

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 confidence. Individuals with eating difficulties may become isolated, feel excluded by others, and be anxious and distressed at mealtime; they often experience considerable limitations in their everyday life. Living with eating difficulties after ABI involves a complex and difficult process of adjusting to a new way of eating, as well as losses involving mealtime activities. Little is known about eating difficulties and adaptation to lasting eating difficulties after discharge from inpatient neurorehabilitation. This pilot study aimed to explore and interpret the way that individuals with ABI, admitted to inpatient neurorehabilitation with severe eating difficulties, experienced eating nine to fifteen months after discharge.

Materials

This pilot study forms one component of a mixed methods investigation of difficulties with swallowing and eating following ABI. The first phase was a prospective randomised controlled trial (RCT) of assessment involving facial- oral tract therapy versus fiberoptic endoscopic evaluation of swallowing during inpatient neurorehabilitation; we compared the risk of aspiration pneumonia in patients with ABI 3 and the time to initiation of oral intake and recovery of total oral intake before discharge.

4 The second phase, which is the focus of this poster, was a preliminary, explorative, qualitative, single interview study conducted to gather the patient perspective of eating nine to fifteen months after discharge, and to refine the methodology for a later longitudinal study.

Four individuals with acquired brain injury were interviewed via qualitative semi-structured interviews.

The inclusion criteria were:

- 1) diagnosed with an ABI and enrolled in the study mentioned below,
- 2) severe dysphagia at the time of admission to inpatient neurorehabilitation
- 3) have or have had a feeding tube, and
- 4) be able to understand the interview questions and express/describe their experience in Danish

Characteristics of the four participants

Pseudonym	Marie	Anne	Hans	Peter
Age	18	27	30	60
Gender	Female	Female	Male	Male
Marital status	Single	Married	Single	Maried
Diagnosis	Head trauma	Encephalitis	Head trauma	Brain stem infarction
Days since injury	278	526	477	473
Type of feeding tube	Nasal	Nasal	Nasal + PEG	Nasal + PEG
Days on feding tube	31	39	137	172

Methods

PEG. Percutaneous Endoscopic Gastrostomy

An explorative study was conducted to study eating difficulties. 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.⁵

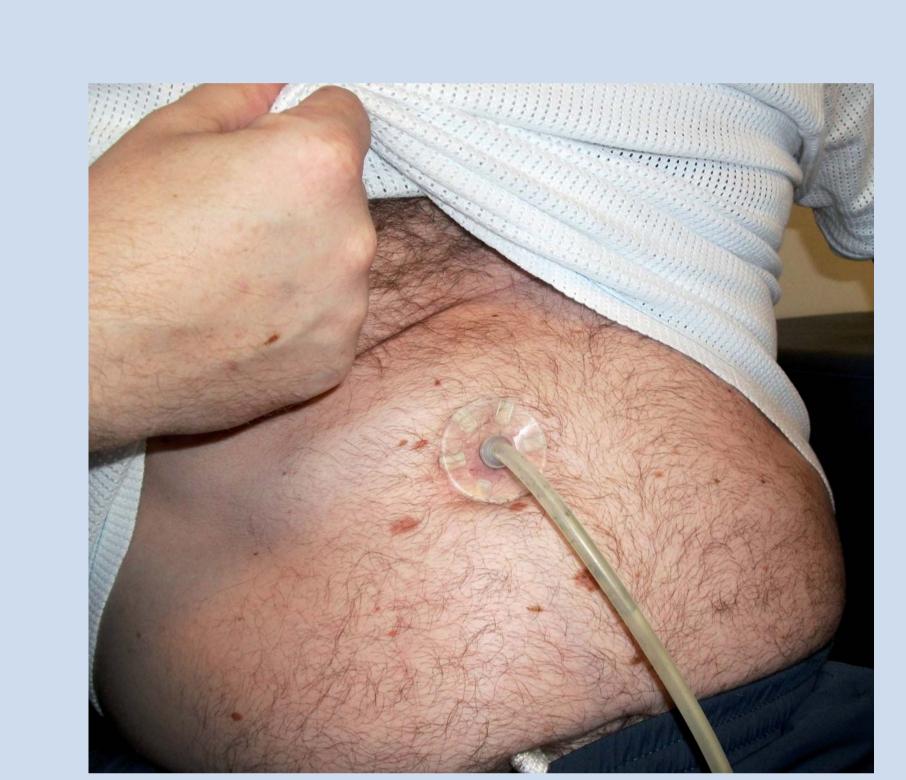


Results

Overall, the preliminary results suggest that the meaning of food and being able to eat and take part in meals may be nearly the same as before the ABI, however, having the ability to eat reduced or lost completely, even temporarily, was unexpected and difficult, and caused strong emotional reactions, even 18 months after injury. The findings provide preliminary information on the patient perspective of adapting to and developing new strategies for activities related to eating. Three predominating patient experiences were: Fed by tube, 'relearning' to eat and eating meals together.

Fed by tube

Especially for the two participants who had to use a PEG long-term, the experiences were something they wanted to forget and Peter found that the feeding tube delayed his initiation of oral intake. Even the two participants needing a nasal feeding tube for a short time described their negative experiences, such as Marie, who remembered the nasal tube as being annoying and affecting her mood. The psychological experience of a period with a feeding tube had a negative, but not persistent, impact on the participants' quality-of-life. After withdrawal of the feeding tube, the situation generally seemed to normalise, and each participant used different strategies to be able to participate in social gatherings. Our findings indicate tube feeding as having an important psychological factor for patients with ABI and a key focus area for the clinical awareness of health professionals in inpatient neurorehabilitation.



Conclusion

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 nearly the same as before the injury, however, having the ability to eat reduced or lost completely, even temporarily, was unexpected and difficult, and caused strong emotional reactions, even 18 months after injury. Time spent using a feeding tube had a negative, but not persistent, impact on quality-of-life. The 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 research is needed.

Future research

The optimal future study population would be patients with brain stem infarction, while they often have severe eating difficulties and still are able to verbally articulate their experiences in a reflective and meaningful manner. A prospective longitudinal design with a larger sample and with repeated interviews, for example prior to discharge and at 6 and 12 month and a more long term follow up 24 months after discharge, are recommended for future research to explore and interpret how people with ABI experienced and adapted to the problem and its resolution over time.

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