A patient perspective on eating difficulties following brain injury

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Background
Eating is not just nutrient supply but entails also socialising and pleasurable experiences, and meals are often the focus of celebrations with family and friends. Dysphagia affects one of the most cardinal of human functions, the ability to eat and drink. Persons with dysphagia can become isolated, feel excluded by others, and be anxious and distressed at meals, and they often experience considerable limitations in their everyday life.

Objective
To explore and interpret how persons with ABI experience and adapt to reduced abilities of swallowing and eating.

Method
The study was an explorative multiple-case study with qualitative interviews of six persons two to 18 months following ABI. The inclusion criteria were: Enrolled in a randomised controlled trial (RCT) of two swallowing assessment approaches: Facial Oral Tract Therapy versus Fiberoptic Endoscopic Evaluation of Swallowing; had or have had a feeding tube and be able to understand the interview question and express/describe their experience. A constant comparative method was adopted for data analysis.

Results
Five main themes emerged from the analysis: 1) Personal factors; 2) Swallowing and ingestion; 3) Eating and drinking; 4) Communication and meals and 5) Inpatient neurorehabilitation of swallowing and eating. The predominating sub-themes are highlighted with selected quotes from the interviews.

What we learned
- Feeding by PEG tube provides an impact on the quality of life and is an experience that the person with acquired brain injury prefers to repress
- Initiation of oral intake is the main treatment goal when the person with ABI has no oral functions and first oral intake provides strong impressions
- The mouth is a very intimate area, but at the same time an area that needs attention in relation to treatment of difficulties in swallowing and eating