Brain injury and severe eating difficulties at admission
- Patient perspective nine to fifteen months after discharge: A pilot study

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Introduction
Eating difficulties can impact social opportunities and the pleasure derived from meals, as well as the quality of social relationships for the person with acquired brain injury (ABI), undermining their health and condition. Individuals with eating difficulties may become isolated, feel excluded from social life, and experience symptoms that can diminish their quality of life. In addition, eating difficulties in individuals with ABI may affect the rehabilitation outcomes and process. A qualitative approach can help to understand the perspectives of patients with eating difficulties during rehabilitation.[1]

Materials & Methods
The pilot study forms one component of a mixed methods investigation of difficulties with swallowing and eating following ABI. The first phase was a prospective unbiased cohort study of swallowing function (SOF) of movement involving facial-tract and tract therapy versus telerehabilitation model intervention of swallowing during inpatient neurorehabilitation; we composed the risk of aspiration pneumonia in patients with ABI and the time to initiation of a swallowing rehabilitation program before discharge. The second phase, which is the focus of this paper, was a preliminary, explorative, qualitative, single interview study of four individuals with ABI.

The inclusion criteria were:
- Diagnosed with ABI and admitted to the RC/OT study, severity dysphagia at the time of admission to inpatient neurorehabilitation, has or has had a feeding tube, and able to understand the interview questions and express/describe their experience in Danish.

The empirical data was collected using semi-structured interviews. The participants were interviewed once in their own homes. The interviews were analysed using content analysis.

Characteristics of the four participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>P1</th>
<th>P2</th>
<th>P3</th>
<th>P4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
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<td>60</td>
<td>27</td>
<td>30</td>
</tr>
<tr>
<td>Gender</td>
<td>Female</td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Marital status</td>
<td>Single</td>
<td>Married</td>
<td>Single</td>
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<tr>
<td>Diagnosis</td>
<td>Head trauma</td>
<td>Head trauma</td>
<td>Head trauma</td>
<td>Head trauma</td>
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<tr>
<td>Time since injury</td>
<td>278 days</td>
<td>526 days</td>
<td>477 days</td>
<td>473 days</td>
</tr>
<tr>
<td>Type of feeding tube</td>
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<td>Nasal</td>
<td>Nasal + PEG</td>
<td>Nasal + PEG</td>
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<tr>
<td>Days on feeding tube</td>
<td>31 days</td>
<td>39 days</td>
<td>137 days</td>
<td>172 days</td>
</tr>
</tbody>
</table>

The thematic data was collected using semi-structured interviews. The participants were interviewed once in their own homes. The interviews were analysed using content analysis.

Results
The findings provide preliminary information on the patient perspective of adjusting to and developing new strategies for activities related to eating. These participating patient experiences were: ‘Feeding tube, ’relearning’ to eat and eating meals together’.

Fed by tube
Especially for the two participants who had a PEG long-term, the experiences were something they wanted to forget and found that the feeding tube delayed their initiation of oral intake. Even for the two participants needing a feeding tube for a short time described their negative experiences, such as Marie, who experienced the nasal tube as being annoying and affecting her face. The psychological experience of a patient with a feeding tube had negatives, but not necessarily, impact the participants’ quality of life. After withdrawal of the feeding tube, the situation gradually seemed to normalize, and each participant used different strategies to be able to participate in social activities. Our findings indicate that feeding tube in feeding as it is for most psychological factor for patients with ABI and also a key focus area for the clinical experiences of health professionals in inpatient neurorehabilitation.

Conclusions
The preliminary results regarding the four participants suggest that the meaning of food and being able to eat and take part in meals may be only rarely the same as before the injury; however, having the ability to eat instead or less completely, unseasonable, very unappetizing and difficult, and caused strong emotional reactions, even 36 months after injury. Time spent using a feeding tube had a negative, but not persistent, impact on quality of life. This preliminary findings provide knowledge regarding the patient perspective of adapting to and developing new strategies for activities related to eating, which is important knowledge of clinical relevance. However, future prospective, longitudinal research is needed.

References

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"When we had rye bread for dinner, it often got stuck in my throat, and I had to leave the table (coughing)"

"It was tiresome having to get up and lie flat on your bed in order to have something to eat... I was fed up with not having taste in my mouth"

"It does not matter. Maybe because I am a realist, and when I have been severely injured, it has been a consequence"

"Fed by tube formula is fine because I had something to eat that way, but I think it prolonged the time where I did not get solid food"