

Locked in syndrome

Lectures

CO07-003-e

Locked in syndrome quality of life: What is a deserving life; consequences on end of life decisions

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QOL of locked-in syndrome (LIS) is considered so atrocious that their life does not seem worth the trouble of living. However, many LIS testify to the contrary. In collaboration with ALIS, we assessed the quality of life (QOL) of chronic LIS (> 1 year, 65 included). Majority profess good well-being, in line with the notion that patients with severe disabilities may report a good QOL despite being socially isolated or having major difficulties in ADL. The principal clinical conditions for requests for euthanasia or physician-assisted death to be legally valid are unbearable suffering and irreversibility of the situation. Self-confidence, recreational and social activities and a longer time in LIS were correlated with happiness. 58% declared they did not wish to be resuscitated in case of cardiac arrest and 7% only expressed a wish for euthanasia. End-of-life decisions, including euthanasia, should not be avoided, but a moratorium to allow a steady state to be reached should be proposed.

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European LIS associations and a LIS European survey

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The European Locked-In Syndrome Federation was born in 2013 following the wish of national associations. Notably ALIS, the French Association, LISA the Italian Association and LIS the German Association. Ten countries have joined LISEF, some of which are not yet registered as such but only represented either by a expert therapist, either by a locked-in person. The main aim of the federation is to improve the quality of life of Europeans LIS; the first action is the creation of a communal European questionnaire, which shall be sent to the LIS persons.

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Ethical, legal and social approach, concerning BCI applied to LIS patients

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Current interviews with people with locked in syndrome (LIS) show that almost all of them rate their quality of life as good or even very good. They are happy with their “classic” communication aids and the services around them (advice, delivery, reimbursement). People with LIS prefer non-technological alphabet system for daily interactions, because face-to-face is more personal and emotional. However, technological communication aids are of utmost importance for privacy and the feeling of independency. Ethical, legal and societal issues need to be considered when designing new assistive technologies such as brain-computer interfaces. For example, interviews suggest that that having high tech is not a guarantee for inclusion of people with LIS in society. People in society are often afraid of people with LIS and the equipment that surrounds them. Thus, BCI sensors should be as invisible as possible or aesthetically pleasing and culturally accepted. The inclusion of people with disabilities will not only require the development of high tech, but - above all - a change in society's attitude towards disability.

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DECODER projet (UE): Implications for consciousness diagnosis and for LIS communication by brain-computer interface (BCI)

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The deployment of brain-computer interfaces (BCI) for locked-in patients provides access to modern communication technology, when no single response is available with “classical” communication technology (ICT). This could be obtained in locked-in patients or in extreme case such as non-responsive patients. DECODER developed a BCI single switch authorizing such patients to communicate. But this also allows new thinking in end of life situations, since medical treatment can extend life, and leaves these patients in an unacceptable condition, according to some care givers or family.

Further reading

Kubler A, Neumann N. Prog Brain Res 2005;150.

<http://dx.doi.org/10.1016/j.rehab.2014.03.1146>