specific rehabilitation unit. This period is crucial for people with LIS, and usually involves a stay of 6–9 months. Afterwards, some return to live at home with their families. For this, it is necessary to first adapt the home to their new needs, and to have family or professional caregivers who can provide 24/7 assistance. The services of other professionals, such as physiotherapists and speech therapists, are also required to continue the rehabilitation process. Other people with LIS instead go to live at a care home for persons with disabilities and receive daily motor and functional rehabilitation services and other treatment (speech therapy, psychology, etc.). In some cases, patients also have to pay for external professional services.

Both France and Spain have several specialized care homes for persons with disabilities. Additionally, since 2016, there is a specialized centre for persons with LIS in France. There is no such centre in Spain. France also has a well-established association for people with LIS and their families (Association du Locked In Syndrome, ALIS),[1] with about two hundred members. The association provides valuable information about resources, professionals, and facilities, and engages members in activities. There is no such association in Spain.

Both the Spanish and French health-care systems are tax-based and cover care services for dependent persons with severe disabilities, but do not cover everything. Whether living at home or in a care home, affected individuals or their families have to bear certain expenses. This can be a significant economic burden. While I will not deal with the economic problematic in this chapter, it is worth noting, as people with LIS and their families are told that recovery (if possible at all) can only be achieved with intensive early rehabilitation followed by continued rehabilitation over time. While the former is available in both the Spanish and the French health-care systems, neither fully covers the latter over the years. Therefore, there is an economic inequality regarding access to services and resources for people with LIS.

Fighting for an uncertain recovery, therefore, has financial, emotional, and moral costs. It implies having technical resources (aids) and continued and specialized professional care for years, as well as perseverance and personal dedication on the part of the affected person—all this without certainty of what the result of so much investment will be.

Methods

This chapter's contribution comes from postdoctoral research (2019–2023) conducted as part of a larger project entitled *Anthropology and Phenomenology of the Locked-in Syndrome*, at the Medical Anthropology Research Centre (MARC) of the University Rovira i Virgili (Tarragona, Spain).[2,3] The overall purpose of the study was to learn about the lived experience of LIS from those suffering from it, and its impact and implications for their close relatives and professional caregivers

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[1] https://alis-asso.fr

[2] This work was supported by the Spanish Ministry of Science and Innovation under Grant PID2019-106723GB-I00, granted to the principal investigator, Fernando Vidal.

[3] This research has been performed in accordance with the principles stated in the Declaration of Helsinki and obtained the ethical approval of the Ethics Committee of the Department of Anthropology, Philosophy and Social Work (DAFiTS), of the University of Tarragona (URV), Spain, where this research was conducted.

(Masana and Vidal 2020; Vidal 2020). I was responsible for the ethnographic research—qualitative methods, fieldwork, data collection and analysis—among other tasks. The data presented here were analysed solely by me.

The data were drawn from written narratives gathered through a qualitative questionnaire specifically designed for the above-mentioned research, together with oral interviews with two participants with LIS who regained speech. These primary data are complemented with the publicly available autobiographical accounts of persons experiencing LIS, such as published books or audiovisual materials on the internet. The names of research participants are pseudonyms to preserve their anonymity, except where I rely on public accounts.

The research participants are persons with LIS from Spain (n=5) and France (n=11). In most cases (14 out of 16) their LIS has a vascular origin. All participants have incomplete LIS, except two with classic LIS. Those with incomplete LIS have regained mobility and speech to different extents. They constitute a heterogeneous group of individuals differing in several factors, such as age, sex, gender, type of LIS, time with LIS, degree of disability, family situation, place and type of residence, and cultural and socioeconomic background. Despite this heterogeneous and non-representative sample, I encountered several commonalities in their narratives regarding the lived experience of LIS in general, and with regards to the certain uncertainty of the prognosis for recovery.

Fieldwork was conducted online—by e-mail or videoconference—between September 2019 and July 2021. Spanish participants were recruited using snowball sampling from a first key participant who had published a memoir about living with LIS. French participants were recruited through ALIS which issued a call to its members, providing information about our research project and its contact details. People willing to participate contacted the project directly by e-mail. All participants in Spain and France received and answered autonomously the same qualitative questionnaire (in Spanish or French). This consisted of 34 open-ended questions about the personal experience of living with LIS and its impact on their life. The participants sent their responses back by e-mail. I followed up on certain responses that needed clarification or asked for further details. I have discussed elsewhere the methodological challenges encountered when designing and conducting ethnographic research with people with LIS (Masana in press; n.d.).

For various methodological reasons, a specific question about the participants' certainty or uncertainty about their prognosis for recovery was not included in the qualitative questionnaire. However, the questionnaire did ask about issues that indirectly refer to the topic, such as the most important things in their lives, their expectations for the future, their experience of immobility, the evolution of their mobility over time, and their quality of life.

It is worth mentioning that regaining speech is key for persons suffering from LIS. It entails lengthy and intensive speech therapy to be able to talk (if possible at all), but also to recover other related functions, such as swallowing and chewing. In this chapter, I focus only on motor recovery, as I have dealt elsewhere with regaining speech and communication in LIS (Masana and Vidal in press; n.d.).

Findings

The findings point to four situations regarding recovery from the point of view of those affected with LIS: *fatal prognosis*, *no recovery*, *partial recovery*, and *full recovery*. These are distinct from, though overlapping with, the medical stages of functional recovery described earlier in this chapter. In each situation, I encountered common narratives that were expressed similarly by different participants.

Fatal prognosis: "They gave me two months to live"

After a stroke in the brainstem, our research participants spend between one and four months in a coma in an ICU. Once they "wake up" or "come out" of the coma (as they say in Spanish and French), and are diagnosed with LIS, the situation is critical from a medical point of view. As mentioned earlier, mortality is high in those early stages. Because of this, the initial prognosis is fatal, and clinicians tell relatives of persons with LIS: "be prepared for death, they could die at any moment". This is a preventive communication strategy used by clinicians to prepare families for a fatal outcome. Another version reported is "they would be better off dead" when doctors realize the extent of brain damage and that the patient will be locked in "forever". This phrasing illustrates the notion of the *disability paradox* (Albrecht and Devlieger 1999), where health professionals, relatives, and other external observers believe that a life with LIS is not worth living: there is no quality of life. In our research, those messages were only given to family and relatives, not to patients themselves who were just awakening after being away for several weeks or months. This is what happened to George.

George is a married man aged 58 years who lives with his wife and two children (now aged 22 and 20 years) in a residential neighbourhood of a small city in the north of Spain. He had a stroke in 2004 when he was 39 years old. At that time, the children were three years and nine months old respectively. George followed the usual illness trajectory for a person with LIS: a month and a half in the ICU, four in the neurology unit of the hospital, and six at a rehabilitation centre, and then back home. Today, he loves music and goes to the gym every day, he says, "to maintain all the achievements I have accomplished".

After the stroke, however, when George awoke from the coma and was diagnosed with LIS, his wife was given the initial fatal prognosis that he might only live two months. Today, 19 years later, he is alive, and his recovery is significant: he has experienced almost full recovery. George himself did not know about the two-month prognosis doctors gave initially. Now he knows, and uses the same narrative which he reconstructed afterwards: "They gave me two months to live, and look at me!" Indeed, patients are usually not made aware of the initial fatal prognosis until much later, when relatives reveal to them what they were told. This means that such persons with LIS could not knowingly, consciously, or voluntarily, do anything to improve their health condition and beat those fatal odds. And yet, George, and others like him, repeat their doctors' fatal prognosis with a sense of having fought it and of achieving victory over their own death.

Coincidentally, George lives in the same neighbourhood as one of the doctors who cared for him in the ICU, in fact the same one who gave his wife that terrible prognosis. George says that, one day, he and the ICU doctor met at the neighbourhood supermarket and recognized each other. George approached the doctor and asked: "Why…?". George explains that the doctor apologized and said he was terribly sorry, and acknowledged that "we did not know, we could not know". Thus, there is also clinical uncertainty around LIS: professionals know that they do not know certain things (e.g., the prognosis), but it may be difficult for some to acknowledge this as it challenges their professional knowledge and status. This is why most choose the preventive communication strategy of "no hope" to prepare relatives for a short life expectancy and their relative's death.

On another occasion, the same ICU doctor met George's wife at the supermarket, and said "Oh dear me, the things we told you!" She explained to him how autonomous George is nowadays, all the things he can do by himself. The doctor responded: "I cannot believe it, how lucky you have been!" I opened this chapter by wondering what sort of "luck" makes recovery happen one way or another, and here it is luck to which the doctor turned to explain or justify (to himself or to George's wife) George's incredible recovery, which he had believed, or said he believed to be impossible. In this case, the use of the expression "being lucky" is founded on a comparison with other persons with LIS who could not recover, and contrasts with the poor clinical prognosis for recovery. The notion of luck is recurrent in the experience of illness and in the medical narrative. Luck with the health professionals who care for you or with the patient you had; luck with the treatment efficacy; luck with the condition itself and its evolution; luck with relatives and friends' responses to illness, disability, or dependency; luck with recovery. Talking about good or bad luck is a culturally and medically framed discourse used by both doctors and patients to avoid talking about disagreements and disappointments, especially in the face of a poor prognosis and uncertainty.

As already noted above, people with LIS with vascular origin who beat the two-month prognosis have a long life expectancy. At the time of writing (2023), the Spanish participants had lived with LIS for between 12 and 37 years, and the French participants for between 4 and 32 years. Living two, three, or almost four decades in classic or incomplete LIS is an achievement in terms of survival, but not in terms of recovery. Life expectancy is a medical measure that is relevant when dealing with a life-and-death situation. Once survival is certain, what matters to people with LIS is the extent to which they can recover their bodily functions and lead an autonomous life. We asked our participants about the evolution of their condition over the years and decades.

No recovery: "No future"?

Only two of all the participants—Phoenix and Calvin—have had classic LIS for extended periods (38 and 11 years respectively) and have not experienced any motor recovery. They only move their eyes and eyelids to communicate, are fed by gastric tube, and breathe via tracheostomy. Their answers to the qualitative questionnaire are brief and do not tell us much about uncertainty, although they do tell us about the absence of expectations for the future and for recovery.

Phoenix is a 66-year-old man who has been married for 40 years. He has two children (now aged 38 and 32 years) and two grandchildren (twins, almost three years old). He lives at home with his wife in a house in a small village in east France, in a quiet area surrounded by nature: "well-flowered and woody", he says. One of his sons, the father of the grandchildren, lives a kilometre away, while the other lives far away (950 kilometres). In 1986, when Phoenix was 28 years old, he was in a car accident which caused brainstem trauma. At that time, one of his sons was one year old. The second was born five years after the accident, when he already had LIS. Phoenix has been in classic LIS for almost 38 years since the accident, with no improvement or motor recovery at all. He can only move his eyelids and eyes to communicate by blinking and using an alphabet board. He uses assisted communication technology (eye-controlled human-computer interface) with a special tablet and computer, and used it to answer the questionnaire autonomously. His answers are very brief, partly because, as he explains, he had a heart attack six years ago and, since then he feels very tired and has difficulty expressing his thoughts. Besides, he says, communicating through the computer interface is tiring for him.

Phoenix had a different illness trajectory than the usual pattern described above, probably because he had a car accident and not a stroke. He spent less than a week under sedation in the ICU, and two years and nine months hospitalized before he could return to home, where he has lived ever since. He describes being in LIS as a "very heavy handicap…". In several of his responses he emphasizes the issue of dependency, and that "being dependent for everything brings no quality of life". In fact, he reports being in complete LIS (instead of classic LIS), which is not the case according to the medical definition, but from his bodily perception. Although he acknowledges receiving very good care from professionals, he does not see room for improving his quality of life "I'm getting older and don't want much anymore." He does not talk of, nor consider, recovery: not for him nor anyone else (family or professionals). He enjoys his family life; spending time with her wife, children, and grandchildren: the most important things in his life. He says that what helped him most for living with LIS is: "my faith in God, the support of my religious community, my family". He attends religious services online or by phone and receives visits from his community at home. His narrative combines what we could call peaceful acceptance with bitter resignation to his condition, with no expectations or projects for the future, but seemingly content with the present. When asked about the future he responds "???", followed by "I don't know, I am a little fed up…".

Calvin is a 59-year-old married man who suffered a stroke when he was 38 years old. He lives in a specialized care centre for people with LIS in France, together with 22 other residents. His wife visits him weekly. Since the stroke 11 years ago, Calvin has had classic LIS. Like Phoenix, Calvin uses assisted communication technology and answered the questionnaire autonomously. His answers are also brief. In the years since his stroke, he has not had any improvement or motor recovery, despite receiving daily physiotherapy. Like Phoenix, recovery is not even considered, yet Phoenix has had LIS for 38 years and Calvin for 11. However, unlike Calvin, other participants with LIS have continued to fight and hold out hope for recovery through similarly long durations (as we will see in the next section). Calvin loves listening to music, watching police serials, receiving visitors, and having conversations with people. His narrative, though, seems bitter and dark. He describes being in LIS as "I have the feeling of being good for nothing", a sense of uselessness and powerlessness which Frank (1995) already described in *chaos narrative*. In his questionnaire responses, Calvin also explicitly writes that LIS is "extremely difficult to live with, why did they save me?", suggesting that letting him die would have been better. This points to the deep suffering experienced by some people with LIS and is consistent with the notion of *disability paradox* as presented by Albrecht and Devlieger (1999). Regarding mobility, he explains he cannot move anything (apart from his eyelids), that he cannot do anything, and that he feels "degraded". "I no longer consider myself a man," he says. As for his expectations for the future, Calvin is explicit and concise: "no future", "no expectations". He wishes only that he could travel to Marseille to see his father.

When analysing the data, another participant, Francis, also seemed to have classic LIS (i.e., no recovery) like Phoenix and Calvin, and explicitly answered the question about the evolution of his mobility and motor recovery as "no evolution". However, I found an online publication—the annual newsletter of ALIS (2017)—and realized that he could move his head, neck, and mouth, and that he has regained the ability to speak. Under the medical definition, therefore, he does not have classic LIS but incomplete LIS, and has experienced minimum recovery. As with Phoenix, Francis' story appears a mismatch between the medical classification of the degree of motor recovery and his personal bodily experience. Francis can move his head, neck, and mouth, and with a special joystick, to manoeuvre his wheelchair and use the computer and home automation devices autonomously. In the ALIS newsletter he says:

> When my daily care [washing, dressing] is finished [by caregivers] and I am put in the chair, I am totally independent! […] I can do everything with my computer, and more importantly, I am free. (Francis, 21 years with incomplete LIS)

Here, Francis is talking about being free, a significant term that could be understood as the highest level of control regained over his life given his severe disability. Yet, in the questionnaire, he states there has been "no evolution". A possible explanation for this underreporting of his functional abilities is that he expected to improve and regain more mobility and, therefore, considers his present state of minimum recovery to be equivalent to "no evolution". But there could be other explanations, such as the moment—the mood, time, day, or circumstances—in which he responded to the questionnaire, or the image of himself he wanted to present, whether in the questionnaire or in the association newsletter, which were aimed at different readers. In other words, the perceived difference between the reality of illness, in this case of disability, by health professionals or by patients, highlights how their explanatory models differ (Kleinman 1988), as well as their expectations of recovery.

Partial recovery: "You have to work hard if you want to recover"

Only some individuals with LIS will, over time, regain partial motor recovery, though nobody knows beforehand the extent to which they will recover, if at all, and which part of the body might recover. Partial recovery is the lay, emic term covering the medical classifications described earlier, of minimum and moderate recovery. Most of our research participants have experienced minimum recovery (minimal voluntary motor return e.g., finger, mouth, head, or neck, but still complete dependence on care).

What is certain in LIS is that recovery requires an enormous investment in rehabilitation (physiotherapy, respiratory, swallowing, and speech therapy). While, nowadays, most hospitals and rehabilitation centres initiate early intensive rehabilitation, this was not always the case. Some health professionals failed to do so, because they did not believe in their patient's chances of recovery, or simply did not know it was needed. As one participant writes in his memoir:

> It is not that I resent him [doctor] for not having been able to recover some more movement (which I am convinced would have been possible), but I will never be able to forget that, in depriving me of that care [early rehabilitation], what he really did is to abandon us, my family and me, to the deepest ignorance [that he

> might be able to recover to some extent] (Carballo 2005: 34; 24 years in incomplete LIS).

The onset of LIS in some of our participants (as in the example quoted above), and in some of the memoirs, dates back to the late 1990s and early 2000s, when little was known about the condition, and health professionals did not know of, or trust, the possibility of recovery, due to its initial severity (quadriplegia and anarthria). I was interested in knowing how much information people with LIS have about recovery, and what professionals tell them about it. Analysing the data, and as the example above shows, little or no information was available at that time. Clinical uncertainty and lack of belief in the possibility of recovery had severe consequences for patients with LIS, both on a motor and moral level. On the one hand, they did not receive the care that would give them a chance to recover; on the other hand, they experienced feelings of abandonment and betrayal by medical professionals who gave up on them in the face of the severity of the condition.

And yet, the uncertainty of recovery is not just a matter of investment in rehabilitation and personal effort, although it is usually presented as such. A common narrative we heard from participants is: "you have to work hard if you want to recover". This came from participants who have regained mobility and speech to some extent (however limited), not from those who are still trying (or not) and have not experienced any motor or functional recovery. The narrative is not free from judgement, since it puts the blame on those who have not made it (yet?), as if they have not worked hard enough. Failure to recover is interpreted as a moral failure. It can also be a source of frustration, despair, and hopelessness (like in Frank's *chaos narrative*, 1995). In the cultural discourse, the popular notion of the "culture of effort" values a "fighting attitude". This was shared by Spanish and French participants and is found in the memoirs of people with LIS from other countries. It involves fighting for your goals actively, daily, with perseverance and discipline.

With LIS, physical and functional changes happen very slowly, if at all. Persons with LIS explain that is a very long and slow process:

> Through a tremendous amount of hard work and perseverance I have gained ever so slowly since my accident and still continue to make gains now (they seem huge gains to others, but they seem far too slow for me—I've got to live through it all), with the much-appreciated help and support of others and a copious amount of extremely hard work and sometimes pain. (Chisholm and Gillet 2005: 94; 23 years with incomplete LIS)

Some persons with LIS can live 10 or more years with no physical improvement at all but, continue investing time, energy, and resources fighting for an uncertain recovery. Others, like Calvin, may not. What drives the former to fight for recovery is puzzling, since we learn from their narratives that they are not very aware, nor informed, about the level of recovery they can achieve. As Conrad explains:

> My relatives, I think rightly, at that time they did not tell me the truth, that I was going to be like this [locked-in, immobile] forever; then I think I would have given it up too soon. For example, the communication programme I'm writing with requires a click, and they told me that if I wanted to use this programme, I had to move a finger, and from then on, with a lot of willpower, I began to constantly try to move my finger until I finally managed to move my finger. (Conrad, 24 years with incomplete LIS)

Knowing the tremendous effort that recovering entails, it is common for every improvement to be valued and to give hope for further recovery: "the moment I started to move my toes (minimally) I already felt that everything was going to change", says George (19 years with incomplete LIS). For some participants, no matter how minimal or partial their recovery is, it is perceived as a victory over the body's limitations and a reward for personal effort, investment, time, perseverance, and discipline, led by the sense of "I can" or at least "I am trying". As Patricia says: "I am very proud of myself, of what I have achieved".

Patricia is a 54-year-old woman, who has been married since 2020 to her long-term partner. She lives in a care home for persons with severe disabilities in a quiet village in the south of Spain. Her spouse visits her once a month and they go out for the weekend to the family house or to the beach, which are about 200 kilometres away. In 2008, when she was 28 years old, she had a stroke. She spent 10 years with classic LIS (no recovery) and only started experiencing motor improvements during the last five years. She can move her head, mouth, fingers, hands, arms, legs (she can walk few steps), and has recovered speech (and is still working on it). Patricia drives her wheelchair autonomously and loves to go into town to shop, visit the hairdresser, go to the movies, and do other activities, alone or with someone. She can autonomously write with a special tablet and computer. She answered the questionnaire by herself and is a profuse writer: aside from the questionnaire, she sent us additional writings about her lived experience with the condition. She started working on her recovery soon after the diagnose of LIS:

> The doctors told my family that I suffered from a rare disease called Locked-in Syndrome, that I was going to be bedridden for life, and they advised them that they could now go find me a care home to put me in. [...] And by trying very hard, based on hard work that I imposed on myself, and thanks to the great support of my partner and help, I have managed to become INDEPENDENT (something unthinkable for me!) and thanks to my perseverance, encouragement, and desire to live, I'm still moving very very slowly, but I'm going against all odds! (Patricia, 10 years with classic LIS and five with incomplete LIS; capitalization in the original).

Again, we find a mismatch between individual body perception (disability reality) as functional and independent—she emphasizes this in capital letters—and the medical reality that she still needs continued care for the basic activities of daily living. Aside from the mismatch in explanatory models (Kleinman 1988), we must consider the lens through which we assess disability and recovery. If we only take a functional view and define recovery in terms of the activities persons with LIS can perform or if, through a social lens, we consider the conditions in the social environment that prevent or enable participation in society for persons with LIS. The sense of independence and autonomy, therefore, varies depending on who is assessing it. And yet, Patricia, like others, recounts her achievements with a sense of victory and having fought the odds, that is, against the certain and uncertain poor prognosis of LIS.

Another excerpt illustrates the kind of "hard work" Patricia refers to. She walks us through her daily life in the care home:

> They wake me up every day at 7 a.m. in the morning, I go to the patio for silence and meditation […]. Then I have breakfast and at 10 a.m. the workshops begin, we do read and writing, mental calculation, cognitive stimulation, sports training, manipulative therapy, musicotherapy, recreational activities, computers, and outings. All this is spread throughout the week in the morning and afternoon. In between I stand up for an hour each day on my standing frame, plus one hour of physio and one hour of speech therapy every day. At 1:30 p.m. I stop to eat and then I go out to the patio to lie down in my chair and to stretch my legs (I have my chair adapted with those functions). At 3 p.m. I continue with the workshops until 5 p.m. I get on an adapted automatic bike, and it moves my legs and arms, I do 20 to 25 kilometres a day and I It feels great, especially on my legs. I'm pedalling until dinner (7:30 p.m.). I take advantage of the mirror in the living room and do the speech therapy exercises, gesticulate, and vocalize, all every day. So, when I fall into bed (I fall dead) I only turn on the TV to watch the news, and that hour of TV, I use it to do breathing exercises with a respirator to strengthen my lungs. At 11 p.m. they put splints on my hands and feet, so they don't become deformed (I look like a robot) and it's uncomfortable. As you can see, I lead a very busy life, and I dedicate the weekends to myself, on Saturdays I go to a private physio for two hours to get massages on my back, lumbar, neck, etc. and the shopping, going to the bar, etc. (Patricia, 10 years with classic LIS and five with incomplete LIS).

As Kleinman (2006: 6) points out: "We employ a variety of strategies to deal with the profound sense of inadequacy and existential fear bred by the limits of our control". In LIS, people lose complete control over their bodies, which results in loss of control over their lives. Staying active and busy working for recovery, as Patricia does, is an attempt to regain some control over her live and fate in a pragmatic way when facing misfortune and uncertainty. It is also a way to show value, power, personhood, and social identity (Whyte 1997). Indeed, her daily hard work is perceived as such, daily work like ordinary people, leading also “a very busy life”. Proof of that is when she says: “and I dedicate the weekends to myself”. Paradoxically, the constant work she does from Monday to Friday for her recovery is not conceptualized as dedicated to herself, that is, she clearly differentiates between work (working toward recovery) and free time for herself (for leisure activities).

Full recovery: “The power of the will”

There was no case of full recovery among our participants, although George, whom we met earlier, comes the closest: he was given two months to live and, against all odds, improved significantly over the years. He explains that he started by moving his toe several months after the stroke and now, 19 years later, leads an autonomous life, saying: “I lead a more or less ‘normal’ life”. He can walk and talk, take care of himself and perform basic daily activities such as washing, dressing, cooking, eating, etc. He goes out and about by himself, shopping, going to the gym daily, meeting friends, etc. He uses a wheelchair and crutches when needed, since he still has balance problems, and complains that he does not “speak well” yet, and that some people have problems understanding him or refuse to talk to him.

As already mentioned, full recovery from LIS is very rare (Bernat 2020; McCusker et al. 1982; Hocker and Wijdicks 2015). A case that caught my attention, and perhaps triggered this chapter, is that of a British woman called Kate Allatt who recovered completely from LIS of vascular origin, and wrote an autobiography entitled *Running Free: Breaking Out from Locked-In Syndrome* (Allatt and Stokes 2011). In 2017, Kate was interviewed on a morning television show (*Good Morning Britain*)[4] and talked about “her incredibly recovery” (as it was presented on the show). When the journalist asked: “How do you physically manage to go from that state to actually being able to walk out of the hospital?”, she responded:

> You know, I’m really glad you asked me that because I didn’t know about neuroplasticity […] I just knew I had the will to be home with my kids. (Kate Allatt, BBC *Good Morning Britain*, 08/02/2017)

Kate’s spontaneous response is striking and informative. Her will to be home with her kids, though not a guarantee of recovery, is what motivated or helped her to work toward recovery. When losing total control over their bodies and lives, people with LIS point to the most important things in their lives. In her book, Kate also lists other

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[4] BBC, *Good Morning Britain*, 08/02/2017, Woman With Locked-in Syndrome Talks About Her Incredible Recovery: https://www.youtube.com/watch?v=F8pNAbmwIfA

factors she believes contributed to beating LIS: her fitness, support from her family and friends, her will, disciplined therapy, setting goals, among others (Allatt and Stokes 2011: 209). On the TV show, as Kate described her will to be home with her children, her doctor (who was also on the show), interrupted her to say that full recovery is extremely rare in cases of LIS, and that the medical profession is learning a lot from Kate's case. He reinforced the *power of the will* message by saying:

> We are learning that, we are talking about neuroplasticity here, the ability of the will to relentlessly pursue getting the voluntary movements back is often down to the patient, and you [looking at the patient] would determine to recover. (Kate Allatt's neurologist, BBC *Good Morning Britain*, 08/02/2017)

Can willpower beat clinical uncertainty and a poor prognosis? It is risky and dangerous to correlate such things, not only because it might not be true or feasible, but because it puts blame on those who cannot make it, as if their will is weaker. Although the doctor repeated several times that recovery is extremely rare, the message of the power of the will was served and reinforced. Nor is this exclusive to Kate's case. Patricia also speaks of the power of the mind for healing.

Such stories are usually presented in the media, either on official channels and programmes or through personal social media, as inspirational: "If she could, others can", or "If I could, you can". In the case of Kate Allatt, the BBC programme presents her as an extraordinary woman with an extraordinary recovery, who beat LIS and its poor prognosis by the power of will. In the case of Patricia, through her Facebook account, she portrays her perseverance, hard work, and power of the mind, and is admired by her followers: "Those who know me say I am an example to follow", she says.

In the social presentation of persons with disabilities in the media (TV, press, magazines, blogs, etc.) it is common to find extraordinary examples of persons who are presented as heroes that beat, endure, and cope with physical constraints and functional disabilities, following the *supercrip* model or stereotype of disability. Those extraordinary examples might be inspirational for some, but may also be a source of frustration and feelings of failure for others who, despite their own will and hard work, could not recover. As with many other chronic conditions, and the paradigmatic example of cancer, the cultural discourse values a fighting attitude, maintaining the hope and positivity associated with getting better (Good et al. 1990; Lupton 1994; Saillant 1990). This notion of willpower or mind power for healing is a social and cultural discourse embedded in a neoliberal context, in which sick persons must do their best to recover and become productive again (Hay 2010; Masana 2011; Parsons 1991). In both the medical and the social spheres, the *restitution narrative* (Frank 1995) is promoted as the preferred cultural option. However, people with LIS might have no option to recover, whether partially or completely. Frank has previously noted that the restitution narrative no longer works for certain chronic illnesses (Frank 1995). And, I add, it is much less applicable for severe disabilities with an uncertain prognosis like LIS. Precisely for this reason, the culturally, socially, and medically promoted discourses of hard work and willpower to recover from LIS are nothing more than a fallacy that adds moral suffering to people with LIS.

Final considerations

As we have seen, the *certain uncertainty* of LIS recovery works as follows: even without proper knowledge and a guarantee of recovery, some individuals choose to work hard and tirelessly to recover (without knowing to what extent), while others do not. The reasons are varied: their personal and health situation, professional help, resources, family support, living circumstances, financial situation, etc. Therefore, each case must be analysed individually; there is no common rule, despite a dominant cultural and medical discourse that promotes fighting to recover, or at least to improve the health condition. Fighting for recovery is, in a way, fighting uncertainty, fighting the odds, fighting doctors' knowledge: "Sometimes I felt like my recovery was one continual fight: me against the medical profession", Kate writes in her memoir (Allatt and Stokes 2011: 150). It is an attempt to prove to oneself or to others that one was right and others were wrong: "I want to prove wrong the persons who have written me off!" (Allatt and Stokes 2011: 108). In other words, it is to regain some control over their bodies and lives that have been, altered, shattered, disrupted by LIS. However, those victory narratives can be and are only written afterwards if recovery was successful.

Seeing the lack, or misleading nature, of information on recovery that patients and families receive, recommendations for good professional practice could include advising health professionals to carefully consider what information they share with their patients about the possibility of recovery: sustaining hope for recovery, not giving too much hope, or none at all. They should also be extremely careful when disclosing, or not, other patients' partial or full recovery. To my knowledge, and according to the data, most patients and families are not aware that full recovery is an option. In fact, what people with LIS (and their relatives) are told about recovery is crucial and has to do with ethical medical practice (caring for and sharing information with patients) and with the issue of decision-making for both professionals and patients (Bernat 2020). How can patients and their families take decisions concerning their care and future lives if they are not aware of their possibilities or probabilities of recovery?

As with many chronic conditions, LIS cannot be cured, and most persons will not recover. In pursuing recovery, we could say that some do not abandon hope: hope to gain access to the *kingdom of the well* (Sontag 1977), hope toward restoring their life before the illness (Frank 1995). Curiously, their narratives are centred on recovery and not on the notion of hope, as I had initially thought. This does not mean that they are hopeless. On the contrary, they keep hoping, but do not express it in a direct way. Paradoxically, this desire or expectation to recover, that would fit the restitution narrative model, does not always work, as it does with many chronic conditions, "because it sets up expectations that are unlikely to be met" (Garret 2001: 100): the restitution narrative is for acute conditions, not for chronic ones. Therefore, with chronic LIS, as with other chronic conditions, hope for recovery could be considered a "false hope" (Garret 2001) and it resembles what Mattingly finds:

> […] cultivating a hopeful stance is paradoxical; it involves an ongoing conversation with embittered despair. To hope is to be reminded of what is not and what might never be. (Mattingly 2010: 3)

For people with LIS, if *certain uncertainty* is sustained, hope for recovery remains a possibility, however faint. Indeed, certainty would crash hope and all possibility.

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References

Albrecht, Gary L., and Patrick J. Devlieger. 1999. The Disability Paradox: High Quality of Life Against All Odds. Social Science & Medicine 48: 977–988.

ALIS (Association du Locked-in Syndrome). 2017. Les 20 ans d'ALIS. La lettre n° 29 d'ALIS (November). Available at: https://alis-asso.fr/wp-content/uploads/2019/03/Lettre_d_alis_29.pdf

Allatt, Kate, and Alison Stokes. 2011. Running Free: Breaking Out from Locked-In Syndrome. Bedlinog: Accent Press Ltd.

Bauer, Gerrit, Franz Gerstenbrand, and Erik Rumpl. 1979. Variables of the Locked-in Syndrome. Journal of Neurology 221: 77–91.

Bernat, James L. 2020. Medical Decision Making by Patients in the Locked-in Syndrome. Neuroethics 13: 229–238.

Bruno, Marie-Aurélie, Frédéric Pellas, Caroline Schnakers, Philippe Van Eeckhout, Jan Bernheim, Karl-Heinz, François Damas, Marie-Elisabeth Faymonville, Gustave Moonen, Serge Goldman, and Steven Laureys. 2008. Le Locked-In Syndrome: La Conscience Emmurée. [Blink and You Live: The Locked-in Syndrome]. Revue Neurologique 164(4): 322–335.

Carballo, Jose Carlos. 2005. El síndrome de cautiverio en zapatillas [The Locked-In Syndrome in Slippers]. Burgos: Rico Adrados SL.

Casanova, Emanuela, Rosa E. Lazzari, Sergio Lotta, and Anna Mazzucchi. 2003. Locked-in Syndrome: Improvement in the Prognosis After an Early Intensive Multidisciplinary Rehabilitation. Archives of Physical Medicine and Rehabilitation 84(6): 862–867.

Chisholm, Nick, and Grant Gillet. 2005. The Patient's Journey: Living with Locked-in Syndrome. *BMJ* 331: 94–97.

Doble, Jennifer E., Andrew J. Haig, Christopher Anderson, and Richard Katz. 2003. Impairment, Activity, Participation, Life Satisfaction, and Survival in Persons with Locked-in Syndrome for Over a Decade: Follow-up on a Previously Reported Cohort. The Journal of Head Trauma Rehabilitation 18(5): 435–444.

Frank, Arthur W. 1995. The Wounded Storyteller: Body, Illness and Ethics. Chicago: The University of Chicago Press.

Garret, Catherine. 2001. Sources of Hope in Chronic Illness. Health Sociology Review 10(2): 99–107.

Good, Mary-Jo Del Vecchio, Byron Good, Cynthia Schaffer, and Stuart E. Lind. 1990. American Oncology and the Discourse on Hope. Culture, Medicine and Psychiatry 14: 59–79.

Halan, Taras, Juan Fernando Ortiz, Dinesh Ready, Abbas Altamimi, Abimbola O. Ajibowo, and Stephanie P. Fabara. 2021. Locked-In Syndrome: A Systematic Review of Long-Term Management and Prognosis. Cureus 13(7): e16727. https://doi.org/10.7759/cureus.16727

Hay, M. Cameron. 2010. Suffering in a Productive World: Chronic Illness, Visibility, and the Space beyond Agency. American Ethnologist 37(2): 259–274.

Hocker, Sarah, and Eelco F.M. Wijdicks. 2015. Recovery from Locked-n Syndrome. JAMA Neurology 72: 832–833.

Kleinman, Arthur. 1988. The Illness Narratives: Suffering, Healing, and the Human Condition. New York: Basic Books.

Kleinman, Arthur. 2006. What Really Matters: Living a Moral Life amidst Uncertainty and Danger. New York: Oxford University Press.

Lupton, Deborah. 1994. Medicine as Culture: Illness, Disease and the Body in Western Societies. London: Sage.

Masana, Lina. In press; N.d. Methodological Challenges When Conducting Ethnographic Research with Persons that Cannot Talk or Move (provisional title).

Masana, Lina. 2011. Invisible Chronic Illnesses Inside Apparently Healthy Bodies. *In* Of Bodies and Symptoms: Anthropological Perspectives on their Social and Medical Treatment. Sylvie Fainzang and Claudie Haxaire, eds. Pp. 127–149. Tarragona: Publicacions URV- Col·lecció Antropologia Mèdica.

Masana, Lina, and Fernando Vidal. 2020. Antropologia i fenomenologia de la síndrome de captiveri [Anthropology and Phenomenology of the Locked-in Syndrome]. Arxiu d'Etnografia de Catalunya, Notes de Recerca 21: 224–230.

Masana, Lina, and Fernando Vidal. 2023. The Lockdown of the Locked-in: Experiences of Persons with Locked-in Syndrome during COVID-19 Pandemic. Disability & Society. https://doi.org/10.1080/09687599.2023.2279484

Masana, Lina, and Fernando Vidal. In press; N.d. Communicating Through Persons and Devices in the Locked-In Syndrome.

McCusker, Elizabeth A., Richard A. Rudick, Gerald W. Honch, and Robert C. Griggs. 1982. Recovery from the 'locked-in' syndrome. Archives of Neurology 39: 145–147.

Mattingly, Cheryl. 2010. The Paradox of Hope: Journeys through a Clinical Borderland. Berkeley: University California Press.

Parsons, Talcott. 1991 [1951]. The Social System. London: Routledge.

Patterson, James R., and Martin Grabois. 1986. Locked-in Syndrome: A Review of 139 Cases. Stroke 17: 758–764.

Plum, Fred, and Jerome B. Posner. 1966. The Diagnosis of Stupor and Coma. Philadelphia: FA Davis.

Rousseau, Marie-Christine, Karine Baumstarck, Marine Alessandrini, Véronique Blandin, Thierry Billette de Villemeur, and Pascal Auquier. 2015. Quality of Life in Patients with Locked-in Syndrome: Evolution over a 6-Year Period. Orphanet Journal of Rare Diseases 10: 88. https://doi.org/10.1186/s13023-015-0304-z

Saillant, Francine. 1990. Discourse, Knowledge and Experience of Cancer: A Life Story. Culture, Medicine and Psychiatry 14(1): 81–104.

Sontag, Susan. 1977. Illness as Metaphor. New York: Farrar, Straus and Giroux.

Vidal, Fernando. 2020. Phenomenology of the Locked-in Syndrome: An Overview and Some Suggestions. Neuroethics 13: 119–143.