

# Brain injury and severe eating difficulties at admission



# - Patient perspective nine to fifteen months after discharge: A pilot study

Annette Kjaersgaard, PhD, OT¹ - Hanne Kaae Kristensen, PostDoc, OT²

<sup>1</sup>Hammel Neurorehabilitation Centre and University Research Clinic, Aarhus University, Denmark and Health Sciences Research Centre, University College Lillebaelt, Denmark

# 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. 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 & 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 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 ABI¹ and the time to initiation of oral intake and recovery of total oral intake before discharge.² The second phase, which is the focus of this poster, was a preliminary, explorative, qualitative, single interview study of four individuals with ABI.

#### The inclusion criteria were:

Diagnosed with an ABI and enrolled in the RCT study, severe dysphagia at the time of admission to inpatient neurorehabilitation, have or have had a feeding tube, and 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

PEG. Percutaneous Endoscopic Gastrostomy

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.



# Results

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 prospective, longitudinal research is needed.

#### References

2015;29(9):1094-104.

<sup>1</sup>Kjaersgaard A, Nielsen LH, Sjolund BH. Randomized trial of two swallowing assessment approaches in patients with acquired brain injury: Facial-oral tract therapy versus fibreoptic endoscopic evaluation of swallowing. Clinical Rehabilitation 2014;2008(3):243-53.

<sup>2</sup>Kjaersgaard A, Nielsen LH, Sjolund BH. Factors affecting return to oral intake in inpatient rehabilitation after acquired brain injury. Brain Injury

