



**CHALMERS**  
UNIVERSITY OF TECHNOLOGY

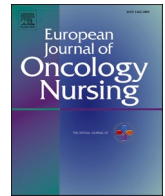
## **Meals are more than nutrition for children with a malignant or non-malignant disorder with a gastrostomy tube: A qualitative study**

Downloaded from: <https://research.chalmers.se>, 2024-10-16 06:46 UTC

Citation for the original published paper (version of record):

Mårtensson, U., Nolbris, M., Mellgren, K. et al (2024). Meals are more than nutrition for children with a malignant or non-malignant disorder with a gastrostomy tube: A qualitative study. *European Journal of Oncology Nursing*, 72.  
<http://dx.doi.org/10.1016/j.ejon.2024.102663>

N.B. When citing this work, cite the original published paper.



## Meals are more than nutrition for children with a malignant or non-malignant disorder with a gastrostomy tube: A qualitative study

Ulrika Mårtensson<sup>a,\*</sup>, Margaretha Jenholt Nolbris<sup>b,c</sup>, Karin Mellgren<sup>b,d</sup>, Helle Wijk<sup>c,e</sup>, Stefan Nilsson<sup>b,c,f</sup>

<sup>a</sup> Faculty of Care Science, Work Life and Social Welfare, University of Borås, SE - 501 90, Borås, Sweden

<sup>b</sup> The Queen Silvia Children's Hospital, SE- 416 50, Gothenburg, Sweden

<sup>c</sup> Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, SE- 405 30, Gothenburg, Sweden

<sup>d</sup> Department of Paediatrics, Institute for Clinical Sciences, Sahlgrenska Academy, University of Gothenburg, SE- 416 85 Gothenburg, Sweden

<sup>e</sup> Chalmers Technology University/Centre for Health Care Architecture, SE- 412 96, Gothenburg, Sweden

<sup>f</sup> Centre for Person-Centred Care, University of Gothenburg, SE- 405 30, Gothenburg, Sweden

### ARTICLE INFO

#### Keywords:

Children  
Hospital  
Gastrostomy tube  
Meals  
Mealtime situations  
Nutrition

### ABSTRACT

**Purpose:** To elucidate mealtime experiences of children hospitalized with a malignant or severe non-malignant disorder—and their parents—after a gastrostomy tube insertion.

**Methods:** A qualitative design involving a child-centred care approach was used. Parents of children aged 1–18 years old who had received a gastrostomy tube during treatment for a malignant or non-malignant disorder were included, as were the children themselves when aged 5–18 years old. Semi-structured interviews with 21 families were carried out and a thematic analysis performed.

**Results:** The findings were presented in four themes: changed meal conditions, a troublesome sensory dimension, aggravating obstacles and solving the unmanageable. Hospitalization involves challenges regarding environmental aspects, hospital food and side effects, contributing to impaired nutritional intake and aggravated mealtime situations.

**Conclusions:** Hospital environment and hospital food have a profound impact on children's nutritional intake and mealtime situations. In addition, sensory aspects and side effects aggravate the child's motivation to eat, resulting in demanding meals. The families described a gastrostomy tube as a valuable strategy for improving mealtime situations.

### 1. Introduction

Meals involve a social construction, an activity enabling a child to interact and socialize (Scaglioni et al., 2018). They are, however, also a source of control linked to the child's willingness to eat (Beckers et al., 2021; Haines et al., 2019). Eating habits develop in early life, which is why parents and their approach to meals and mealtime situations have a profound impact on a child's eating behaviour (Beckers et al., 2021; Haines et al., 2019). Nevertheless, children's meals are not only influenced by the mealtime environment, sensory impressions and socializing (Haines et al., 2019), but also by culture and norms (Larson and Story, 2009).

A disease or illness may affect the body, which can have an impact at

the child's nutritional intake and meals (Larsen and Uhrenfeldt, 2013), aspects which are of greatest importance throughout a hospitalization (The National Food Agency) and oncology treatments such as a hematopoietic stem cell transplantation (HSCT) (Fuji et al., 2015; Joffe and Ladas, 2020; Fuji et al., 2015). This is why the child can be in need of enteral nutrition (EN) via a gastrostomy tube (G-tube) (Trehan et al., 2020).

To our knowledge, there is a lack of research based on children and their perspective regarding meals and a G-tube within the paediatric care. In addition, it has not yet been elucidated how children with malignant and severe non-malignant disorders and their parents experience meals after a G-tube insertion. There are no studies following a complete health-care process, which is why further research is needed to improve

\* Corresponding author. Faculty of Care Science, Work Life and Social Welfare, University of Borås, Allégatan 1, SE - 501 90, Borås, Sweden.

E-mail addresses: [ulrika.martensson@hb.se](mailto:ulrika.martensson@hb.se) (U. Mårtensson), [margaretha.nolbris@fhs.gu.se](mailto:margaretha.nolbris@fhs.gu.se) (M. Jenholt Nolbris), [karin.mellgren@vgregion.se](mailto:karin.mellgren@vgregion.se) (K. Mellgren), [helle.wijk@gu.se](mailto:helle.wijk@gu.se) (H. Wijk), [stefan.nilsson.4@gu.se](mailto:stefan.nilsson.4@gu.se) (S. Nilsson).

<https://doi.org/10.1016/j.ejon.2024.102663>

Received 29 November 2023; Received in revised form 5 July 2024; Accepted 8 July 2024

Available online 16 July 2024

1462-3889/© 2024 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

meals and the physical environment for hospitalized children who have received a G-tube.

## 2. Background

A child undergoing oncology treatment or a HSCT usually experiences an impaired ability to eat due to side effects such as nausea, vomiting (Beaulieu-Gagnon et al., 2019; Loves et al., 2020) and oral mucositis (Donohoe et al., 2018; Joffe and Ladas, 2020). Changes in taste (Loves et al., 2019; van den Brink et al., 2021) and smell may also occur (Beaulieu-Gagnon et al., 2019; van den Brink et al., 2021). The child's food intake may be adversely affected with risk of reduced appetite (Beaulieu-Gagnon et al., 2019; Loves et al., 2020), impaired nutritional status and malnutrition (Fuji et al., 2015; Joffe and Ladas, 2020). Parental responsibility involves providing the child with adequate nutrition (UNICEF., 2021). However, obligations and nutritional concerns may aggravate the situation, contributing to challenging meals (Beaulieu-Gagnon et al., 2019; Fleming et al., 2015). Such circumstances can arise due to aspects having an adverse impact on the child's food intake including treatment and its negative side effects, as well as issues concerning the hospital food itself (Arpaci et al., 2018; Beaulieu-Gagnon et al., 2019). As a result, routines and strategies to manage the situation may be changed (Beaulieu-Gagnon et al., 2019; Gibson et al., 2012), affecting the feeding approach and thus mealtime situations (Beaulieu-Gagnon et al., 2019; Brinksma et al., 2020). Food intake has a profound impact on nutritional status (Viani et al., 2020), thus affecting the child's survival (Joffe and Ladas, 2020; Wiernikowski and Bernhardt, 2020). Consequently, a G-tube may be required, involving a bodily alteration for the child (McGrath and Hardikar, 2019; Trehan et al., 2020).

A G-tube placement is a common and safe intervention used in children (Homan et al., 2021), also in severe long-term illnesses such as childhood cancer (Heuschkel et al., 2015; Homan et al., 2021; Trehan et al., 2020) and for those who undergo a hematopoietic cell transplantation (HCT) (Mellgren et al., 2023). However, the child's need of a G-tube requires an individual consideration, assessment and decision (Heuschkel et al., 2015; Homan et al., 2021; Homan et al., 2021; McGrath and Hardikar., 2019). A G-tube can be placed proactively (Kotch et al., 2023; McGrath and Hardikar, 2019; Kotch et al., 2023) or reactively (McGrath and Hardikar, 2019) depending on the child's condition and needs (McGrath and Hardikar, 2019). It has been demonstrated that a G-tube insertion due to malignant disorders (Evans et al., 2021; Kairiene et al., 2023), as well as severe non-malignant disorders (Kairiene et al., 2023) and its treatments, for example HSCT (Kairiene et al., 2023) and bone marrow transplant (BMT) (Evans et al., 2021), can result in both benefits and positive outcomes for the child (Evans et al., 2021; Kairiene et al., 2023).

### 2.1. Theoretical framework

The Five Aspect Meal Model (FAMM) emphasizes not only the physical environment (the room and the atmosphere), but also further aspects (the meeting, the product and the managing control system) affecting meals and associated experiences (Edwards and Gustafsson, 2008; Gustafsson et al., 2006). It thus constitutes the basis of the Modified version of the Five Aspect Meal Model (M-FAMM), adapted specifically for children with a G-tube within paediatric care (Mårtensson et al., 2021a, 2021b). M-FAMM encompasses two further aspects – bodily discomfort and time of change and acceptance – which seems necessary to consider when facing potential challenges in conjunction with mealtime situations (Mårtensson et al., 2021a, 2021b).

## 3. Overall aim

To elucidate mealtime experiences of children hospitalized with a malignant or severe non-malignant disorder—and their parents—after

a G-tube insertion.

## 4. Methods

### 4.1. Design

In this study, a qualitative design was used. Individual, semi-structured interviews were carried out with the children and their parents. A child centred care (CCC) approach (Nilsson et al., 2015; Söderbäck et al., 2011) was central. The child's perspective was represented, along with the necessary and complementary parental perspective, which was the main focus of this study. The M-FAMM (Mårtensson et al., 2021a, 2021b) was used as a theoretical framework to elucidate meals and the mealtime environment.

Data was repeatedly collected from children and parents throughout the complete healthcare process between May 2018 and April 2021 to elucidate the hospital mealtime experiences of children after a G-tube insertion, see Fig. 1. A thematic analysis was used to analyse the qualitative data gathered (Braun and Clarke, 2006; Braun and Clarke, 2021). Standards for Reporting Qualitative Research (Equator Network, 2022) was used to ensure the quality of the study.

### 4.2. Data collection

#### 4.2.1. Setting

Data collection was performed between 2018 and 2021 at a Childhood Cancer Centre in Sweden. The Childhood Cancer Centre, also a HSCT centre, consists of two paediatric oncology units where both children with malignant and severe non-malignant disorders receive care and treatment. The children diagnosed with a severe non-malignant disorder, for examples see Table 1, required equivalent oncology care and treatments (included a HSCT), as those with a malignant disorder. As a result, the children included in the study had similar prerequisites since they all underwent comparable care and treatment, but also were offered similar food.

To achieve a holistic perspective of the children and their parents' mealtime experiences, the data collection was performed repeatedly during the child's complete health care process, see Fig. 1.

The child comes to the hospital unit (I) where the oncology diagnosis is determined (II). The child and his/her parents receive information about the disease as well as planned care and treatment (III). The child undergoes examinations (IV) and procedures (V). A G-tube is mostly necessary (V) since treatments (VI) can result in side-effects (VII), see Fig. 1.

#### 4.2.2. Participants and participant recruitment

Parents of children aged 1–18 years old who had received a G-tube for medical reasons during treatment for a malignant or severe non-malignant disorder were asked to participate in the study, as were the children themselves when aged between 5 and 18 years old. Children within a wide range of ages were offered to participate in the study. This in order to involve a total population, aiming to gain a variety of experiences. Children who had a serious medical condition (assessed by physicians and nurses on the ward) and who declined participation or were younger than five years old were excluded from the data collection (see Fig. 2).

A total of 11 families were excluded for various reasons (see Fig. 2). All families were included regardless of language, culture and origin. Interpreters were available when participants were not sufficiently competent speaking or writing in Swedish or English.

#### 4.2.3. Interviews

Semi-structured individual interviews were carried out with a total of 21 families, including 8 boys and 13 girls born between 2003 and 2017. From these 21 families, 9 children (1 boy and 8 girls) and 29 parents (17 mothers and 12 fathers) participated (see Table 2).

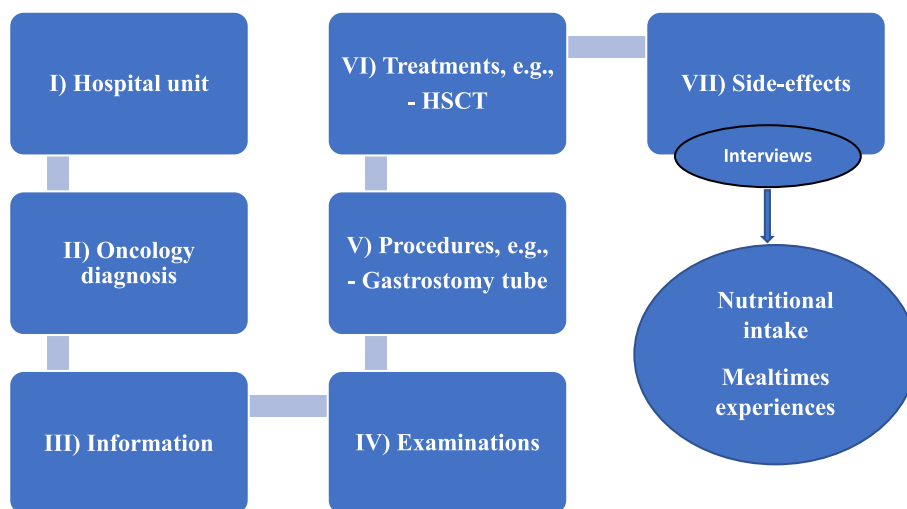


Fig. 1. The child's health care process.

**Table 1**  
Overview of participating children and conducted interviews.

Diagnosis	Children	Sex	Born	HSCT	Date of G-tube insertion	Date of interview(s) Child	Date of interview(s) - Parents F = Father M = Mother
Malignant							
Brain tumour	2	Girl	2009	No	Nov 2018	Feb. 2019	M = Feb. 2019
		Girl	2015	Yes	Dec 2019	No one	M = July 2020 + Sept. 2020 + March 2021
Leukaemia	5	Boy	2007	Yes	Jan 2020	No one	F = June 2020 + Nov. 2020
		Boy	2014	Yes	May 2018	No one	F = June 2018 M = June 2018
		Boy	2014	Yes	Apr 2020	Oct. 2020 + April 2021	F = Oct. 2020 + April 2021
		Boy	2016	No	Dec 2018	No one	M = May 2019
		Girl	2016	Yes	Oct 2018	No one	M = May 2019 + April 2020
Neuroblastoma	1	Boy	2017	Yes	Dec 2018	No one	M = Feb. 2019
Sarcoma	3	Girl	2005	No	Oct 2019	No one	M = June 2020
		Girl	2009	No	Nov 2018	Feb. 2019	M = Feb. 2019 F = Feb. 2019
		Girl	2014	No	May 2019	No one	M = June 2020 + Sept. 2020 + March 2021
							F = June 2020
Wilm's tumour	1	Girl	2012	Yes	Oct 2018	Mars 2019 + May 2020	M = March 2019 + May 2020
Non-malignant							
Aplastic anaemia	2	Girl	2009	Yes	Jan 2018	May 2018	F = May 2018 M = May 2018
		Girl	2010	Yes	Feb 2019	April 2019 + Feb. 2020	F = March 2019 + Feb. 2020
Hurler's disease	1	Boy	2017	Yes	Apr 2018	No one	F = June 2018 + Sept. 2018
							M = June 2018 + Sept. 2018 + March 2020
SCID	1	Girl	2016	Yes	Mars 2018	No one	F = May 2018 + Sept. 2018
							M = May 2018 + Sept. 2018 + Feb. 2019
Sickle cell anaemia	3	Girl	2006	Yes	Sept 2019	Nov 2019 + June 2020	M = Nov. 2019 + June 2020
		Girl	2009	Yes	Jan 2019	March 2019 + April 2020	M = March 2019 + April 2020
		Boy	2015	Yes	Aug 2019	No one	M = June 2020 + F = June 2020
Thalassemia	2	Boy	2003	Yes	Sept. 2018	No one	F = Oct. 2018 + Apr. 2019 + March 2020
		Girl	2008	Yes	Jan 2018	May 2018 + Sept. 2018	F = May 2018 + Sept. 2018 M = May 2018

The children had received the following diagnoses: aplastic anaemia (2), brain tumour (2), Hurler's disease (1), leukaemia (5), neuroblastoma (1), sarcoma (3), SCID (1), sickle-cell anaemia (3), thalassemia (2) and Wilms' tumour (1) (see Table 2). In total, 64 semi-structured interviews (15 with children and 49 with their parents) were carried out, each lasting between 14 and 35 min (mean: 23 min) for the children — and between 16 and 69 min (mean: 35 min) for the parents. See Tables 1 and 2

All interviews were performed after the child's G-tube insertion. Nine children were interviewed, which resulted in a total of 15 child interviews. Three children were interviewed once each and six children twice each, see Tables 1 and 2 and Fig. 2. Complementary interviews were performed with 12 of their parents, which resulted in a total of 18 parental interviews. One parent was interviewed once, seven parents twice each and one parent at three times, see Tables 1 and 2 and Fig. 2. A total of 17 parents represented their children by proxy interviews, which resulted in 31 interviews. Four parents were interviewed once each, six

parents twice each and five parents three times each, see Tables 1 and 2 and Fig. 2. A total of 49 parental interviews were conducted, see Tables 1 and 2 and Fig. 2 These by proxy interviews gave an additional view and a parental perspective of the child's situation to the results. All interviews were conducted one to three times over the course of the total healthcare process between 2018 and 2021. One child and two parents needed interpreters during the interviews. See Tables 1 and 2

The first author (U.M.) (female PhD-student) individually conducted semi-structured face-to-face interviews (Polit and Beck, 2016) with the children and their parents after the G-tube insertion, and then repeatedly during the child's care and treatment — or until the G-tube was removed (see Table 1). A long-term relationship was thus established with the participants, leading to them having a clear awareness of the first author's (U.M.) occupation and goal of research. Interviews continually carried out over the course of the healthcare process enabled the participants to comment and reflect on the content of the process as a whole.

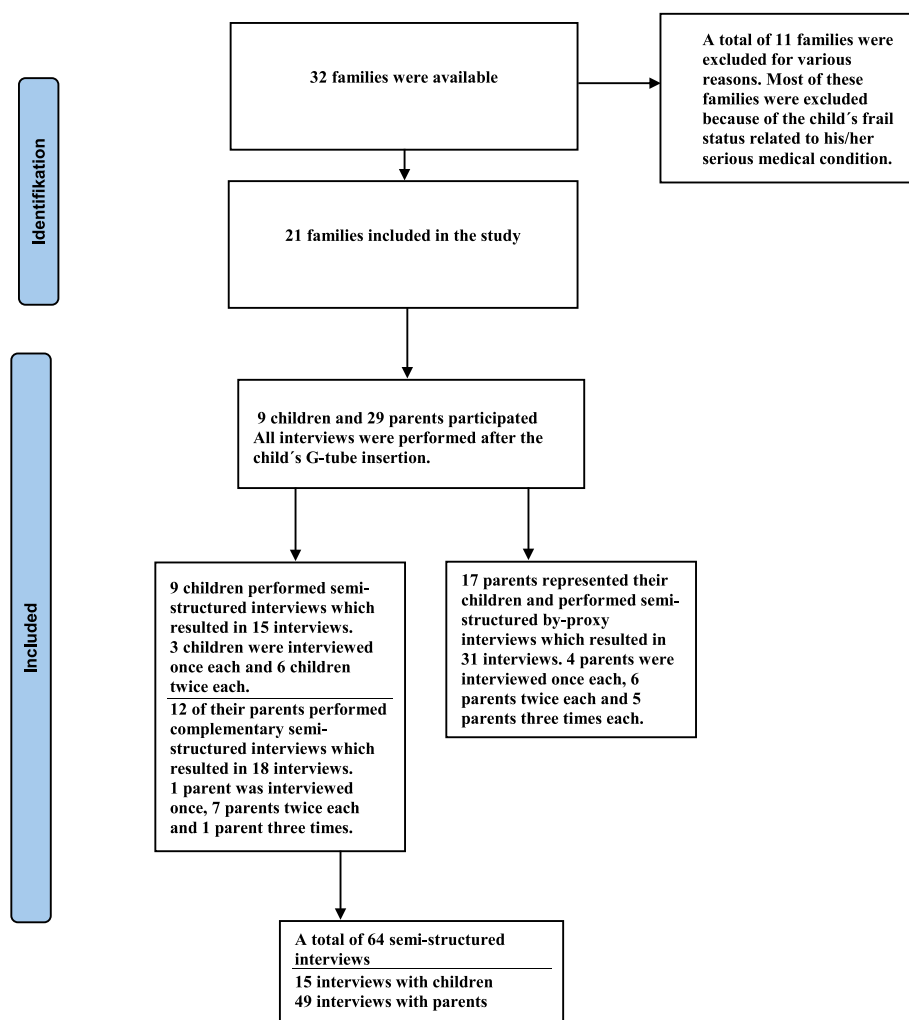


Fig. 2. Overview of the recruitment process.

**Table 2**  
Overview of the data collection.

Data collection		
Included children (n = 21)	Boys (n = 8)	Girls (n = 13)
Children interviewed (n = 9)	Boys (n = 1)	Girls (n = 8)
Parents interviewed (n = 29)	Fathers (n = 12)	Mothers (n = 17)
Parental complementary interviews (n = 12)	Fathers (n = 5)	Mothers (n = 7)
Parental by-proxy interviews (n = 17)	Fathers (n = 7)	Mothers (n = 10)
Total number of interviews (n = 64)	Children (n = 15)	Parents (n = 49)
Length of interviews	14–35	16–69
Number of opportunities for interviews	1–3	1–3
Interview guide	The M-FAMM	The M-FAMM

The interviews were audio recorded but no field notes were taken. The previously adapted M-FAMM (Mårtensson et al., 2021a, 2021b) served as a basis for the interviews. This means that the questions in the interviews were based on the aspects included in FAMM, namely the room, the meeting, the product, the management control system and the atmosphere (Edwards and Gustafsson, 2008; Gustafsson et al., 2006) as well as the aspects added into the M-FAMM, namely bodily discomfort and time of change and acceptance (Mårtensson et al., 2021a, 2021b).

The children were introduced to the research area via a questionnaire with visualized information supported by pictures, e.g., regarding the G-tube and meals. The interviews made it possible for the children to self-report their own experiences. In the interviews, the conversation

started with pictorial support material, and the child’s own G-tube served as a starting point for their story. If the children were not able or had the opportunity to participate by themselves, both the parents were asked to share their parental views and perspectives of the child’s situation.

All children and parents were interviewed separately. The children were given the choice of whether they wanted their parents to be present during the interviews or not. The interviews were conducted face-to-face, both at the hospital and in the family’s home. From the spring of 2020, restrictions due to the COVID-19 pandemic required social distancing, which thus necessitated a shift to digital interviews (e.g., by facetime and zoom), in order to carry out the data collection (Morgan and Hoffman, 2020). The first author (U.M.) met and interviewed the majority of participants physically at least once before the Covid-19 pandemic started, and had thereby established a contact, which facilitated further interviews.

#### 4.3. Analysis

Since the M-FAMM framework served as a foundation (Mårtensson et al., 2021a, 2021b), the participants discussed and emphasized various aspects influencing meals and mealtimes during the interviews. In this study, we analysed data concerning meals and mealtime experiences from the interviews. Data focusing on pain and discomfort from the interviews have been summarized in another study (Mårtensson et al., 2023).

Thematic analysis was used to identify, analyse and interpret the qualitative data (Braun and Clarke, 2006; Clarke and Braun, 2017), since this method is flexible and lends itself to use in research which includes a framework, but also a large sample of data involving a focus on lived experiences (Clarke and Braun, 2017). The large sample of compiled data contributed to achieving saturation (Polit and Beck, 2016). All the data, both the child interviews as well as the complementary and by proxy parental interviews, were read and analysed continuously and in parallel during the process. By using thematic analysis as a tool during the analysis process, the researchers could develop codes and themes within the data (Braun and Clarke, 2006; Clarke and Braun, 2017). The children's interviews and their child perspective were central during the process even if all the transcripts were seen as a whole during the analysis. As a result, both the child's perspective and the parental child perspective are represented in the results.

The first (U.M.) and last author (S.N.) analysed and discussed the compiled data regularly before identifying possible codes and themes. The six steps in the analysis process involved getting to know the collected data, create codes, identify, process and establish themes as well as create the manuscript, and were adapted from Braun and Clarke (2006). The longitudinal process made it possible for the first author (U.M.) to reflect upon meanings in the collected data, and if necessary, carry out member checks (Carter et al., 2014; Polit and Beck, 2016). The participants could therefore verify the data, thus strengthening the trustworthiness of the study. The analysis involved qualitative data only with no use of software.

#### 4.4. Ethical considerations

The study was approved by the Regional Ethics Review Board (937-17 and 2019-05671). The first author (U.M.) informed all the children and their parents about the study, both verbally and in writing. All the caregivers gave their written consent, and the children gave their assent to participate in the study.

## 5. Results

The results highlight mealtime experiences of children after a G-tube insertion due to oncological treatment and HSCT at a paediatric oncology ward, as well as those of their parents. The analysis of the transcripts resulted in the following themes: *changed meal conditions*, *a troublesome sensory dimension*, *aggravating obstacles* and *solving the unmanageable*.

Most of the interviews were complementary parental interviews, but the child's own perspectives were also highlighted, since a CCC approach was central to this study. Thus, the results include the child's perspective (Nilsson et al., 2015; Söderbäck et al., 2011), even if the parent's complementary perspective on the child is predominant, all to obtain a broader point of view about mealtime experiences in daily life. This is important as meals are social occasions when children and parents interact (Scaglioni et al., 2018). The results are therefore presented from three perspectives: the child's, the mother's and the father's. As a result, triangulation (Carter et al., 2014) between three different perspectives was possible, which strengthens the trustworthiness of the study.

### 5.1. Changed meal conditions

Hospitalization resulted in an unfamiliar situation for the children. The change to their mealtime environment aggravated their ability to eat, while the parents' ability to create appealing meals worsened.

The child's hospitalization involved a new and unknown context. It was described as sterile and impersonal, and meals had to be served in this environment. Most of the children had to stay isolated in their rooms due to factors such as risk of infection (aggravated by the Covid-19

situation), and this minimized their ability to socialize. The isolation negatively affected the children's motivation to eat: "... I enjoy eating with my siblings more ... When I'm eating alone, I don't want anything" (a ten-year-old girl). Lack of space and furnishing also contributed to challenges, which aggravated meals and mealtime situations further: "I think it was the environment in the room itself, it was not great ..." (father of a seventeen-year-old boy).

The environment was associated with treatments, procedures and chaotic feelings, as well as experiences of pain and bodily discomfort, which contributed to meals being perceived as unappealing: "It's somewhere medications are given, unpleasant things are happening most of the time ... it isn't a place where x finds [...] meals pleasant" (mother of a four-year-old boy).

Ongoing treatments, side effects and the child's condition contributed to meals being served in bed, which is why medical equipment such as beeping machines, drip stands and tubes constituted a central and inevitable part of mealtime experiences: "Most often x was eating in bed because it was the easiest thing to do with all the drip stands and tubes ..." (mother of a three-year-old boy).

In addition, interruptions to mealtime situations were common due to care such as medication, checks and controls, which contributed to impaired food intake, mess and consequently unappealing meals: "... there was constantly something going on, there was someone entering the room or some medications to take or check-ups ... there was always a lot going on around, so eating did not work out ..." (mother of a three-year-old girl). Thus, mealtime situations became associated with a task related to treatment, leading to feelings of control and additional requirements: "... x started to have special times when x should have the nutrition ... I felt as if I did nothing other than push food into x ..." (mother of a five-year-old boy). Meals and mealtime situations changed focus, with familiar and social activity disappearing, only to be replaced by stress and pressure: "... it was not like when we used to get together ... now we're going to eat and ... we would have a cosy time together [before], all that just stopped ..." (mother of a four-year-old girl).

### 5.2. A troublesome sensory dimension

Hospital food was bothersome for children undergoing oncology treatment. Sensory aspects such as smell, taste and visual impression of the food adversely affected the meals and contributed to reduced appetite, as well as difficulty in maintaining nutritional intake. Hospital food was reported to be a major concern since it resulted in pronounced sensory challenges. For example, most children described the smell as awful — an unpleasant impression that permeated mealtimes: "... I don't think it smells good ..." (a seven-year-old girl). Most parents shared their children's opinion regarding the smell, as it contributed to bodily discomfort, impaired nutritional intake and unappealing meals for the children: "... the food in the hospital ... everything tastes and smells really bad ..." (father of a ten-year-old girl). The smell of the food contributed to most children starting to use an avoidance tactic, as facing food was too difficult to manage and involved strong reactions: "... it happened many times that x said ... please leave, I am feeling sick" (mother of a nine-year-old girl). The process of removing the lid from the plate was described as overwhelming due to the odour, which is why meals mostly ended up with the food being rejected.

The taste of the hospital food was also described as bothersome — an additional concern because this aggravated nutritional intake: "... it is so weird and disgusting ... it is such bad food" (a ten-year-old girl). Most children had negative experiences regarding the food and described the taste as awful and unbearable: "... it was the most disgusting thing I have ever eaten" (a ten-year-old girl). The taste aggravated food intake and amplified any side effects, which contributed to additional bodily discomfort and thus made meals problematic and unappealing: "This food was very spicy ... some very strong spices ... we were in the paediatric ward ... children don't usually like spices so much ... x could not eat, especially if x had sores in the mouth ..." (mother of a fourteen-year-old girl).

The taste of the hospital food was not considered appropriate for the children and their needs, nor was it adapted to suit severely ill children on a paediatric oncology ward, which is why mealtime situations mostly ended up in feelings of disappointment and failure: "... hospital food ... I already know how it tastes ... I do not want it ..." (a nine-year-old girl).

The visual impression, i.e., the arrangement of the hospital food, had a great impact on the children's meals. The food, which came prepared on a covered plate on a tray, was brought to the child's room, thus limiting the scope to arrange attractive meals. This had a negative effect on the children: "... if you just toss a food tray [into the room] without saying anything, and it is just positioned there, it does not appeal ..." (father of a six-year-old boy). The appearance of the food was crucial in motivating the child to taste it: "... then you lift this lid ... X did not even want to taste, because it looked disgusting ..." (mother of a seven-year-old girl). In addition, food colour influenced the children's mealtime experiences, a critical aspect affecting nutritional intake: "... the soup comes in a bowl, a beige bowl containing a beige soup ... all the soups have the same colour ... it's terrible. X did not even want to eat it" (mother of a thirteen-year-old girl).

Portion sizes were also highlighted as a factor making mealtime situations unmanageable for most children: "It looks ... like so much ... I mean the irony of the situation ... you are admitted [to the hospital] ... there are a lot of children with a very poor appetite and then ... there is this big portion for an adult on a plate ..." (mother of a seven-year-old girl). Large portions, described as inappropriate, were met with dismay as the children were already having trouble eating. As a result, children and parents tried to adapt and solve the situation themselves to create more favourable conditions: "... you felt disgusted by so much food ... then I just had to dish it out in smaller portions. It felt better ..." (a fourteen-year-old girl).

### 5.3. Aggravating obstacles

Aggravating obstacles such as side effects and complications due to the oncology treatment contributed to challenges at mealtimes. Sensory changes, as well as pain and bodily discomfort, contributed to a complex eating situation, mostly with reduced appetite and food rejection as a result.

Oncology treatments contributed to experiences of altered smell and taste, resulting in frustration and disappointment because dishes that were once the child's favourites did not taste the same anymore: "You put something inside [in the mouth] that you know tastes nice and then it tastes really weird" (a thirteen-year-old girl). Consequently, sensory changes contributed to food refusal, which led to a sense of powerlessness and frustration for both children and parents, as no amount of encouragement or attempts to get the child to eat worked: "... x said ... that's disgusting ... x knew it would be like that ... x knew that it would not taste anyway ... it is an extremely difficult situation ..." (father of a seven-year-old boy). As a result, the children gradually resigned themselves to not being able to taste the food, making it increasingly difficult to get them to eat.

Most children struggled with a reduced appetite: "... x did not want to eat ... it was ... difficult ... x did not have much of an appetite ..." (father of a ten-year-old girl). In addition, side effects such as oral mucositis contributed to painful food intake and made meals unappealing: "... when x had received the stem cell transplant, x felt pain in the mouth, x got blisters ... so x stopped eating ... since then, x has not eaten anything ..." (mother of a two-year-old boy). Noticeable bodily discomfort—for example, caused by nausea and vomiting—contributed to developing a food aversion: "... I can feel nauseous ... then you are not so hungry" (a nine-year-old girl). As a result, the atmosphere during mealtimes became stressful and associated with constant concern: "I know x wants to eat but x cannot [eat] or has no appetite ..." (father of a ten-year-old girl).

The children struggled to manage the situation and their psychosocial well-being became affected, leading to feelings of failure: "I just got annoyed when the food was served, because I was never hungry" (a fourteen-

year-old girl). However, commencing tube feeding could also contribute to bodily discomfort at meals: "... if it comes quickly, I will feel sick and I will vomit" (a ten-year-old girl). The rate and amount of food given was problematic to adjust and balance and could therefore result in negative experiences: "X usually throws up when x takes the food through the button [the G-tube] ... when it comes too fast, x will throw up" (father of a one-year-old boy). As a result, the parents struggled with feelings of inadequacy and a permanent concern for the child's well-being at mealtimes: "... now there is a concern every time they switch on the food, because I know x will get a lot of stomachache and then probably vomit ..." (mother of a two-year-old girl). In addition, some of the children found the taste and smell of the tube feeding aggravating and problematic, which complicated the situation further: "... x does not like the smell from the food [the tube feeding] ... x says ... it smells bad. X burps and feels that it is disgusting ..." (mother of a ten-year-old girl).

### 5.4. Solving the unmanageable

As illustrated by the patient feedback, nutritional intake was troublesome and constituted a major concern for the hospitalized children. To help remedy this, they were offered their preferred foods at the hospital, and the parents cooked or brought homemade food to encourage their children to eat. Nevertheless, the G-tube became a necessary complementary measure to ensure the children received adequate nutrition during their treatment for a life-threatening disorder.

Mealtime situations became associated with expectations and requirements. Most attempts to eat ended up in disappointment and feelings of failure: "I started to cry inside because I could not eat" (a seven-year-old boy). Despite being offered several meal options to encourage their food intake, the children's motivation and ability to eat remained poor: "... there were a few different options ... that x would be able to choose from, but x still did not want that food ..." (mother of a ten-year-old girl). Even when the children were offered their preferred food, the taste was unappealing, thus doing nothing to improve food intake: "... x got her own choice of foods ... the food was probably just tasteless ..." (father of a nine-year-old girl). The children seemed to prefer cold food; they would sometimes experience cravings for snacks offered between ordinary meals.

However, food intake was not noticeably improved despite attempts to eat the food they desired: "... X used to sometimes say that she wanted yoghurt ... but as soon as they give it to her, she does not eat it anyway" (mother of a six-year-old girl). In some cases, children expressed cravings for specific food or dishes they preferred to eat at home before the treatment process and the parents made an effort to resolve the situation to meet their children's needs: "... when you are admitted to hospital, then you can choose ... so you can bring stuff with you and cook and so on ..." (mother of a ten-year-old girl). The parents cooked food in the hospital kitchen or brought homemade dishes to the child: "She can cook outside here ... she usually cooks it for me ... then I eat a few spoonful's because I can't eat that much" (a ten-year-old girl).

The parents tried to accommodate all the requests but mostly without success: "... x talked about our food ... when he was offered [our food] he still did not eat ..." (father of a four-year-old boy). They would even go shopping any time of the day to encourage the child to eat but this mostly ended in disappointment: "... x started to get cravings for some specific foods, so I went out shopping ... I went out and bought what she wanted. But obviously she did not eat" (mother of an eleven-year-old girl).

As a result, the joy of food gradually disappeared, with meals and mealtime situations instead being associated with feelings of seriousness and concern, as nutritional intake was a crucial part of the child's treatment. Feeling stress and pressure due to a sense of huge responsibility, the parents struggled to manage their child's food intake, adding to the demanding situation surrounding meals: "X used to just say no, he used to refuse all the time when he was offered food" (father of a thirteen-year-old boy). Most attempts to motivate the child to eat were unsuccessful, gradually leading to feelings of failure and resignation in

conjunction with mealtime situations: “*X has given up and we have given up because it does not matter ...*” (father of a two-year-old girl). Ensuring the child received the required nutrition thus became problematic, which was why a G-tube became necessary.

Some parents considered the G-tube as an additional medical necessity, a supportive aid to manage the child’s problematic food intake, while other parents viewed the child’s food intake as a basic need which was their responsibility, and thus initially associated the G-tube with parental failure: “... *These meal situations are full of tension ... the body needs to get nutrition ... as a parent it is your task to ensure your child gets that nutrition ...*” (mother of an eight-year-old girl). As a result, some parents at first struggled with their feelings and needed time to accept the change and see the G-tube as a necessary complement, facilitating the child’s nutritional intake and meals.

However, most children felt the G-tube provided an immediate improvement. The G-tube brought relief and reduced the requirements and pressure to eat, leading to improved mealtime situations: “*It was good, it helped ... in reality I was hungry, but I did not want to eat anything*” (an eleven-year-old girl). Some parents nevertheless needed time to see the advantages, gradually realizing that the G-tube made it possible to ensure the child had necessary nutrition and resulted in more relaxed meals: “*It was very safe to have it ... to avoid this nagging ... so you had that option ...*” (father of a five-year-old boy). This changed the focus of eating, as the G-tube provided a solution, alleviating distress and helping to restore the appeal of mealtime situations: “... *it was almost our saviour ... we could stop nagging at her ... and feed her with the tube [the G-tube], it gave her peace of mind, and so she also started eating more on her own ...*” (mother of a fifteen-year-old girl).

A G-tube could also contribute to feelings of loss, a divergent mealtime experience that affected psychosocial well-being: “*It becomes more practical ... technical ... you just get on with it ... it became a thing you do alone*” (mother of a three-year-old boy). Nevertheless, the G-tube was mostly associated with security, and seen as a supportive and necessary complement, facilitating meals and mealtime situations: “... *you know that x is getting what she needs ... you can relax. Because it isn’t much fun to force someone to eat when they aren’t capable*” (father of a six-year-old girl).

## 6. Discussion

This is a novel study, elucidating the impact of mealtime experiences after a G-tube insertion throughout a complete healthcare process in hospitalized children and their parents within the oncology care and the field of HSCT. To our knowledge, there is a lack of research based on children and their perspective within the research field, why the findings of this study partly are discussed in contradiction of research performed in adults.

This study demonstrates that hospitalized children with a G-tube struggle with their meals and mealtime situations. The findings show that the hospitalization and the hospital environment are central, negatively affecting the child’s food intake and meals — an observation which is in line with previous research (Arpaci et al., 2018; Beaulieu-Gagnon et al., 2019), also in hospitalized adults (Furness et al.; Treleaven et al.; Young et al., 2024).

Being isolated in small rooms seems to have a great impact on children’s meals, which correspond with findings that a lack of contact with family members (Arpaci et al., 2018; Klanjsek and Pajnikihar, 2016) and the stress of being hospitalized (Beaulieu-Gagnon et al., 2019; Viani et al., 2020) may contribute to eating problems (Arpaci et al., 2018; Beaulieu-Gagnon et al., 2019; Klanjsek and Pajnikihar, 2016) and consequently an impaired nutritional status (Viani et al., 2020).

Medical equipment, interruptions, checks and controls were aggravating aspects that limited the scope to create appealing meals. Similar results are lacking in the case of children and the paediatric care, but have been demonstrated in hospitalized adults (Treleaven et al., 2024; Young et al., 2024), for whom disruptions resulted in impaired meals

and mealtime situations (Kozica-Olenski et al., 2021; Ottrey et al., 2018). Based on a CCC approach (Nilsson et al., 2015; Söderbäck et al., 2011), the results of the present study indicate that the physical mealtime environment within paediatric oncology needs attention.

The hospital food was reported as a major concern, greatly influencing food intake and meals, which is in agreement with previous research (Arpaci et al., 2018; Beaulieu-Gagnon et al., 2019). Sensory aspects such as smell, taste and visual impression contributed to challenging mealtime situations. This effect that has been well-documented previously in children (Arpaci et al., 2018; Beaulieu-Gagnon et al., 2019), and in adults (Furness et al.). The child may react with vomiting (Plessis et al., 2019) or food rejection, contributing to negative experiences of hospital food, not only for the children themselves, but also for their parents (Beaulieu-Gagnon et al., 2019; Klanjsek and Pajnikihar, 2016). Previous research has showed that most parents considered hospital food to be bothersome and unappealing. Consequently, having a discussion with parents about how they act during mealtime situations is very important (Arpaci et al., 2018; Klanjsek and Pajnikihar, 2016), particularly since the child mostly eats less than required (Goddard et al., 2019).

It is critically important to act and revise the hospital food served within paediatric oncology care to meet the specific needs of severely ill children undergoing oncology treatments and HSCT. This is necessary because the food served in hospital does not match hospitalized patients’ expectations and requirements (Gürcan and Atay Turan, 2021; Trinca et al., 2021). Regardless of the oncology disorder or required treatment, the paediatric care team needs to ensure the child’s nutritional needs are met and that they have the prerequisites to achieve best possible health (Viani et al., 2020). The paediatric care team need to focus on both the child’s and the parents’ experiences, and include them in dialogues (Quaye et al., 2021) regarding food and meals.

Our results showed that treatment-related side effects caused bodily discomfort, which adversely affected the children’s food intake significantly, in line with previous findings (Beaulieu-Gagnon et al., 2019; Joffe and Ladas, 2020). Bodily discomfort has been emphasized as a critical aspect of the M-FAMM (Mårtensson et al., 2021a, 2021b) that requires further attention in order to make meals and mealtime situations appealing for children with a G-tube. In present study, both the smell and taste of the hospital food changed sensory impressions — or a combination of these may have resulted in the food being perceived as disgusting and unmanageable from the outset. Involving the children seems to be of the utmost importance regarding hospital food and meals (Gürcan and Atay Turan, 2021) and this relies on all involved parties and their approaches being aligned (Quaye et al., 2019).

Side effects such as oral mucositis, nausea and vomiting were present for the children in this study, which contributed to reduced appetite and further nutritional challenges, comparable with previous research (Brinksma et al., 2020; Joffe and Ladas, 2020). It is important for the paediatric oncology care team to find additional interventions (Brinksma et al., 2020; Joffe and Ladas, 2020), aiming to reduce problematic side effects and thus improve the child’s requirements in mealtime situations (Brinksma et al., 2020). Reduced appetite due to oncology treatment is common (Beaulieu-Gagnon et al., 2019; Joffe and Ladas, 2020), with risk of feeding difficulties (Beaulieu-Gagnon et al., 2019; Brinksma et al., 2020) and malnutrition (Joffe and Ladas, 2020; Wiernikowski and Bernhardt, 2020). For this reason, nutritional assessment and interventions appear to be essential to paediatric oncology care (Joffe and Ladas, 2020; Viani et al., 2020).

For the hospitalized children included in this study, there was a choice of food, but few alternative dishes were available. It has been reported that a child’s opportunity to choose food during hospitalization may be limited (Beaulieu-Gagnon et al., 2019; Skolin et al., 2006). This results correspond also with research performed in hospitalized adults (Furness et al.). To resolve this and improve meals and mealtime situations for their children, parents brought food to the ward — a practice that has also been highlighted by previous research (Beaulieu-Gagnon



et al., 2019; Gürçan and Atay Turan, 2021). Nevertheless, the children seemed to prefer cold food offered between the ordinary meals. These findings are in line with experiences of children hospitalized with cancer (Klanjsek and Pajnikihar, 2016).

The arrangement of food had a significant impact on the children in this study, consistent with previous research on both children (Arpaci et al., 2018; Beaulieu-Gagnon et al., 2019) and adults (Furness et al.). The amount of food affected the children's motivation to eat, which earlier findings emphasized (Arpaci et al., 2018). This was also found to be the case in hospitalized elderly people (Hope et al., 2016; Jonsson and Nyberg., 2022). Large portions were overwhelming, which contributed to meals being associated with discomfort and failure. In this study, the hospital system involved ordering and delivering portions of food to the ward. It has been highlighted that regulations and systems at the hospital may affect meals and mealtime situations (Hope et al., 2016; Jonsson et al., 2021; Jonsson and Nyberg., 2022) and these may be limiting factors in, for example, the preparation of food (Jonsson et al., 2021; Ottrey et al., 2018).

The children needed a G-tube to maintain and improve nutritional intake during the oncology treatment and having the tube mostly brought immediate relief as meals then became easier. Using a CCC approach is important (Nilsson et al., 2015; Söderbäck et al., 2011), especially since some parents in the study considered the G-tube insertion to be a parental failure. The paediatric care team need to include both the child and their parents in the process, as their interaction may affect mealtime situations (Edwards et al., 2016; Joffe and Ladas, 2020). Thus, using a CCC approach —where both the parents' perspective regarding the child and the child's own perspective are included — is necessary to provide children with the opportunity to be involved in their care (Quaye et al., 2019).

It is essential to involve the child (Quaye et al., 2019), especially with regard to a G-tube insertion (McGrath and Hardikar, 2019), which requires awareness and flexibility regarding the child's and parents' specific situation (Quaye et al., 2021). Time was a decisive aspect that influenced acceptance of the change, as reflected by the M-FAMM (Mårtensson et al., 2021a, 2021b). Time contributed to a gradual change whereby the parents eventually considered the G-tube as a relief — a temporary solution in an unmanageable situation. These findings comply with previous research emphasizing enteral tube feeding as positive, contributing to reduced concerns and pressure in relation to food and mealtime situations (Cohen et al., 2017). This is in agreement with the results of the present study, where the G-tube facilitated nutritional intake, contributed to more relaxed mealtime situations and resulted in a change in focus, which enabled the parents to recreate social and attractive meals.

### 6.1. Methodological considerations

The first author (U.M.) gained experience in this area during years of carrying out data collection at a Childhood Cancer Centre. In addition, the second author (M.J.N.), the third author (K.M.) and the last author (S.N.) have many years of experience in paediatric oncology care. Consequently, the overall competence within the research area can be seen as a strength.

Involving children in research is important, although interviewing them may be challenging. The first author (U.M.) was trained in interviewing children and had practical experience of interviewing both children and parents within paediatric oncology care (Mårtensson et al., 2021a), which can be seen as advantageous.

Most children chose to have their parents present during the interviews. It is important to be aware that this aspect may have affected how the children chose to share their experiences. In addition, the M-FAMM (Mårtensson et al., 2021a, 2021b) formed the basis of the interview guide, which may also have affected the answers. The first author transcribed most of the interviews, which is a strength linked to familiarization with the data. A specialized transcription company was

used to transcribe a small part of the data.

In Sweden, relatively few children receive oncology treatments or undergo HSCT due to malignant or severe non-malignant disorders. Among these, some require a G-tube. In conclusion, the number of children receiving a G-tube due to oncology treatment or a HSCT is in Sweden limited. In this study, children 1–18 years were available. The children's different ages, needs and prerequisites can be seen as a challenge, simultaneously as an additional dimension became illuminated.

In this study, 21 families had the opportunity to describe their experiences of meals during their child's hospitalization, which can be considered a strength. The life-threatening disorder, side effects and the daily condition of the patient affected the child's —as well as their parents'— ability to participate, which is why the number of interviews differ and did not go as planned. For example, critical situations, unplanned investigations or different kind of medical procedures could result in postponed or cancelled interviews. This also exemplifies why the number of interviewed children was fewer than expected and why the parental perspective, rather than the children's own perspectives, became overrepresented. This imbalance can be seen as a challenge.

A part of the data collection has been conducted during the Covid-19 pandemic, which may have affected the participants' answers. However, the first author (U.M.) met and interviewed the majority of the participants before the Covid-19 pandemic, which can be seen as a strength.

Another strength of the study is that it met the aim of developing and explaining the mealtime situation in terms of a CCC approach (Nilsson et al., 2015; Söderbäck et al., 2011), as most previous research only assumed a by-proxy perspective (Söderbäck et al., 2011). Conducting interviews with interpreters and also using digital platforms enabled participation for more families, which can be seen as a further strength of the study.

## 7. Relevance to clinical practice

The mealtime and the mealtime environment for hospitalized children within paediatric care needs attention and a change. Meals and mealtimes need designated time and protection and should be regarded as an important part of the child's hospitalization and nursing care. It is imperative to act and revise the hospital food to meet the specific needs of severely ill children undergoing oncology treatment. Sensory aspects such as smell, taste, visual impression and amounts of food need to be discussed and reflected upon to create appealing meals for hospitalized children in paediatric oncology care. In addition, it is crucial emphasize that G-tube insertion involves a significant change and challenge, potentially leading to unexpected reactions and emotions for the entire family. This knowledge needs to be highlighted in order to meet and optimize the children's needs in conjunction to meals and mealtime situations after that the G-tube insertion has been performed.

## 8. Further research

Further research is needed regarding how proposed changes can be implemented in paediatric oncology care to improve meals and mealtime experiences for this vulnerable group of children. Changes in nutritional care also need to be evaluated in a larger sample of children.

## 9. Conclusions

The novelty of this study elucidating mealtime experiences in hospitalized children within the oncology care and the field of HSCT. To our knowledge, this is the first study giving voice to central aspects affecting children's mealtime situations after a G-tube insertion, which is unique. The findings demonstrated that the environment and the food offered have a profound impact on hospitalized children's nutritional intake and meals. Sensory aspects such as smell, taste and the visual impression of hospital food affect the child's ability and motivation to eat, and

treatment-related side effects aggravate meals further. A G-tube may be necessary to ensure the child receives enough nutrition. Time may be required for acceptance of the changes arising from the procedure, even though it can bring an immediate improvement to the child's mealtime situations.

## Funding

This work was supported by grants from The Swedish Childhood Cancer fund, Ebba Danelius Foundation and RBU's forskningsstiftelse.

## CRedit authorship contribution statement

**Ulrika Mårtensson:** Writing – original draft, Methodology, Investigation, Formal analysis, Conceptualization. **Margaretha Jenholt Nolbris:** Writing – review & editing. **Karin Mellgren:** Writing – review & editing. **Helle Wijk:** Writing – review & editing. **Stefan Nilsson:** Writing – review & editing, Methodology, Investigation, Funding acquisition, Formal analysis, Conceptualization.

## Declaration of competing interest

The authors declare that they have no competing interests.

## Acknowledgements

The authors would like to thank both the children and their parents who participated in the study for giving generously of their time and sharing their experiences.

## References

- Arpaci, T., Toruner, E., Altay, N., 2018. Assessment of nutritional problems in pediatric patients with cancer and the information needs of their parents. *A Parental Perspective. Asia Pac J Oncol Nurs.* 5 (2), 231–236. <https://doi.org/10.4103/apjon.apjon.78.17>.
- Beaulieu-Gagnon, S., Bélanger, V., Marciel, V., 2019. Food habits during treatment of childhood cancer: a critical review. *Nutr. Res. Rev.* 32 (2), 265–281. <https://doi.org/10.1017/S0954422419000131>.
- Beckers, D., Karssen, L.T., Vink, J.M., Burk, W.J., Larsen, J.K., 2021. Food parenting practices and children's weight outcomes: a systematic review of prospective studies. *Appetite* 158 (105010). <https://doi.org/10.1016/j.appet.2020.105010>.
- Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. *Qual. Res. Psychol.* 3 (2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>.
- Braun, V., Clarke, V., 2021. *Thematic Analysis: A Practical Guide*. Sage Publications Inc.
- Brinksmä, A., Sulkers, E., I, L.J., Burgerhof, J.G.M., Tissing, W.J.E., 2020. Eating and feeding problems in children with cancer: prevalence, related factors, and consequences. *Clin. Nutr.* 39 (10), 3072–3079. <https://doi.org/10.1016/j.clnu.2020.01.012>.
- Carter, N., Bryant-Lukosius, D., Dicenso, A., Blythe, J., Neville, A.J., 2014. The use of triangulation in qualitative research. *Oncol. Nurs. Forum.* 41 (5), 545–547. <https://doi.org/10.1188/14.ONF.545-547>.
- Clarke, V., Braun, V., 2017. Thematic analysis. *J. Posit. Psychol.* 12, 297–298. <https://doi.org/10.1080/17439760.2016.1262613>.
- Cohen, J., Wakefield, C.E., Tapsell, L.C., Walton, K., Cohn, R.J., 2017. Parent, patient and health professional perspectives regarding enteral nutrition in paediatric oncology. *Nutr. Diet.* 74 (5), 476–487. <https://doi.org/10.1111/1747-0080.12336>.
- Donohoe, C., Bosi, J., Sykes, A., Lu, Z., Mandrel, B., 2018. Clinical characteristics of children and adolescents undergoing hematopoietic cell transplantation who develop oral mucositis. *Oncol. Nurs. Forum.* 45 (4), 457–462. <https://doi.org/10.1188/18.ONF.457-462>.
- Edwards, J.S.A., Gustafsson, I.B., 2008. The five aspects meal model. *J. Foodserv.* 19 (1), 4–12. <https://doi.org/10.1111/j.1745-4506.2007.00075.x>.
- Edwards, S., Davis, A.M., Bruce, A., Mousa, H., Lyman, B., Cocjin, J., Dean, K., Ernst, L., Almadhoun, O., Hyman, P., 2016. Caring for tube-fed children: a review of management, tube weaning, and emotional considerations. *J. Parenter. Enteral Nutr.* 40 (5), 616–622. <https://doi.org/10.1177/0148607115577449>.
- Evans, J., Gardiner, B., Green, D., Gibson, F., O'Connor, G., Lanigan, J., 2021. Systematic review of gastrostomy complications and outcomes in pediatric cancer and bone marrow transplant. *Nutr. Clin. Pract.* 36 (6), 1095–1327. <https://doi.org/10.1002/ncp.10724>.
- Fleming, C.A., Cohen, J., Murphy, A., Wakefield, C.E., Cohn, R.J., Naumann, F.L., 2015. Parent feeding interactions and practices during childhood cancer treatment. A qualitative investigation. *Appetite* 89, 219–225. <https://doi.org/10.1016/j.appet.2014.12.225>.
- Fuji, S., Einsele, H., Savani, B.N., Kapp, M., 2015. Systematic nutritional support in allogeneic hematopoietic stem cell transplant recipients. *Biol. Blood Marrow Transplant.* 21 (10), 1707–1713. <https://doi.org/10.1016/j.bbmt.2015.07.003>.
- Furness, K., Harris, M., Lassemillante, A., Keenan, S., Smith, N., Desneves, J.K., King, S., 2023. Patient mealtime experience: capturing patient perceptions using a novel patient mealtime experience tool. *Nutrients* 15 (12), 2747. <https://doi.org/10.3390/nu15122747>.
- Gibson, M.F., Shipway, M.L., Barry, M.A., Taylor, M.R., 2012. What's it like when you find eating difficult: children's and parents' experiences of food intake. *Cancer Nurs.* 35 (4), 265–277. <https://doi.org/10.1097/NCC.0b013e31822cbb40>.
- Goddard, E., Cohen, J., Bramley, L., Wakefield, C.E., Beck, E.J., 2019. Dietary intake and diet quality in children receiving treatment for cancer. *Nutr. Rev.* 77 (5), 267–277. <https://doi.org/10.1093/nutrit/nyy069>.
- Gürçan, M., Atay Turan, S., 2021. Examining the expectations of healing care environment of hospitalized children with cancer based on Watson's theory of human caring. *J. Adv. Nurs.* 77 (8), 3472–3482. <https://doi.org/10.1111/jan.14934>.
- Gustafsson, I.B., Öström, Å., Johansson, J., Mossberg, L., 2006. The Five Aspects Meal Model: a tool for developing meal services in restaurants. *J. Foodserv.* 17 (2), 84–93. <https://doi.org/10.1111/j.1745-4506.2006.00023.x>.
- Haines, J., Haycraft, E., Lytle, L., Nicklaus, S., Kok, F.J., Merdji, M., Fisberg, M., Moreno, L.A., Goulet, O., Hughes, S.O., 2019. Nurturing children's healthy eating: position statement. *Appetite* 137, 124–133. <https://doi.org/10.1016/j.appet.2019.02.007>.
- Heuschkel, R.B., Gottrand, F., Devarajan, K., Poole, H., Callan, J., Dias, J.A., Karkelis, S., Papadopoulou, A., Husby, S., Ruemmele, F., Schäppi, M.G., Wilschanski, M., Lionetti, P., Orel, R., 2015. ESPGHAN position paper on management of percutaneous gastrostomy in children and adolescent. *J. Pediatr. Gastr. Nutr.* 60 (1), 131–141. <https://doi.org/10.1097/MPG.0000000000000501>.
- Homan, M., Hauser, B., Romano, C., Tzivinikos, C., Torroni, F., Gottrand, F., Hojsak, I., Dall'Oglio, C., Thomson, M., Bontemps, P., Narula, P., Furlano, R., Oliva, S., Amil-Dias, J., 2021. Percutaneous endoscopic gastrostomy in children: an update to the ESPGHAN position paper. *J. Pediatr. Gastroenterol. Nutr.* 73 (3), 415–426. <https://doi.org/10.1097/MPG.0000000000003207>.
- Hope, K., Ferguson, M., Reidlinger, D.P., Agarwal, E., 2016. "I don't eat when I'm sick": older people's food and mealtime experiences in hospital. *Maturitas* 97, 6–13. <https://doi.org/10.1016/j.maturitas.2016.12.001>.
- Joffe, L., Ladas, E.J., 2020. Nutrition during childhood cancer treatment: current understanding and a path for future research. *Lancet Child Adolesc Health* 4 (6), 465–475. [https://doi.org/10.1016/s2352-4642\(19\)30407-9](https://doi.org/10.1016/s2352-4642(19)30407-9).
- Jonsson, A.-S., Nyberg, M., 2022. Hospitality through negotiations: the performing of everyday meal activities among nursing staff and meal hosts. A qualitative study. *Int. J. Gastron. Food Sci.* 27 (100478). <https://doi.org/10.1016/j.ijgfs.2022.100478>.
- Jonsson, A.S., Nyberg, M., Jonsson, I.M., Öström, Å., 2021. Older patients' perspectives on mealtimes in hospitals: a scoping review of qualitative studies. *Scand. J. Caring Sci.* 35 (2), 390–404. <https://doi.org/10.1111/scs.12866>.
- Kairiene, I., Vaisvilas, M., Vasciunaite, A., Tubutyte, G., Nedzelskiene, I., Pasauliene, R., Muleviciene, A., Rascon, J., 2023. Impact of percutaneous endoscopic gastrostomy on pediatric bone marrow transplantation outcomes: retrospective single-center cohort study. *J. Parenter. Enteral Nutr.* 47 (3), 390–398. <https://doi.org/10.1002/jpen.2479>.
- Klanjsek, P., Pajnikihar, M., 2016. Causes of inadequate intake of nutrients during the treatment of children with chemotherapy. *Eur. J. Oncol. Nurs.* 23, 24–33. <https://doi.org/10.1016/j.ejon.2016.03.003>.
- Kotch, C., Elgarten, C., McWhorter, J., Schmus, C., Wilhelm, D., Li, Y., Minturn, J., 2023. The impact of proactive gastrostomy tube placement on treatment related outcomes in Young children with high-grade central nervous system tumors. *J. Pediatr. Hemtol. Oncol.* 45 (6), 333–338. <https://doi.org/10.1097/MPH.0000000000002694>.
- Kozica-Olenski, S., Treleven, E., Hewitt, M., McRae, P., Young, A., Walsh, Z., Mudge, A., 2021. Patient-reported experiences of mealtime care and food access in acute and rehabilitation hospital settings: a cross-sectional survey. *J. Hum. Nutr. Diet.* 34 (4), 687–694. <https://doi.org/10.1111/jhn.12854>.
- Larsen, L.K., Uhrenfeldt, L., 2013. Patient's lived lived experiences of a reduced intake of food and drinks during illness: a literature review. *Scand. J. Caring Sci.* 27 (1), 184–194. <https://doi.org/10.1111/j.1471-6712.2012.00977.x>.
- Larson, N., Story, M., 2009. A review of environmental influences on food choices. *Ann. Behav. Med.* 38, 56–73. <https://doi.org/10.1007/s12160-009-9120-9>.
- Loves, R., Plenert, E., Tomlinson, V., Palmert, S., Green, G., Schechter, T., Tomlinson, D., Vettese, E., Zupanec, S., Dupuis, L.L., Sung, L., 2019. Changes in taste among pediatric patients with cancer and hematopoietic stem cell transplantation recipients. *Qual Life Res. Qual. Life Res. : Int. J. Qual. Life Aspect. Treat. Care Rehabil.* 28 (11), 2941–2949. <https://doi.org/10.1007/s1136-019-02242-5>.
- Loves, R., Plenert, E., Tomlinson, V., Palmert, S., Green, G., Schechter, T., Tomlinson, D., Vettese, E., Zupanec, S., Dupuis, L.L., Sung, L., 2020. Changes in hunger among pediatric patients with cancer and hematopoietic stem cell transplantation recipients. *Support. Care Cancer.* 28 (12), 5795–5801. <https://doi.org/10.1007/s00520-020-05425-w>.
- Mårtensson, U., Jenholt Nolbris, M., Mellgren, K., Wijk, H., Nilsson, S., 2021a. The five aspect meal model as a conceptual framework for children with a gastrostomy tube in paediatric care. *Scand. J. Caring Sci.* 35 (4), 1352–1361. <https://doi.org/10.1111/scs.12957>.
- Mårtensson, U., Cederlund, M., Jenholt Nolbris, M., Mellgren, K., Wijk, H., Nilsson, S., 2021b. 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.* 16 (1), 1942415. <https://doi.org/10.1080/17482631.2021.1942415>.

- Mårtensson, U., Nilsson, S., Jenholt Nolbris, M., Wijk, H., Mellgren, K., 2023. Pain and discomfort in children with gastrostomy tubes - in the context of hematopoietic stem cell transplantation. *J. Pediatr. Nurs.* 70, 79–89. <https://doi.org/10.1016/j.pedn.2023.02.005>.
- McGrath, K.H., Hardikar, W., 2019. Gastrostomy tube use in children with cancer. *Pediatr. Blood Cancer.* 66 (7), e27702 <https://doi.org/10.1002/pbc.27702> n/a-n/a.
- Mellgren, K., Nicolajsen, T., Christoforaki, T.P., Juan, S.M., Mårtensson, T., Toporski, J., Casswall, T.H., Gustafsson, B., 2023. A retrospective case-control study of gastrostomy use in children undergoing hematopoietic cell transplantation. *Pediatr. Transplant.* 27 (4), e14520 <https://doi.org/10.1111/ptr.14520>.
- Morgan, D., Hoffman, K., 2020. Qualitative data collection in an era of social distancing. *Int. J. Qual. Methods* 19. <https://doi.org/10.1177/1609406920937875>.
- Network, Equator, 2022. Standards for reporting qualitative research: a synthesis of recommendations. <https://www.equator-network.org/reporting-guidelines/srqr/>.
- Nilsson, S., Björkman, B., Almqvist, A.-L., Almqvist, L., Björk-Willén, P., Donohue, D., Enskär, K., Granlund, M., Huus, K., Hvit, S., 2015. Children's voices—Differentiating a child perspective from a child's perspective. *Dev. Neurorehabil.* 18 (3), 162–168. <https://doi.org/10.3109/17518423.2013.801529>.
- Ottrey, E., Porter, J., Huggins, C.E., Palermo, C., 2018. "Meal realities" — an ethnographic exploration of hospital mealtime environment and practice. *J. Adv. Nurs.* 74 (3), 603–613. <https://doi.org/10.1111/jan.13477>.
- Plessis, J., Stones, D., Meiring, M., 2019. Family experiences of oncological palliative and supportive care in children: can we do better? *Int. J. Palliat. Nurs.* 25 (9), 421–430. <https://doi.org/10.12968/ijpn.2019.25.9.421>.
- Polit, D.F., Beck, C.T., 2016. *Nursing research. Generating and Assessing Evidence for Nursing Practice*, tenth ed. Wolters Kluwer, Philadelphia. ed.
- Quaye, A.A., Coyne, I., Söderbäck, M., Hallström, I.K., 2019. Children's active participation in decision-making processes during hospitalisation: an observational study. *J. Clin. Nurs.* 28 (23–24), 4525–4537. <https://doi.org/10.1111/jocn.15042>.
- Quaye, A.A., Castor, C., Coyne, I., Söderbäck, M., Hallström, I.K., 2021. How are children's best interests expressed during their hospital visit?—an observational study. *J. Clin. Nurs.* 30 (23–24), 3644–3656. <https://doi.org/10.1111/jocn.15886>.
- Scaglioni, S., De Cosmi, V., Ciappolino, V., Parazzini, F., Brambilla, P., Agostoni, C., 2018. Factors influencing children's eating behaviours. *Nutrients* 10 (6), 706. <https://doi.org/10.3390/nu10060706>.
- Skolin, I., Wahlin, Y.B., Broman, D.A., Koivisto Hursti, U.-K., Vikström Larsson, M., Hernel, O., 2006. Altered food intake and taste perception in children with cancer after start of chemotherapy: perspectives of children, parents and nurses. *Support. Care. Cancer.* 14 (4), 369–378. <https://doi.org/10.1007/s00520-005-0904-6>.
- Söderbäck, M., Coyne, I., Harder, M., 2011. The importance of including both a child perspective and the child's perspective within health care settings to provide truly child-centred care. *J. Child Health Care* 15 (2), 99–106. <https://doi.org/10.1177/1367493510397624>, 5.
- The National Food Agency, 2020. Nationella riktlinjer för måltider på sjukhus. <https://www.livsmedelsverket.se/globalassets/publikationsdatabas/broschyrrer-foldrar/riktlinjer-for-maltider-pa-sjukhus.pdf>.
- Trehan, A., Viani, K., Cruz, Da, L. B., Sagastizado, S.Z., Ladas, E.J., 2020. The importance of enteral nutrition to prevent or treat undernutrition in children undergoing treatment for cancer. *Pediatr. Blood Cancer* 67 (3), e28378. <https://doi.org/10.1002/pbc.28378> n/a-n/a.
- Treleaven, E., Matthews-Rensch, K., Garcia, D., Mudge, A., Banks, M., Young, A., 2024. Mealtimes matter: measuring the hospital mealtime environment and care practices to identify opportunities for multidisciplinary improvement. *Nutr. Diet.* 21 <https://doi.org/10.1111/1747-0080.12863>.
- Trinca, V., Duizer, L., Keller, H., 2021. Putting quality food on the tray: factors associated with patients' perceptions of the hospital food experience. *J. Hum. Nutr. Diet.* 35 (1), 81–93. <https://doi.org/10.1111/jhn.12929>.
- UNICEF, 2021. Convention on the rights of the child, 1989. <https://www.unicef.org/child-rights-convention/convention-text>.
- van den Brink, M., I, I.J., van Belkom, B., Fiocco, M., Havermans, R.C., Tissing, W.J.E., 2021. Smell and taste function in childhood cancer patients: a feasibility study. *Support. Care Cancer* 29 (3), 1619–1628. <https://doi.org/10.1007/s00520-020-05650-3>.
- Viani, K., Trehan, A., Manzoli, B., Schoeman, J., 2020. Assessment of nutritional status in children with cancer: a narrative review. *Pediatr. Blood Cancer* 67. <https://doi.org/10.1002/pbc.28211> n/a-n/a.
- Wiernikowski, J.T., Bernhardt, M.B., 2020. Review of nutritional status, body composition, and effects of antineoplastic drug disposition. *Pediatr. Blood Cancer* 67 (3), e28207. <https://doi.org/10.1002/pbc.28207> n/a-n/a.
- Young, A.M., Byrnes, A., Mahoney, D., Power, G., Cahill, M., Heaton, S., McRae, P., Mudge, A., Miller, E., 2024. Exploring hospital mealtime experiences of older inpatients, caregivers and staff using photovoice methods. *J. Clin. Nurs.* 33 (5), 1906–1920. <https://doi.org/10.1111/jocn.17009>.