

A patient perspective on eating difficulties following brain injury

Annette Kjaersgaard, PhD OT ¹, Hanne Kaae Kristensen, PhD OT ², Tove Borg, PhD OT ¹

¹ Hammel Neurorehabilitation and Research Centre, Hammel, Denmark,

² The Clinical Institute, University of Southern Denmark and Odense University Hospital, Odense, Denmark

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

Treatment goal

"I very quickly got a treatment goal, because on Christmas Eve I wanted duck for dinner - and duck I had!"

Social interactions

"They did not invite us for a birthday party because they felt sorry for me This annoyed me because it affected my partner."

Worries

"I never worried about getting pneumonia, but it annoyed me that everybody else painted things in the darkest colours."

Guidance from the OT

"At the beginning of the rehabilitation I was damned that nothing happened, but now I see the purpose. I thought it took too long trying new things and all the time they talked about pneumonia."

Feeding by tube

"I was tube fed for more than five months. It was a tough time getting formula. Now I do not remember it because I would rather forget it. There are things that you push into the background, and bad experiences are things I push away."

Oral stimulation

"I hated when they gave me mouth massage or whatever it is called. I was fed up with it. I find this form of therapy very intimate and did not like it."

First oral intake

"I have never found yoghurt as tasty as when at last I was allowed to eat. It was like having a feast."

Mobilisation of the tongue

"It was somewhat different to have your tongue pulled, but the fact that it was effective was reason enough for me to find it okay."



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.

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