Is life worth living in Locked-In Syndrome?

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Overview

Definition
Overview

Definition

Cognitive function
Overview

Definition
Cognitive function
Electrophysiology
Overview

Definition
Cognitive function
Electrophysiology
Quality of life and Ethics

Conclusion
Overview

Definition
Cognitive function
Electrophysiology
Quality of life and Ethics
Conclusion
Definition
Locked-In Syndrome

Laureys, Owen and Schiff, Lancet Neurology, 2005
Locked-In Syndrome

- Classical LIS
- Incomplete LIS
- Total LIS

Bauer, Gerstenbrand and Rumpl, Journal Neurology, 1979
Locked-In Syndrome

Laureys et al., Progress in Brain Research, 2005
Communication

• Eyelid blinks or vertical eye movements code
• Eyelid blinks or vertical eye movements code

• ESARIN / vowel and consonant method
# Communication

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Communication

- Eyelid blinks or vertical eye movements code
- ESARIN / vowel and consonant method
Communication

- Eyelid blinks or vertical eye movements code
- ESARIN / vowel and consonant method
- Eye tracking system
Communication
Communication

- Eyelid blinks or vertical eye movements code
- ESARIN / vowel and consonant method
- Eye tracking system
- Brain computer interface (BCI)
Cognitive Function
Cognitive Function

Executive functioning

Attention

Short term memory

Verbal intelligence

Schnakers et al., Journal of Neurology, in press
Electrophysiology
Active ERP paradigms

Complete locked-in syndrome (n=1)

Passive other name
Count other name
Passive own name
Count own name

Schnakers et al., submitted

www.comascience.org
Quality of life and Ethics
Quality of life in LIS
Quality of life in LIS

Short Form-36
N=17
duration 6±4 y

Laureys et al., Progress in Brain Research, 2005
Suicidal ideation

Suicidal ideation in the locked-in syndrome (n=54)

- Eye communication (median duration 3 y): 14
- Head communication (median duration 4 y): 8
- Verbal communication (median duration 5 y): 8

Laureys et al., unpublished
Conclusion
Conclusion

• LIS patients self-report a meaningful quality of life

• LIS patients have the right to make health care decisions about themselves including to accept or refuse life-sustaining therapy

• “Don’t judge a book by it’s cover”
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the patients & families