Locked-in syndrome in Norway – first results from a new national service

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Background

In 2012, the Norwegian Department of Health established a National Rehabilitation Unit for Locked-in Syndrome at Sunnaas Rehabilitation Hospital, with the following assignment:
- **Provide health care** for all patients in need of the specialized service
- **Observe and disseminate treatment results**
- **Participate in research and establish research network**
- **Contribute to relevant education** of health-care professionals
- **Provide counseling and advise** for users and for health and other relevant services
- **Ensure equal access** to the service
- **Contribute to implementation of national guidelines and evidence-based practice**

Definition and classification

Locked-in syndrome is caused by damage to the ventral pons, usually due to stroke. The syndrome is infrequent, epidemiology is not known (incidence ~1 per 4 mill per year? (Pantke 1998))

Traditional definition and classification:
- **Tetraplegia** and **anarthria with preserved consciousness**
- **Total LIS:** total immobility and total loss of communication function
  - **Classic:** tetraplegia, anarthria, vertical eye movements
  - **Incomplete:** as classic, but some voluntary movements in addition to vertical eye movement (Bauer, Gerstenbrand, Rumpl 1979)

We use the following definition for our service:
- **Functional level**
  - Large pareses in all 4 extremities and severe communication impairment and normal or close to normal cognition (at the very least oriented for time, place and situation) and completely depending on help in ADL and condition is permanent or long-lasting.
- **Etiology**
  - Acquired brain injury, i.e. not congenital or degenerative condition.
- **Other factors concerning in-patient rehab**
  - Motivation
  - Medical stability (especially concerning respiration)
  - No other severe conditions implying pure prognosis

Description of Norwegian LIS-patients

Per date, we know about 22 patients living with LIS in Norway. None of them has complete LIS. Data from 19 patients who have been assessed in more detail during follow-up visits, are presented:

<table>
<thead>
<tr>
<th>Etiology</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infarction</td>
<td>16</td>
</tr>
<tr>
<td>Subarachnoid hemorrhage</td>
<td>2</td>
</tr>
<tr>
<td>Intracerebral hemorrhage</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Description</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at injury</td>
<td></td>
</tr>
<tr>
<td>Age of today</td>
<td></td>
</tr>
<tr>
<td>Years living with LIS</td>
<td></td>
</tr>
<tr>
<td>Tracheostoma</td>
<td>11</td>
</tr>
<tr>
<td>Need 2 or more persons for transfer</td>
<td>3</td>
</tr>
<tr>
<td>Able to control electric wheelchair</td>
<td>9</td>
</tr>
<tr>
<td>Pain problems (4 severe)</td>
<td>6</td>
</tr>
</tbody>
</table>

Services

Clinical services:
- **Acute:** counseling of stroke unit personnel by videconference / visit; information to personnel, patient and relatives
- **Subacute:** direct transfer to in-patient rehabilitation as soon as patient is medically stable
- **Phase of transfer to community:** team member visits local team, transfer meetings per telemedicine; follow-up visit from team at community 1 month after discharge
- **Further follow-up:** yearly follow-up by phone, videconference or visit; re-admission as required

Center of excellence services:
- Educational and counseling services for patients, relatives and health care and other personnel, including brochures, website, lectures etc.
- Quality register
- Research

Organization

Clinical team
- Interdisciplinary team (MD, nursing staff, OT, PT, SLT, social worker, neuropsychologist) at regional rehabilitation centre including a number of facilities (laboratories, training facilities, specialist consultants etc.)

Center of excellence
- Led by head physician (FB) and run by coordinator (KF). Some members of clinical team have assigned % of working hours.

External reference group
- Representatives from each of the 4 Norwegian Health regions, family doctor and user representative

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