

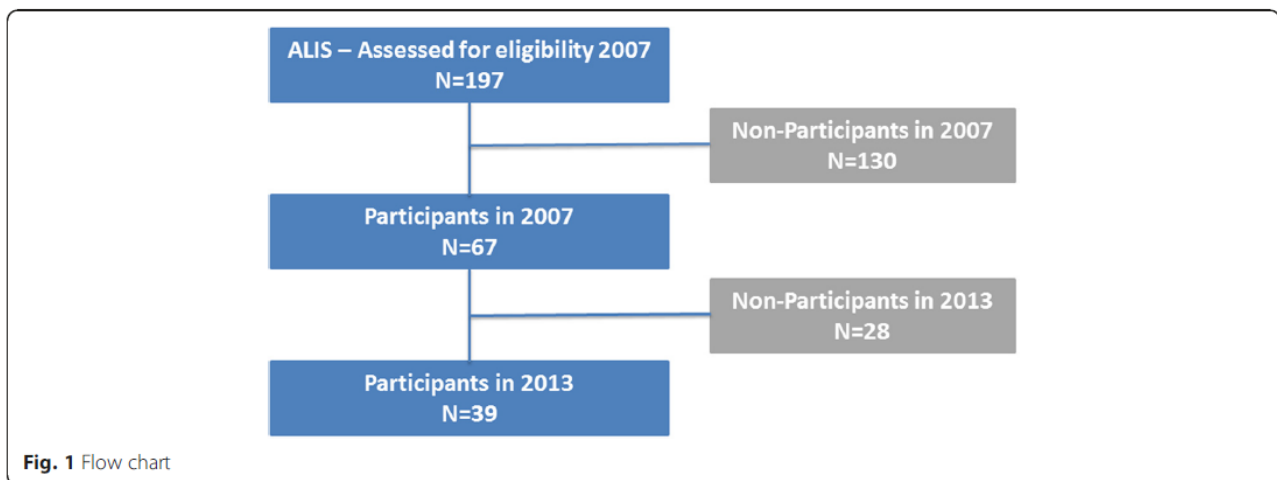
Summary of the paper

“Quality of life in patients with locked-in syndrome: Evolution over a 6-year period”

The life expectancy of LIS is improved with appropriate medical care. However, what we are focused in here is the quality of life (QoL) of the patients.

According to previous studies, **it appears that the QoL of LIS is often in the same range as that of healthy individuals**, despite their extreme physical impairment. It also appears that determinants of QoL is disability/handicap statues, medical devices, social/familial support and depression. Also, sociodemographic variables are not really QoL predictors. However, these studies are only ponctual, and do not study the evolution of the QoL over time. This is the goal of this paper.

This study has been made on adult patients, that agreed to participate, with LIS diagnosis (according to Plum and Posner definition, which is: complete or near-total loss of motor function, preservation of eye movement, anarthria, preserved consciousness and intellectual function). Patients with major motor recuperation were not taken into account.



In order to evaluate the QoL, a questionnaire is sent to eligible patients (197), in 2007. 67 of them responded (through electronic communication devices or with the help of someone) in 2007. The same questionnaire is sent 6 years later in 2013. 58% of those who returned the questionnaire in 2007 returned it in 2013, **which represents 19,7% of the original group in 2007**. After collecting data for these patients, models have been made in order to see what are the factors of QoL.

The type of data collected are:

- sociodemographic data (including gender, age, living status, marital status, children, educational level, income, religious status)
- clinical data (the type of LIS (total, classical, partial), the disease duration, the cause of the pathology, physical/handicap status and psychological status)
- self-reported QoL, based on Anamnestic Comparative Self-Assessment (**ACSA**) which gives an evaluation of the quality of life based on their best memory before LIS (graded as +5) and their worst memory (graded as -5). Higher score means better QoL.

- Integration in life (a 4-point Likert scale has been used (no, mostly no, mostly yes, yes) due to minimal communication. The result is normalized to 100). The patients were also asked about end-of-life issues (wish to be reanimated and willing for euthanasia).

A statistical analysis has been made on these data, to seek for the relevant factors. The mean ACSA score for 2007 and 2013 has been compared. This gives a delta ACSA and then two groups: those who have a positive delta ACSA (increase of QoL) and those who have a negative or null delta ACSA (decrease of or stable QoL). Then multivariate analyses has been done, using multiple linear regressions. Two models were made: 1) a model including sociodemographics, LIS characteristics and health status at 2007; 2) a model including sociodemographics, LIS characteristics and health status at 2013.

Individuals with use of yes-no code reported a significantly lower QoL in 2013 compared to non users. Also, individuals with an electric wheelchair reported a greater QoL in 2013 compared to non users. No significant differences were found in terms of gender, age, living status, marital status, having children, educational level, income, or religious status. No statistical relationships of QoL with disease duration, LIS type, or LIS etiology were found. One interesting result is that the QoL levels in 2013 did not differ between people that exhibited objective deterioration in physical/handicap statuses and subjects with stable or improved physical/handicap statuses.

From the first multivariate model, we get that autonomous electric wheelchair in 2007 and use yes-no code in 2007 are not significantly linked to the ACSA score at 2013. From the second multivariate model, use yes-no code in 2013 and suicidal thoughts in 2013 were selected and only suicidal thoughts is significantly associated with ACSA QoL score at 2013.

One important thing here is that LIS patients showed a **rather good QoL stability** throughout the 6 years: around 75% of the patients reported a stable or improved QoL at 6 years. In this period, the health/handicap statuses (both physical and psychological) of some patients changed. It was not observed in this paper a relationship between the objective parameters of the health/handicap statuses and the QoL. Likewise, the 11 patients (out of 39) that objectively showed deterioration in their health/handicap statuses had their QoL scores not different from those of the other patients. So, it has been observed that patient's subjective QoL is not related to physical impairment. It illustrates the "disability paradox" reported by Albrecht and Devlieger. QoL being self-reported by the patient, it might be influenced by the "response shift phenomena" which corresponds to the adaptation to the illness. This may result in over- or underestimation of the true changes and results in challenges in interpreting QoL measures.

The proportion of patients who preferentially used a yes-no code to communicate tended to decrease over time, from 77 % in 2007 to and 62 % in 2013. This last restrictive mode of communication was the single parameter that was associated with a significantly lower QoL. Also, the autonomy afforded by an electric wheelchair is recognized as an important element for an LIS patient. In this study, nearly 60 % of the LIS patients stated that they were autonomous with a powered electric wheelchair and reported feelings of sufficient autonomy at home, and such feelings were associated with higher QoL scores, although this difference was not significant.

Concerning the life conditions of the patients, the patients living in institutional settings showed systematically higher scores than those living at home which could be explained by the soothing role of a medical environment. However, the difference is not significant.

Having suicide thoughts unsurprisingly influence the QoL score of the patients. Lastly, family members, careers and medical professionals frequently assume that LIS persons would choose to die, but **this was not true**. The results indicate that the demand for euthanasia was almost nonexistent in our group of patients, and a great number of the patients expressed a desire for resuscitation if necessary.

To finish, one word about the limitations of these results. The sample size is arguably too small. Larger samples could confirm these first observations. Moreover, it was not collected the information whether the patient him/herself responded or if someone filled the questionnaire on behalf of the patient. This can lead to inaccurate estimation of the patient QoL. Nevertheless, this study suggests that the QoL of LIS patients is more or less stable and that this life is worth living, in contrast to the general and widespread opinion. The possibility to communicate helps the LIS patients to live as normaly as possible. But again, that study should be made on larger groups.