

Children and their parents' experiences of mealtimes when the child lives with a gastrostomy tube

Akademisk avhandling

Som för avläggande av filosofie doktorsexamen vid Sahlgrenska akademien, Göteborgs universitet kommer att offentlig försvaras i hörsal Arvid Carlsson, Academicum, Medicinaregatan 3, Göteborg, den 8 april klockan 13:00.

av **Ulrika Mårtensson**

Fakultetsopponent: Docent Pernilla Pergert, Karolinska Institutet, Sverige

Avhandlingen baseras på följande delarbeten

- I. Mårtensson U, Jenholt Nolbris M, Mellgren K, Wijk H, Nilsson S. The five aspect meal model as a conceptual framework for children with a gastrostomy tube in paediatric care. *Scand J Caring Sci.* 2021 Dec;35(4):1352–1361. doi: 10.1111/scs.12957.
- II. Mårtensson U, Cederlund M, Jenholt Nolbris M, Mellgren K, Wijk H, Nilsson S. Experiences before and after nasogastric and gastrostomy tube insertion with emphasis on mealtimes: a case study of an adolescent with cerebral palsy. *Int J Qual Stud Health Well-being.* 2021 Dec;16(1):1942415. doi: 10.1080/17482631.2021.1942415.
- III. Mårtensson U, Nilsson S, Jenholt Nolbris M, Wijk H, Mellgren K. Pain and discomfort in children with gastrostomy tubes - in the context of hematopoietic stem cell transplantation. Submitted, 2021.
- IV. Mårtensson U, Jenholt Nolbris M, Mellgren K, Wijk H, Nilsson S. Experiences of mealtime situations in hospital when a child with a malignant or non-malignant disorder lives with a gastrostomy tube – a qualitative study. In manuscript, 2021.

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Abstract

Oncology treatments and hematopoietic stem cell transplantation (HSCT) commonly contribute to side effects which influence the child's ability to eat and thus cause meals to be stressful. Bodily dysfunctions linked to the disability may cause long-lasting feeding difficulties in children with cerebral palsy (CP). This is why these groups of children may require enteral nutrition (EN) via a feeding tube to ensure their nutritional intake. It is not elucidated how children in different contexts of paediatric care experience meals before and after the placement of a feeding tube. Furthermore, no meal model was available within paediatric care with the purpose of describing mealtime situations in children. **The overall aim** of the thesis was to describe children and their parents' experiences of mealtime situations before and after a gastrostomy tube (G-tube) insertion and to develop a child-centred meal model focusing on meals and related environmental aspects. **Methods:** Semi-structured interviews and structured interviews (including questions with fixed answer options) were conducted with children (1–18 years of age) and their parents during the data collection carried out from 2018–2021. A qualitative-directed content analysis (Study I), an interpretive description approach (Study II), a mixed method design including descriptive statistics and a qualitative content analysis (Study III) and a thematic analysis (Study IV) were used during the analysis. **Findings:** Studies I and IV emphasised that the mealtime environment, hospital food and treatment-related side effects, along with sensorial challenges, aggravated meals and mealtime situations in children who underwent oncology treatments and HSCT. A G-tube insertion can cause postsurgery pain, which successively decreases after the healing process (Study III). A gastrostomy tube can be experienced as an alleviation, facilitating meals and mealtime situations, but also involves physical and psychosocial challenges (Studies I, II and IV). **The overall conclusion** is that children struggle with mealtime situations before and after the G-tube insertion. A G-tube facilitates meals but also presents physical and psychosocial challenges. For this reason, the paediatric care team must offer both children and their parents support and appropriate strategies in order to positively manage mealtime situations after G-tube insertion.

Keywords: Children, gastrostomy tube, mealtime situations, nursing, nutrition