

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

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'Maten har fått stå ett tag...jag är inte hungrig. Nej, men jag blir lite, inte äcklad men liksom, det luktar inte gott och smakar inte gott. Antingen så känner jag ingen smak eller så känner jag jättemycket smak. Man stoppar in någonting som man vet är gott och så smakar det jättekonstigt'.
(Flicka, sicklecellanemi)

*'Alltså man tappar mycket av den normala vardagen...gå på bio och äta popcorn med dom andra...vi behöver käka någonting, vi får gå till McDonalds typ och hon sitter där och kan inte äta... Eller hon åker hem till en kompis, och kompisens föräldrar har lagat mat, ja, nej, jag ska ha min sondmat...'.
(Mamma till flicka med sarkom)*

‘Face the facts of being what you are, for this is what changes what you are’.

-Soren Kierkegaard

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 was 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

SAMMANFATTNING PÅ SVENSKA

Barn som genomgår onkologiska behandlingar och hematopoietisk stamcellstransplantation upplever biverkningar såsom exempelvis illamående, kräkningar och mukositet, men också smak- och luktförändringar, vilket vanligen leder till ett försämrat matintag och bekymmersamma måltider. Hos ett barn med cerebral pares kan funktionsnedsättningen istället orsaka fysiska komplikationer såsom svårigheter att hantera maten i munnen men också sväljningen kan vara försämrad vilket försvårar matintag och måltider. För att på ett säkert sätt tillgodose och upprätthålla barnets intag av näring, kan enteral nutrition via en nässond eller gastrostomiport vara nödvändigt. Det är inte belyst hur barn i olika kontext inom barnsjukvården upplever måltider före och efter insättandet av en gastrostomiport. Vidare finns ingen måltidsmodell tillgänglig inom barnsjukvården med syftet att beskriva måltidssituationer för barn. Det **övergripande syftet** med avhandlingen var att beskriva barns (1–18 år) och deras föräldrars erfarenheter av måltidssituationer före och efter insättandet av en gastrostomiport och att utveckla en barncentererad måltidsmodell som fokuserar på måltider och dess miljörelaterade aspekter. **Metoder** som användes under datainsamlingen som pågick mellan 2018–2021 var semi-strukturerade intervjuer och strukturerade intervjuer (frågor med fasta svarsalternativ) med barn (1–18 år) och deras föräldrar. Analysmetoder som användes var kvalitativ riktad innehållsanalys (Studie I), interpretive description (Studie II), mixed-methods design inkluderat deskriptiv statistik och en kvalitativ innehållsanalys (Studie III), och en tematisk innehållsanalys (Studie IV). **Resultatet** påvisade att insättandet av en gastrostomiport kan vara förknippat med både ovisshet, oro och smärta varför nödvändig information men också behovet av adekvat smärtlindring postoperativt behöver säkerställas (Studie III). Insättandet av en gastrostomiport är för majoriteten av barn och föräldrar förknippat med en lättnad till följd av minskade krav i samband med måltid (Studie I, II och IV). Föräldrarna kan dock till en början se interventionen som ett misslyckande samtidigt som ingreppet successivt skapar en trygghet i vardagen (Studie IV). Näringsintag och måltider underlättas även om förändringar och nya utmaningar måste hanteras (Studie I, II och IV). Den fysiska måltidsmiljön har en betydande inverkan på barnens måltidssituationer där isolering, medicinsk apparatur, men också ständiga avbrott till följd av nödvändiga omvårdnadsåtgärder såsom exempelvis medicinering och kontroller i samband med måltid försvårar situationen ytterligare. Sjukhusmaten och relaterade sensoriska intryck såsom exempelvis lukt, smak, presentation och portionsstorlekar tillsammans med behandlingsrelaterade biverkningar är aspekter mycket svåra att hantera för de barn som behandlas inom barnonkologi (Studie I och IV). Stigmatiseringen i

samhället medför svårigheter för barn som fått en gastrostomiport, men också för deras familjer. Att se annorlunda ut kan vara svårt att hantera och förstärker upplevelsen av både sjukdom och funktionsnedsättning, vilket i sin tur medför fysiska och psykosociala utmaningar (Studie I och II). Måltidssituationer och måltidsvanor förändras när barnet kan få näring via nässond eller gastrostomiport. Samvaro och gemenskap i samband med måltider prioriteras bort och ersätts istället av en mer teknisk procedur där näringsintaget, och inte barnet, sätts i fokus. Som en konsekvens hamnar barnet i skymundan och erbjuds mat vid andra tidpunkter och platser än vid den övriga familjens måltider (Studie I, II och IV). **Konklusion.** Barn med maligna och svåra icke-maligna sjukdomar upplever under sin sjukhusvistelse måltidsmiljön och sjukhusmaten som problematisk med bekymmersamma måltider som följd. Sensoriska utmaningar tillsammans med behandlingsrelaterade biverkningar försvårar matintag och måltider ytterligare. Insättandet av en gastrostomiport innebär att barnets måltidssituationer underlättas, men medför även fysiska och psykosociala utmaningar, vilket påverkar hela familjen. Kunskap och medvetenhet om de utmaningar som kan uppkomma är av största betydelse för att som sjuksköterska och övrig hälso- och sjukvårdspersonal kunna möta och stödja dessa familjer med målsättningen att de ska kunna återfå en positiv känsla i samband med mat och måltider.

LIST OF PAPERS

This thesis is based on the following studies, here referred to by their Roman numerals in the text.

- 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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ABBREVIATIONS

CCC	Child-centred care
CP	Cerebral palsy
EN	Enteral nutrition
FAMM	Five Aspect Meal Model
G-tube	Gastrostomy tube
HSCT	Haematopoietic stem cell transplantation
M-FAMM	Modified version of the Five Aspect Meal Model
MICCAD	Meals in long-term Child Conditions and Disability
NG tube	Nasogastric tube
PN	Parenteral nutrition

PREFACE

As a paediatric nurse with several years' experience in habilitation, I saw that nutritional and gastrostomy tube (G-tube) care in children with disabilities was common. Those children who required nutritional care had mostly experienced long-lasting feeding difficulties because of the disability and its complications. Parents often expressed concerns about the child's severities in respect to mealtime situations. My experience is that the paediatric care team was also concerned as it was difficult to ensure that the child had sufficient nutrition; insufficient nutrition in many cases resulted in an impaired physical condition. Nevertheless, the existential part of the mealtime situations, the mealtime environment or the child's own experience of the meals seemed seldom reflected upon, nor prioritised as a natural part of the care. A majority of the children in need of nutritional care also had cognitive dysfunctions and/or a deteriorated ability to communicate, which made them dependent on their parents or assistants in daily life. Consequently, their ability to share experiences became aggravated and limited and was an ethical dimension that required consideration.

My experience is that meals and mealtime situations are important for all children and a desire to eat orally exists, even if it is not necessary. My experience has shown me that something essential is lost as a result of troublesome mealtime situations, since the main focus is transferred to the importance of and parental responsibility to ensure the child with necessary nutrition. This was the starting point of my interest in meals and mealtime experiences in children, as my perception was that a gap of knowledge existed regarding the meaning and importance of this essential and necessary daily activity.

1 INTRODUCTION

Meals and mealtime experiences before and after a G-tube insertion constitute the central concept of this thesis. To describe aspects that may have an impact on the child's meals and mealtime experiences in daily life, different contexts such as a hospital context within paediatric oncology care and a home environment linked to the care at a habilitation centre have been included. These contexts illustrate only examples, in which larger groups of children who may need a G-tube because of nutritional issues exist. In this thesis, the children's diagnosis is not the focus. Nevertheless, it is relevant to be aware that the included children who live with malignant or severe non-malignant disorders, as well as cerebral palsy (CP), have eating difficulties and problematic meals because of specific causes, and that the purpose of the child's need for a feeding tube may differ. By including different contexts and dimensions of meals and G-tube use, it has been possible to obtain a broader perspective and richer point of view regarding children's mealtime experiences.

Children with CP may experience bodily dysfunctions and complications related to the disability, such as dysphagia, which contribute to multifaceted nutritional issues throughout life (1). As a result, recurrent troublesome meals are common (2). Insufficient food intake may contribute to a decreased ability to grow (3) and the development of malnourishment (1), which is why a G-tube may be required to enable safe and adequate meals (4). Children who are receiving paediatric oncology care can also have challenging treatments and hematopoietic stem cell transplantation (HSCT), and these patients may experience discomfort due to for instance mucositis, resulting in impaired food intake and aggravated mealtime situations (5, 6). Thus, a G-tube may be needed to facilitate the care, treatment and recovery process (7, 8).

Food and meals are essential parts of daily life, (9), and they constitute a crucial part of nursing care (10). These important aspects need to be prioritised; they affect the child's general condition and their ability to achieve healthiness and well-being (5, 11). However, mealtime situations may undergo a change when a child becomes ill (12), and this is why their significance can change and fluctuate (13). A G-tube insertion involves further change, as it is no longer a matter of course that the child participates in ordinary meals as previously (14). Thus, it is of the utmost importance to guide and support children with malignant and severe non-malignant disorders or disabilities and their parents' before and after a G-tube insertion to improve meals and mealtime experiences.

However, including these groups of children in data collection can involve difficulties (15, 16), as here, as they can have an impaired ability to share their experiences (16). This is why unknown and uncharted experiences of meals and mealtime situations before and after a G-tube insertion exist in these children. The current thesis presents pieces of a puzzle to create an overall description of how meals and mealtime situations in children can be experienced in daily life before and after a G-tube insertion.

2. BACKGROUND

Children with malignant and severe non-malignant disorders in need of oncology treatments and HSCT within paediatric oncology care, as well as an older child with CP in need of habilitation, are the focus of the present thesis. The background included here describes the conceivable causes of reduced possibilities of oral food intake and its impact on meals and mealtime situations, which may result in the need of a G-tube.

2.1 Meals

During childhood, dependency on and the need for adults is present. How they act affects the child (17) as do the methods they use to feed the child (17, 18). Meals constitute a major part of all children's daily needs (17, 19); they include ingestion, but also opportunities for the child to participate and spend time with others (20). Meals involve complex and multifaceted situations (17, 21), which present the possibility to create relationships and practice conversing with others (17, 22). As a result, disagreements and various forms of social control linked to food can occur as part of the meals (9). Food and meals are associated with a variety of sensorial impressions which may affect the mealtime experience, just as several contextual dimensions do (21, 23). To become sick involves bodily alterations, which may affect food consumption and mealtime situations (24). During hospitalisation, food and meals are emphasised as being essential (10). Simultaneously, children within paediatric oncology care can experience meals as an unprioritized activity (13). To manage a bothersome oral intake, different approaches can be used (25, 26). An approach that promotes the child in mealtime situations involves, for instance, supportiveness (17, 26), while other more negative ones may have the opposite result (17, 25, 26).

2.1.1 Meals in two different contexts

Children within paediatric oncology care are dependent on the paediatric care team and their routines at the hospital ward for their meals and mealtime situations, although the situation for children with CP may differ. To gain an understanding of the children's presumptions in mealtime situations, a description of their circumstances is given below.

At the Childhood Cancer Centre, specifically the paediatric oncology ward referenced in this thesis, all children were offered breakfast, lunch and dinner at predetermined times each day. Beyond this, snacks were offered between the scheduled meals. All children had the opportunity to choose food from a planned offering of a variety of dishes. In cases where the child did not like the offered food, they could choose from other special dishes adapted for children. The routines at the hospital ward required that the food be selected a day or days before it would be served, and this was aggravating for the children because of their fluctuating conditions and well-being. The routine at the hospital ward included warm dishes served at lunch and dinnertime. These meals were already cooked, placed on plates covered with a lid and stored in a canteen before being presented on a tray. As a result, the children had no opportunity to be involved in the cooking or preparation of the food. The children were not able to pick up the food by themselves and could not affect the presentation or the amount of food served.

The paediatric care team or parents brought the food into the children's room because of their vulnerable condition and the risk of infections. The child's current condition, treatment and experienced side effects had a great impact on the child's ability to eat, what to eat and where to eat. For instance, treatments such as HSCT involve specific rules and regulations regarding the food that can be consumed. At the hospital, meals and mealtime situations usually occurred in the child's room or sometimes in the hospital ward's kitchen because of the risk of infections. If the child's recovery process was proceeding successfully, it was possible for the child to eat outside the hospital or in the home environment.

Children who live with CP eat mostly at home; that is, meals occur in a home environment with parents and family. For the older child discussed in this thesis, meals could also occur in school, and she needed the support of an assistant to manage food and mealtime situations.

Depending on the existing severities, in mealtime situations, various adaptations can be required to facilitate the ability to eat (11, 27). Children with CP as well as their parents may be offered support from the paediatric care team at the habilitation centre to find strategies to optimally manage food, meals and mealtime situations in everyday life.

2.2 Long-term conditions within paediatric oncology care

Food intake, meals and mealtime situations are negatively affected in children within paediatric oncology care. This is because of the malignancy itself, but it is also due to oncology treatments such as HSCT and their impact (5). Children with long-term conditions such as malignant and severe non-malignant disorders treated within paediatric oncology care constitute small groups of children. This is why it is important that a nurse or another member of the paediatric care team possesses knowledge and is aware of the child's diagnosis and background to those nutritional difficulties that may result in problematic and challenging meals and mealtime situations. This will enable the best possible nutritional care and treatment of the disorder and be of great value in the eventual palliative phase. As a result, some diagnoses relevant for the children discussed in this thesis are given below.

2.2.1 Malignant disorders in children

The survival rates of childhood cancers in Sweden have increased by up to 85% (28, 29). Approximately 310-370 children are diagnosed yearly with cancer in Sweden (28, 29). Malignant disorders in childhood may diverge from those affecting older people (30), for instance in terms of origin (31). In children, leukaemia, brain tumours, lymphomas and solid tumours constitute the most frequent malignant disorders (28, 31).

Leukaemia comprises around one-third of all childhood cancer diagnoses in Sweden, where acute lymphoblastic leukaemia and acute myelogenous leukaemia are the most common subtypes (28). This malignant disorder can involve, for instance, contusions, but also more general characteristics and thus, it is problematic to detect and differentiate it from possible alternative diagnoses (32). Brain tumours constitute in Sweden almost one-third of all childhood cancers (28), and a division can be made based on the time of occurrence; however, all are linked to a high risk of fatal outcomes (33). In children with this form of malignant disorder, several symptoms, such as headaches, can be present (34).

Lymphomas, sarcomas and neuroblastomas are all solid tumours that can affect children. Of these, lymphomas constitute nearly 13% of all childhood cancers in Sweden (28). This malignant disorder involves cancer in the lymph nodes and is divided into Hodgkin's and non-Hodgkin's lymphoma, where symptoms in the child's respiratory tract may be one indication of the disorder (35). In Sweden, sarcomas encompass approximately 10% of all childhood cancers (28). This group of childhood cancers involves both bone and soft tissue sarcomas (36). In such cases, bone sarcomas mostly affect those in adolescence, and bodily discomfort, such as pain, constitutes one typical sign of the disorder (37). In Sweden, about 4.5% of all childhood cancers constitute neuroblastoma (28). It affects a majority of small, younger children and their sympathetic nervous system (38). Signs of this malignancy can involve the presence of its growth, here, mostly asymptomatic (38).

2.2.2 Severe non-malignant disorders in children

Around 200 children in Europe are born with sickle cell disease every year (39). Hereditary causes contribute to this non-malignant disorder, and anaemia and several acute conditions can be the result (39, 40). A severe form of thalassemia is present in around 100 individuals in Sweden (41). Thalassemia has hereditary causes, is divided into alpha- and beta-thalassemia and results in a number of symptoms, such as anaemia (41, 42). In Sweden, around 15 to 20 individuals are diagnosed and live with mucopolysaccharidosis type 1, of which Hurler's disease is included (43). The lack of an enzyme results in a serious multisystem condition in which multiple bodily and intellectual functions are affected (43, 44). Aplastic anaemia constitutes a threat to life since the disorder affects the child's bone marrow, which contributes to several severe symptoms in addition to anaemia (45, 46). Approximately three or four children yearly are born in Sweden with Severe Combined Immunodeficiency (SCID), a life-threatening disorder where the child's immune system is affected because of multiple genetic deficiencies, and this results in severe infections (47).

2.2.3 Treatments and side-effects in children within paediatric oncology care

Malignant and severe non-malignant disorders require oncology treatments and HSCT, which result in troublesome side effects that negatively affect food consumption and meals (5). As a nurse or another member of the paediatric care team, it is important to possess knowledge and be aware of these aspects to enable the best possible nutritional care and treatment. Therefore, for the purposes of this thesis, background on some oncology treatments and their side effects, relevant to the children discussed here, is presented below.

Malignant disorders may require various intense treatments, such as chemotherapy, surgery and radiotherapy (31, 48), but also immunotherapy (48, 49) and HSCT (48, 50, 51). Treatments differ according to the child's diagnosis (48). For instance, a child with acute lymphoblastic leukaemia may undergo long and intensive treatment consisting of chemotherapy, and in some cases, an allogenic HSCT (51, 52), while a child with a brain tumour requires a surgical procedure as the first treatment (53). Moreover, children with leukaemia seem to be particularly vulnerable to problematic conditions post-HSCT (54).

A severe non-malignant disorder may require an HSCT to relieve suffering or enable the ability to live (40, 42, 44, 46, 47, 55). Approximately 15,000 allogenic HSCTs and twice as many autologous HSCTs are performed globally every year (50). Prior to HSCT, the severely ill child needs to undergo both chemotherapy treatment and irradiation (50).

Side effects that negatively influence food consumption and meals commonly occur in children who undergo oncology treatments as well as HSCT (5, 56). Aggravating circumstances such as nausea, vomiting and painful mucositis may contribute to troublesome eating difficulties and unappealing mealtime situations for these children (5, 56). Furthermore, oncology therapies and HSCT can cause and contribute to troublesome meals because of an altered sense of taste (57, 58). These children may, in addition, struggle with a changed sense of smell, which may also have a great impact on the meals (58, 59). As a result, this group of children can experience a lack of desire to eat (59, 60), which in turn may contribute to malnourishment (5, 56), thus indicating why optimal meals are of the greatest importance.

2.3 Children with cerebral palsy (CP)

Children with CP constitute a small group within paediatric care, and they are mostly treated within a habilitation centre. In these cases, meals are most often negatively affected because of the disability and related medical complications (2, 4). Thus, it is important as a member of the paediatric care team to possess knowledge and be aware of the child's diagnosis and background of nutritional difficulties that may result in problematic meals and mealtime situations. This will enable the best possible nutritional care and treatment. To better describe this condition, the background of the CP diagnosis is given below.

Over a period of three years in the 2000s, approximately 205 children were diagnosed with CP in a region of Sweden (61). CP has multiple underlying causes, and damage linked to the brain arises prior, under or after the child's birth (62, 63). CP can be described in different subgroups which denominate the child's specific severities of motorial functioning (62, 63). There are some methods available to assess the child's ability to perform different activities of daily living (64-67). A child with CP usually experiences several complications linked to the diagnosis. Spasticity, pain and troublesome food consumption can be present (63, 68), but epilepsy and scoliosis are also common (69). Because of this, the care needs to be interprofessional to offer the child the best possible treatment (63, 70).

2.3.1 Complications, treatments and side-effects in children with CP

CP involves complications and bodily dysfunctions which may affect the child's meals and mealtime situations. For instance, the severities of their condition make it difficult to manage eating, and an inability to swallow the food can adversely affect daily life (3, 70), which is why these groups of children may also develop malnourishment (71). Accordingly, these children may be in need of adaptations to facilitate their mealtime situations; both meal-related and surrounding aspects must be taken into account (11, 68). The paediatric care team needs to be aware that the child can also be in need of sensorial support due to, for instance, problematic drooling, as this may affect meals negatively (68). As a result, care and treatment linked to the child's nutrition is of greatest importance (11), especially since this factor has been emphasised and seems to be generally deficient in this group (72).

Children with CP may, due to the disability and related bodily dysfunctions, require various medicines which can have troublesome impacts that aggravate nutritional intake and consequently meals and mealtime situations (73). Children with CP commonly experience spasticity; as a result, the paediatric care team has an important task to relieve these symptoms, which is why oral medications such as benzodiazepines and baclofen may be required (62, 71). It is important that the paediatric care team possesses knowledge and is aware of these medicines' risk of causing a negative impact which may negatively affect both food intake and meals (73). Botulinum toxin injection is another possible treatment for these children (3, 62), but it may also affect the child's ability to eat, which is why meals can become unappealing as a result (73).

2.4 Non-oral feeding in children

As a nurse or another member of the paediatric care team, it is important to be aware that children with malignant and non-malignant disorders who undergo oncology treatments such as HSCT as well as children with CP, despite nutritional interventions, can be in need of non-oral feeding as a replacement of or as a complement to the oral intake. Thus, a description of non-oral feeding techniques used for children is given below.

2.4.1 Enteral and parenteral nutrition

For those who undergo oncology treatments and HSCT, the importance of adequate food consumption is particularly emphasised (5, 56), as it is for those who live with CP (11). Enteral nutrition (EN) involves nourishment offered to the child via a feeding tube, such as a nasogastric tube (NG tube) or a G-tube (7, 8, 11). EN is a recommended technique and preferable to use in children within paediatric oncology care (7, 74), but also in children with disabilities such as CP (4, 11). Several advantages have been emphasised with the use of EN compared with the use of parenteral nutrition (PN) in children who undergo oncology treatments and HSCT (74, 75). PN may, however, contribute to a higher degree of severities (74, 75) and consequently may just be used in cases where the child suffers from severe mucositis or malnourishment (75, 76).

2.4.2 Feeding tubes

In children who require EN during a predictable phase, an NG tube may be the first choice (4, 7, 77). This intervention can be experienced as unpleasant, and its visibility may affect the child negatively (8, 78). Simultaneously, the child may experience discomfort and severities after the placement (7, 77). This is why when children who need long-term EN, a G-tube may be considered instead (4, 7). However, it has been demonstrated that several obstacles exist in the changeover when replacing an NG tube with a G-tube (79). This is because the option to insert a G-tube is more multifaceted (11, 79, 80). However, the placement of a G-tube involves an established and recommended procedure (81) even if it is common that the child may experience fewer inconveniences (8, 81). When the child has received a G-tube, it is not obvious that the tube feeding includes and becomes a part of the regular meals at home (82). Also, tube feeding and meals with a G-tube involve various dimensions and may contribute to altered experiences (82-84). This is why the child can perceive both advantages and disadvantages during meals (14, 85).

3 THEORETICAL FRAMEWORK

A central concept within caring science consists of the care recipient, in this case the child, and their experiences in daily life where the challenge to comprehend and grasp what they need to feel well constitutes the epistemology (86). The central concept of this thesis was to describe the children and their parents' experiences of mealtime situations before and after a G-tube insertion, and why the theoretical framework includes two parts: a child-centred care (CCC) approach (87, 88) and the Five Aspect Meal Model (FAMM) (23, 89).

A CCC approach, including the child's perspective and their right to be involved, but also the parent's complementary perspective (87, 88) was chosen to describe and explain the meals in this thesis and consequently served as a form of guidance throughout the research process. This is because meals involve social situations and opportunities for gathering (17) and why both perspectives are needed to achieve a realistic, but also a broader and richer understanding of the phenomenon. Thus, it was key that the child's voices, needs and rights be emphasised and clarified in the research, not to mention in their care. The choice to use the FAMM (23, 89) was assessed to be appropriate since a holistic approach and environmental aspects are seen as central in conjunction with meals, but also to investigate if this explanatory model could be used in the contexts of nursing, i.e. within paediatric care.

The distinction between nutritional intake and meals and their meaning in this thesis needs to be clarified. Here, the author of the thesis has defined nutritional intake as the child's need for nutrition, a basic need involving the intake of calories in general and specifically protein, fat and carbohydrates. These are essential nutritional components that all human beings, in this case, the child, need to survive. All children, healthy or those who suffer from a disorder, need adequate nourishment to achieve the best possible well-being throughout childhood (90, 91). Children who undergo oncology treatments and HSCT have specific needs. To achieve an optimal balance, a dietician with specific expertise may be required to calculate the child's requirements and give advice (5). However, the situation is also complex regarding the nutritional needs in children with CP (11). Within nursing care, meals and mealtime situations are emphasised as crucial (10). This is why meals in this thesis constitute the central concept, including mealtimes (time for meals), mealtime situations (context of meals) and mealtime experiences (the child's experience of meals), as shown in Figure I.

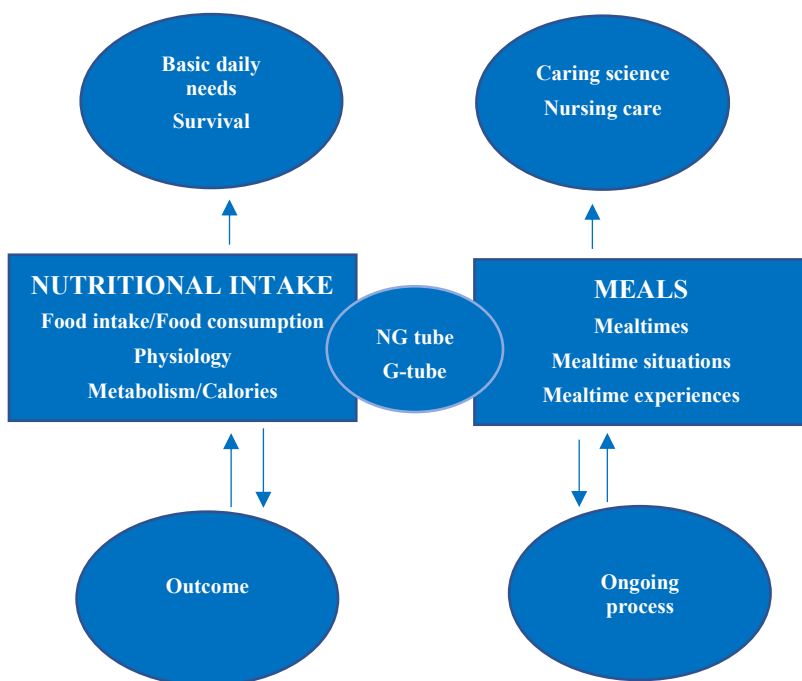


Figure I. Overview – distinction between nutritional intake and meals.

3.1 A CCC approach

Children are not small adults; they are a group of patients with specific needs requiring care and treatment adapted especially for them (87, 92). A CCC approach emphasises the value and importance of possessing knowledge of children and their specific presumptions and needs (87). Children who become ill and have a life-threatening disorder struggle to grasp and manage the situation (93). One approach that enables the child to understand their needs and challenges is to let them take part in their treatment (87, 94). Severely ill and hospitalised children want to be aware of their changed circumstances (94-96), so it is essential that the paediatric care team takes the child's perspective into account (87, 94). A CCC approach also considers the child's relationship with and dependency on the family (94, 97). Consequently, enabling the child to take part in research is a balancing act because of the parent's need to simultaneously take care of them (98) and be fully aware of the child's unique situation. In the current thesis, a CCC approach (87, 88) constituted the basis to develop and explain the mealtime situation and why the child's perspective and their parent's complementary child perspective is central and relevant to emphasising a realistic and broader point of view about meal and mealtime situations in daily life.

3.2 Meal models used within healthcare

Meal models are necessary to explain and explore meal and mealtime situations in different contexts. Meal models exist which are based on or use the FAMM (23, 89) (explanation, see subsection 3.3) as a framework (10, 99). *Making the most of mealtimes* (M3) is one of these models, focusing on mealtimes in elderly patients, such as those with dementia (99). M3 consists of the concepts 'meal quality', 'meal access' and 'mealtime experiences', which are described as being influenced by surrounding aspects (99). For example, the patient's ability to *chew* and *swallow*, may eventually require adaptations to ensure *safety* during meals (99). Another meal model, which consists of six different aspects based upon the FAMM (23, 89) was developed by the National Food Agency (NFA) and used within general healthcare in Sweden (10).

The Hospitable Meal Model (100), which reflects upon both the FAMM (23, 89) and the M3 (99), has been developed in the context of adult patients within healthcare and focuses on how meals may be perceived as linked to hospitality (100). The model involves concepts such as 'conditional and unconditional hospitality', 'co-creation and provision' and "routine and disruptive micro-events" (100).

However, a shortcoming of existing meal models used within healthcare is that they focus exclusively on adults and the elderly and their needs; consequently, they are not adaptable for children within paediatric care and their specific needs (10, 99, 100).

3.3 The Five Aspects Meal Model (FAMM)

As mentioned earlier (see subsection 3.2), the FAMM (23, 89) has served as a basis or framework for meal models used within healthcare (10, 99), but has also been used in a global context, such as with the elderly (101). Furthermore, the FAMM (23, 89) has been used in Swedish documents and guidelines (19, 102-106), as a framework (107, 108) but also as a part of an analysis (109).

The FAMM is a prevailing, reputable and explanatory meal model with the purpose of ameliorating meals in restaurants (23, 110). As a basis, the Michelin Guide and its concepts have been used to explain why the FAMM is built upon five dissimilar aspects, that is, *the room*, *the meeting*, *the product*, *the management control system* and *the atmosphere*, with the aim of emphasising how the surroundings may affect meals (23, 89).

According to the FAMM, food is eaten within a *room* even if the location and its context can vary, which is why the physical environment can be decisive for the mealtime experience (23, 89). Furthermore, the FAMM advocates that the *meeting*, described as how persons linked to the meal interact, also influence the mealtime experience and why competence and awareness within this area is required (23, 89). Nevertheless, the *product*, that is, food and drink, is highlighted as an essential aspect as it affects meals to a large extent (23, 89). Thus, comprehensive competence within the area is considered crucial for an appreciated meal since sensorial impressions are emphasised as being central (23, 89). Administrative assignments in the FAMM are linked to the *management control system*, which is considered to have an overall impact (23, 89). Finally, the FAMM consists of *the atmosphere*, an entirety with sensorial dimensions and the ability to communicate (23).

In conclusion, there is a gap in knowledge regarding how the physical environment and considerable other aspects affect meals and mealtime experiences for children, especially those who are hospitalised and live with a G-tube. Furthermore, no meal models adapted specifically for children or children with G-tubes are available within paediatric care. The FAMM (23, 89) was thus selected as a theoretical framework to determine whether the model may be appropriate for use within nursing care, that is, in children with a G-tube, thus exploring the environmental aspects and their impact on children's mealtime experiences with the purpose of emphasising and improving their nutritional needs.

4 RATIONALE

The ontology of caring science, where the *existence*, the aspects of *being* and *life* are central, also constitutes a part of nursing care (86, 111). Caring science focuses on the care of recipients in terms of their comfort and situations in daily life (86). That is why the child and their needs in conjunction with meals and mealtime situations is central in this thesis, and why this can be seen as an essential part of nursing care. The metaparadigm of nursing involves the concepts '*person*', '*health*', '*environment*' and '*nursing*' (112, 113), which all can be linked to caring science (86), to our comprehension of dimensions such as '*place and space*' and their meaning and importance within healthcare (114), but also in respect to the environmental aspects in the FAMM (23, 89) as well as in the CCC with the child as a person of importance (87, 88).

A context that heals assumes care based on a holistic approach, which is also connected to mealtime situations (95). This is why the value and importance of contextual aspects and their effects on the individual's health need to be emphasised (114). As a part of nursing care, the paediatric care team expects to support children during problematic and troublesome meals (13); however, knowledge is missing when it comes to G-tubes and their impact on meals and mealtime situations for children in their daily lives. In addition, no meal model adapted for these children is available, so it is unclear how different aspects, such as the physical environment, affect the child during mealtime situations. This is why it is essential to allow children to take part in treatment and share their experiences (87, 94). Few studies have focused on the child's experiences of living with a G-tube and its impact on their mealtime experiences (14, 85), which is why further knowledge is necessary to support these children in order to improve their meals, mealtime situations and mealtime experiences.

5 AIM

The overall aim of this thesis was to describe children (1–18 years of age) and their parents' experiences of mealtime situations before and after a G-tube insertion and to develop a child-centred meal model focusing on mealtime situations and their environmental aspects.

5.1 Specific aims

- I To determine whether the FAMM could be appropriate to use within caring science and for children with a G-tube in paediatric care, but also to see if the model could be developed or adapted, and if so, in what way.
- II To describe and better understand how one adolescent with cerebral palsy and her parents experienced mealtimes before and after an NG tube and G-tube insertion and how the use of these feeding tubes was experienced in daily life.
- III To explore pain and discomfort in this vulnerable group of children with malignant and severe non-malignant disorders during the transplantation and post-transplantation time until the G-tube was removed.
- IV To elucidate the impact of mealtime experiences on hospitalised children with a malignant or a severe non-malignant disorder and their parents before, and after a G-tube insertion.

6 METHODS

6.1 Research design

This thesis includes four studies, and both qualitative and quantitative methods were used to achieve the overall aim, that is, to describe children and their parents' experiences of mealtime situations, and to develop a child-centred meal model that considers environmental aspects. The purpose of each study acted as a guide for choosing an appropriate study design. A qualitative approach was used in Studies I, II and IV, while a mixed-methods design was used in Study III (see Table I).

Table I. Overview of the study design.

	Study I	Study II	Study III		Study IV
Design	Qualitative	Qualitative	Mixed-methods		Qualitative
Data collection	Semi-structured interviews	Semi-structured interviews	Structured interviews including questions with fixed answer options	Semi-structured interviews	Semi-structured interviews
Participants	3 families <i>3 children</i> <i>4 parents</i>	1 family <i>1 child</i> <i>2 parents</i>	16 families <i>8 children</i> <i>21 parents</i>	14 families <i>7 children</i> <i>19 parents</i>	21 families <i>9 children</i> <i>29 parents</i>
Diagnosis	Malignant disorders	Cerebral palsy	Malignant and severe non-malignant disorders	Malignant and severe non-malignant disorders	Malignant and severe non-malignant disorders
Data analysis	Qualitative-directed content analysis	Interpretive description	Descriptive statistics	Qualitative Content analysis	Thematic analysis

6.1.1 Design of the studies

Study I involved a qualitative design that was already developed, and established steps were used (115), originally defined by Fawcett (116). The specific steps in the model (115) allowed the author of the thesis to achieve a clear pronounced direction, which facilitated the research process. The design (115, 116) was considered and assessed as suitable for Study I because of its original purpose (116). Consequently, this made it possible to apply the FAMM (23, 89), but also link and analyse the meal model in relation to the chosen variables (115).

Study II involved a case study design, with the aim of apprehending the diversity and multifaceted aspects of a specific single case (117). Since the purpose of study II was to achieve a profound and extensive comprehension, in this case, of an older child's experiences, a case study design (117) was considered and assessed as relevant. The choice of design was also strengthened because no prior research and knowledge within this area was discovered. The design enabled the author of the thesis to focus on one multifaceted situation (117), also aiming to increase comprehension regarding mealtime experiences and the use of different feeding tubes within clinical paediatric care. In this study, a theoretical framework, i.e. the modified version of the Five Aspects Meal Model (M-FAMM) (developed in Study I) was used.

Study III involved a mixed-methods design (118) aiming to collect data at specified time points during the child's oncology care and treatment from 2018 to 2021. This design enabled the author of the thesis to use different angles of approach, and permitted an opportunity to gather complementary data (119) which strengthened the findings of the study. This was for the purpose of achieving a deepened comprehension within the study area (119). A CCC approach was included as a part of the study (87, 88).

Study IV involved a qualitative design (120) with the purpose of gathering data at specified time points during the child's oncology care and treatment from 2018 to 2021. A CCC approach (87, 88) constituted an essential concept in the study. To facilitate the research process, a theoretical framework was used – the M-FAMM (developed in Study I, used in Study II and Study III).

6.2 Settings and participants

6.2.1 The Childhood Cancer Centre

Six paediatric oncology centres are found in Sweden, located in Gothenburg, Linköping, Lund, Stockholm, Umeå and Uppsala. The children who participated in this study received treatment at one of these childhood cancer centres.

At the childhood cancer centre, the children received paediatric oncology treatment due to either a malignant disorder or a severe non-malignant disorder (e.g. a benign blood, haematological or immunological disorder). The children underwent treatments such as chemotherapy, radiotherapy, surgery and HSCT.

The included childhood cancer centre involved two units: one for inpatient and one for outpatient care, depending on the children's need for care and treatment. The inpatient unit offered extensive care and treatment to critically ill children, while the outpatient unit offered treatment such as blood transfusions, chemotherapy, investigations, controls and examinations. The paediatric care team consisted of physicians, paediatric- and/or specialist nurses, nurses, assistant nurses, dietitians, psychologists, social workers, physiotherapists, occupational therapists and dentists. At the specific childhood cancer centre, a special paediatric care team was available, enabling the coordination and planning of the care and treatment for the children who needed to undergo HSCT.

6.2.2 The habilitation centre for children

In Sweden, several habilitation centres offer care and treatment for children with long-term disabilities. In the Västra Götaland region, habilitation centres for children are available in Alingsås, Borås, Frölunda, Hisingen, Kungälv, Lidköping, Skövde, Uddevalla and Vänersborg. For the purposes of this thesis, one habilitation centre in the Västra Götaland region was the focus.

The habilitation centres for children in the Västra Götaland region offer specialised paediatric care and treatment, but a referral is required. A child with a severe neurological disorder (e.g. CP) usually requires extensive care, numerous contacts within paediatric care are common, and collaboration among various specialties is preferred. At the habilitation centre, healthcare professionals work in teams. The paediatric care team can consist of physicians, paediatric- and/or specialist nurses, nurses, dietitians, occupational therapists, social workers, psychologists, physiotherapists and speech and language therapists. The paediatric care team offers care and treatment to

children, parents and relatives. Parents can receive guidance and advice via telephone, and the child can receive care treatment at the habilitation centre, but also at home or in school.

6.2.3 Studies I, III and IV

Children and parents were included in these studies from January 2018 until April 2021 (Study I was conducted in February and March 2019). The inclusion criteria were established to obtain a broad target group of children to describe how meals and mealtime situations were experienced, as well as during the complete healthcare process, in different age and cultural groups after a G-tube insertion.

The criteria for inclusion in Studies I, III and IV involved children of 1–18 years of age who received oncology care and treatment because of a malignant or severe non-malignant disorder at one of the childhood cancer centres in Sweden and who had undergone G-tube insertion for medical reasons. The choice to include all children from 1 and 18 years of age was based on the opportunity to achieve a rich and varied sample regarding both ages and diagnoses. Children and their parents with different backgrounds, cultures and languages were included in the study.

Children less than one year old were excluded because they are considered infants and are mostly still breastfeeding. Infancy was not assessed as relevant because the focus was mealtime situations post-feeding when children can eat by themselves. In addition, only a few infants are diagnosed with malignant or severe non-malignant disorders. Moreover, an NG tube – not a G-tube – is most often used if feeding difficulties occur during infancy. Infants are also a heterogenic group that would not provide an accurate picture of reality.

Children who, at the time of inclusion, had an acute and severe medical state of health, as assessed by the paediatric oncology care team, were also excluded. Children younger than five years of age or who had a cognitive developmental level corresponding to that age group were excluded. As a result, these children were only represented by their parents and excluded from answering questions with fixed answer options and from participating in the interviews.

In Study I, three children and their parents were the first participants in the data collection; the children had a malignant disorder and had received a G-tube. The purpose of Study I was to examine the early stage of the research process and to test if the ideas regarding the meal model, i.e. the FAMM (23, 89), were appropriate to use within the context of caring science. Consequently, a total of three families with three children born in the period from 2009 to 2012 who

had a malignant disorder and received care and treatment within paediatric oncology care and four of their parents participated. The decision to, at an early stage, stop inclusion, reflect upon the data and analyse existing data from these families was beneficial. It was clear from the findings that the FAMM (23, 89) was not suitable to use within paediatric oncology care for children with a G-tube, and why a modification was required for the M-FAMM, which was later used in the research process. The author of the thesis also realised that the first families (i.e. in Study I) received questions later included in the M-FAMM, which is why these interviews were subsequently included in Study IV.

In Study III, all included children had undergone HSCT due to a malignant or severe non-malignant disorder. In total, 16 families were included in the quantitative part; eight children participated on their own, while the other eight children were represented by their parents. In total, 21 parents of the 16 children participated. Of the 16 included families, 14 also participated in the qualitative part of the study. Seven children participated on their own, while the other seven were represented by their parents. In total, 19 parents of the 14 children participated. The ages of the children at inclusion ranged from 1–15 years of age.

In Study IV, 21 families were included. The included children were born in 2003 through 2017 and lived with malignant or severe non-malignant disorders. In total, nine children participated on their own, while 12 children were represented by their parents. In total, 29 parents of the 21 children participated in the study.

6.2.4 Study II

In Study II, one older child who was 14 years of age and her family were included. This older child had CP and participated with her parents. Only older children with experiences of living with dissimilar sorts of feeding tubes (i.e. NG tubes and G-tubes) for a longer period were appropriate for inclusion according to the aim of the study. In this case, the author of the thesis chose to use purposive sampling at one habilitation centre in the Västra Götaland region.

Table II. Overview of all children included in Study IV, some of these were also represented in Studies I and III.

Children	Number	Gender	Study	Year of birth	HSCT
Malignant disorders					
Leukaemia	6	1 boy 1 boy 1 boy 1 boy 1 boy 1 girl	III/IV III/IV III/IV IV III III/IV	2007 2014 2014 2016 2012 2016	HSCT HSCT HSCT NO HSCT HSCT HSCT
Brain tumour	2	1 girl 1 girl	I/IV III/IV	2009 2015	NO HSCT HSCT
Neuroblastoma	1	1 boy	IV	2017	HSCT
Sarcoma	3	1 girl 1 girl 1 girl	IV I/IV IV	2005 2009 2014	NO HSCT NO HSCT NO HSCT
Wilms' tumour	1	1 girl	I/III/IV	2012	HSCT
Non-malignant disorders					
Hurler's disease	1	1 boy	III/IV	2017	HSCT
SCID	1	1 girl	III/IV	2016	HSCT
Sickle cell anaemia	3	1 girl 1 girl 1 boy	III/IV III/IV IV	2006 2009 2015	HSCT HSCT HSCT
Aplastic anaemia	2	1 girl 1 girl	III/IV III/IV	2009 2010	HSCT HSCT
Thalassemia	3	1 boy 1 boy 1 girl	III/IV III III/IV	2003 2009 2008	HSCT HSCT HSCT

6.3 Data collection and process of recruitment

The children's (1–18 years of age) degree of development and maturity, were aspects taken into consideration during the data collection of the studies included in this thesis, because these factors influence mealtime situations. However, the children who participated by themselves in the data collection, were from 6 and 14 years of age. It is a challenge to involve children of a wide age range because their needs may differ greatly, affecting the attitudes, interaction and relations with family during mealtime situations. There is a discrepancy regarding young and older children's ability to manage different situations, for instance, being involved in research, which needs to be taken into consideration (98). To meet with and talk to children of dissimilar ages thus requires both attentiveness and sensitiveness as a researcher (87).

6.3.1 Studies I, III and IV

In Studies I, III and IV, data collection was undertaken both at the childhood cancer centre (a hospital environment) and in the family's home environment. The author of the thesis conducted all the semi-structured interviews, and pictorial support material was available throughout the complete process. All semi-structured interviews were conducted face-to-face, while the questions with fixed answer options (Study III) were obtained face-to-face or via telephone until the beginning of spring 2020. After that, the author of the thesis, due to the COVID-19 pandemic, was forced to employ digital methods during the remaining part of the data collection.

In Studies III and IV, families from various parts of the world participated, which is interesting and unique because several contexts, cultures and languages bring a broader dimension to the phenomenon studied, and there seem to be few studies performed with children where interpreters have been involved. Interpreters were available where the child and/or the parents did not speak or write the Swedish or English languages. The author of the thesis gave all the involved interpreters information about the study and its purpose before their involvement in the data collection. In cases where the participants needed an interpreter, they were provided complete information about the study with applicable research personnel information included to ensure that aims of the studies were understood correctly.

An interpreter was used during data collection to facilitate the answering of questions with fixed answer options (Study III) and during the semi-structured interviews (Studies III and IV) if necessary. All interpreters were hired from a specific interpreter agency, a corporation that regularly provides interpreters in healthcare, that is, to the included childhood cancer centre and the included habilitation centre. The interpreters were impartial and bound by confidentiality.

In Study I, the author of the thesis performed seven face-to-face semi-structured interviews (120) with children and their parents, individually and on separate occasions. The FAMM (23, 89) was used as a framework in the study; its five aspects were central to the interview process.

In Study III, structured face-to-face or phone interviews (120), later conducted digitally, resulted in 117 sessions where questions with fixed answer options were presented and where both children and parents participated. The questions were content validated and originated from a questionnaire developed for children with a G-tube within paediatric oncology care (121).

However, most of the chosen questions could also be linked to well proven and validated tools commonly used within different areas of paediatric care (122, 123). In addition, a total of 50 semi-structured interviews (120) were individually conducted repeatedly with children and their parents from 2018 to 2021. In this qualitative part of the study, the M-FAMM (developed in Study I and used in Study II), acted as a basis for the interview guide.

In Study IV, 64 semi-structured interviews (120) were conducted individually with the participants repeatedly during a long-term period during the child's oncology care from 2018 to 2021. The M-FAMM (developed in Study I and used in Study II and Study III) served as a framework and as the basis for the interview guide.

6.3.2 Study II

In Study II, the author of the thesis conducted semi-structured interviews (120), six individually with one family, so a triangulation could also be performed (124). The three participants were all interviewed separately and at two different times. The M-FAMM (developed in Study I) served as a framework and as the basis for the interview guide.

6.3.3 Preunderstanding

To avoid negative risks during the research process, regular cooperation regarding the data and analysis was recurrently made together with the research group. Preunderstanding of various degrees and contexts (e.g. paediatric oncology care, paediatric habilitation centres, care of elderly and environmental aspects) within the research group functioned as a quality assurance and was a definite strength of the research process.

Several years as a paediatric nurse at a habilitation centre specialised for children with disabilities contributed to the author of the thesis being possessed of knowledge of and experience with the paediatric care, children with disabilities, nutrition and G-tubes. The researcher's preunderstanding can be seen as advantageous (120, 125), but also disadvantageous, depending on the specific situation (120). Thus, it is necessary to be aware of one's own preunderstanding because it may have a great impact on the whole research process, including data collection and analysis of the data, but also the findings and outcomes of the study (120, 125).

During the data collection of Study II, the author of the thesis perceived that existing knowledge and experience within the area of CP, nutrition and G-tubes contributed to a sense of familiarity and acquaintance, which facilitated the ability to create relationships with the participants. The author's understanding of the situation contributed to a sense of trust and confidence, facilitating the willingness of participants to share experiences about their family. Other questions, aspects and views could be emphasised, bringing an extra dimension to the research. However, a well-known and accustomed area can also contribute to the loss of a naive approach, which can be a risk because important aspects may not be perceived correctly, thus negatively affecting the research process.

In the beginning of the data collection, a preunderstanding of children with disabilities stood in contrast to a non-existent preunderstanding in the field of paediatric oncology care. However, for the author, the existing preunderstanding regarding nutrition and G-tubes was also applicable and useful in an unknown area. Nevertheless, a non-existent preunderstanding within the area of paediatric oncology care may have contributed to a naiver approach, which could have resulted in the author managing the research process in a different manner in comparison with the one at the habilitation. As a result, the author regularly spent a significant amount of time at the paediatric oncology ward to gain knowledge and a view of the care, routines, and treatments. Therefore, a collaboration with the paediatric care team was created, which contributed to a sense of trust and confidence, facilitating access to the children and their families at the wards. This is in line with prior research, emphasising the significance of establishing an affiliation with the paediatric oncology care team to gain support for the planned process (126). As the data collection had been ongoing during several years, the preunderstanding for the author had developed and changed, which meant that additional knowledge and awareness within the area of paediatric oncology care and treatment was obtained.

6.4 Data analysis

6.4.1 A qualitative approach: Studies I, II and IV

In Studies I, II and IV, a qualitative approach was used to analyse gathered data, that is, a qualitative-directed content analysis (Study I) (127), an interpretive description approach (Study II) (125) and a thematic analysis (Study IV) (128).

In Study I, a qualitative-directed content analysis approach was used (127). The method was considered and determined to be relevant since the purpose of the study was to determine whether the FAMM (23, 89) could be utilised within paediatric care, why its key concepts (23, 89) functioned as predetermined categories during the analysis. The qualitative-directed content analysis involved a deductive approach, where a guidance facilitated the process to successively categorise, compare and code gathered data (127) into aspects of the FAMM (23, 89). However, some gathered data could not be categorised (23, 89), so the author in this phase was required to use an inductive approach. A qualitative-directed content analysis assumes that the author reflects upon the results in relation to the used model (127). This is why the FAMM (23, 89) and its usefulness within paediatric care was debated in one section of the study. The author of the thesis chose in this study to use specific criteria with the purpose of evaluating the model (129).

In Study II, an interpretive description approach (125) was used during the analysis, which made it possible for the author of the thesis to gain knowledge and comprehend a multifaceted situation, in this case involving an older child and her parents' lived experiences of mealtime situations and different feeding tubes. This single case focused on an older child and her daily life, but also included an area of interest for the clinical nursing care, which strengthened the author's choice of analysis method. The author had prior experience, i.e. possessed a preunderstanding in the area of children with disabilities and G-tubes, which facilitated the choice of using interpretive description as the researcher's existing preunderstanding is assessed as valuable and adds an extra perspective (125). The inductive analysis process identified patterns within data, which later on were transformed and ended up in conceptual descriptions (125), and were finally summed up into thematic patterns that described the older child and her parents' lived experiences. In this study, the author used the Standard for Reporting Qualitative Research (SRQR) with the purpose to optimise the research (130).

In Study IV, the author of the thesis chose to use a thematic analysis (128). The choice to use thematic analysis was assessed as appropriate according to the purpose of the study, i.e. to elucidate the impact of mealtime experiences, but also because of the great amounts data, which also involved the participants' lived experiences (128, 131). The data collection was conducted over a long-term period, here, and the thematic analysis enabled a continuous process between the analysis and writing (128), which the author assessed as an advantageous aspect. The author chose to use predetermined stages, which enabled a structure in the analysis process, and later on, the identification of codes and themes (128). In this study, the author chose to use the Consolidated

Criteria for Reporting Qualitative Research (COREQ) checklist (132, 133) with the purpose to guarantee an optimal standard of the research.

6.4.2 A mixed-methods approach: Study III

A mixed-methods approach (118) was used in Study III. The author of the thesis analysed qualitative data by using qualitative content analysis (134), while quantitative data instead was described by the use of descriptive statistics (120). A manifest qualitative content analysis (134) was used to describe the qualitative part of Study III. The method was assessed to be appropriate according to the purpose, but also since the study involved a great number of interviews. Using an inductive qualitative content analysis enabled the processing of data into codes and categories, which through an abstraction ended up in the findings (134). To structure and estimate the quantitative part of Study III, IBM SPSS version 25 (IBM, Armonk, NY, USA) was used, and descriptive statistics were assessed to be appropriate as an analysis method of gathered data (120). This was chosen because the purpose of the study was to explore pain and discomfort in a specific and proportionately small sample of children.

6.5 Ethical considerations

The Regional Ethics Review Board approved the studies included in the present thesis (Approval numbers 937-17 and 2019-05671). Information about each specific study was given by the author of the thesis in written format as well as orally to all included participants. The research information was adapted for adults, but also for the children of different ages, with pictorial support added as needed. All the parents who took part provided the author of the thesis with both their verbal and written consent to participate in the studies. In addition, all parents added their verbal and written consent to their child's consent to participate. In cases where the participants did not possess a mastery of the Swedish or English language, an interpreter translated and explained both research and consent information regarding the studies. Nonetheless, the risk of participants not comprehending the information correctly due to the translation process (135-137) could be seen as a risk and an ethical dilemma.

Below, the ethical considerations for the respective studies are presented.

6.5.1 Studies I, III and IV

Young people have often been considered an extraordinarily exposed group; however, this viewpoint has changed, and a greater focus has been placed on the value and need to more effectively integrate them into research (98). To integrate younger people is important, especially because most prior data have been presented from the point of view of older people (138). However, several ethical aspects need to be taken into account (98, 139, 140). For instance, to invite a child with a life-threatening diagnosis can be seen as an ethical dilemma (141).

During the data collection, the author of the thesis observed ethical dilemmas for children, parents and the paediatric care team. An example was when the paediatric care team wanted to give the child the best possible treatment (142), and identified the research as a threat for the child's well-being. Consequently, the research process always involved a balancing act (98), where the child's daily condition and ability to manage the situation was taken into consideration. This is why questions or interviews often needed to be postponed indefinitely. Due to the life-threatening disorder, the children's conditions could fluctuate and their situations could rapidly change. This meant that question sessions and interviews were not always possible to conduct as planned due to such factors as necessary and acute impairments, investigations or treatments. As a result, question sessions and interviews frequently needed to be postponed indefinitely. A negative circumstance concerning the child could result in crisis and distress for the parents, which then prevented them from participating and sharing their experiences as planned. Some of the children passed into a palliative phase, which included an ethical dilemma for all involved parties. Also, the data collection required an awareness of several ethical principles (98), thus the author of the thesis needed courage, knowledge and ability to reflect upon the process. Consequently, it was important to discuss and collaborate regarding ethical issues in relation to the purpose and goals of the study with, for example, key nurses at the ward and the paediatric care team but also the research group.

6.5.2 Study II

Children who live with a disability such as CP are generally not in a life-threatening situation, but unlike a child with a malignant or a severe non-malignant disorder, they do not have the prospect of recovery. An impaired ability to comprehend or communicate can aggravate the involvement in research (88), which is why this group of children is at risk of exclusion and the knowledge of adequate approaches to use is crucial (16, 88). Those who live with disabilities can, in contrast to healthy children, be dependent and

cared for by elderly individuals, and this is why their involvement in data collection requires a high degree of ethical consideration (16). Children with CP are aware of their differences in contrast to others, and the general and public view contributes to their experience of this discrepancy (143). Thus, for the purposes of this study, it was especially important to include an older child with CP and enable her participation, thus providing a further dimension to the area studied. However, the older child with CP included in Study II had no cognitive dysfunction and no severities to communicate stood in the way of allowing her to give her own approval to participate in the study, which facilitated the ethical consideration.

7. RESULTS

The findings of the thesis include both children and their parents' experiences before and after a G-tube insertion with a focus on mealtime situations, but are also linked to the development of a child-centred meal model for children with a G-tube. This section concludes with a summary of the findings, which later serves as a guide for the discussion.

7.1 Study I: Mealtime experiences in children and the need for a meal model

The findings of Study I were linked to the predetermined aspects in the FAMM and demonstrated that further dimensions were required to explain mealtime experiences before and after a G-tube insertion in children with malignant disorders within paediatric oncology care. This was done since the aspects of '*bodily discomfort*' and '*time of change and acceptance*' were prevalent factors noted in the gathered data.

The child's hospitalisation involved a contextual change, that is, prior meals at home were replaced with mealtime situations in small rooms at the paediatric oncology ward. The findings emphasised that the prevailing mealtime environment at the hospital, for instance, the presence of various medical equipment, but also regular disruptions during meals, contributed to unappealing mealtime situations. In addition, the offered hospital food was highlighted as being unappealing. The presentation, the amounts of food and its taste and smell were aspects mentioned as especially troublesome to manage and consequently associated with negative mealtime experiences. Awkward treatment-related side effects, and troublesome sensorial impressions adversely affected the child's experiences further with unmanageable

mealtime situations as a result. Thus, it was common that the children refused to accept the food and why the mealtime situations often became occasions associated with negative feelings. As a result, the parents tried to cater to the child's longings by offering their own homemade food.

This is why the child's nutritional intake became the focus. The importance and awareness of the child's need for sufficient nutrition became an additional stressful task to manage for the parent, and was most often associated with a feeling of failure. Prior enjoyable moments became replaced by struggle-filled meals, where the pressure to participate but also to eat negatively affected the child as well as the whole family's well-being. As a result, the interaction during meals became impaired, and this adversely affected the relationship between the parents. In this context, the G-tube became experienced as an alleviation, a nutritional intervention that facilitated the child's meals and mealtime situations in daily life. The G-tube involved safety, an assurance, which made it possible for the parents to feel secure that the child would receive enough nourishment independent of their condition.

However, the G-tube (and the NG tube) also involved physical and psychosocial challenges. This occurred since both of these feeding tubes can contribute to experiences of discomfort; in addition, NG tube contributes to a changed appearance. The children struggled with their oral intake while as the parents saw the social value of the meals. Moreover, the children seemed to prefer tube feeding in private. In conclusion, the findings gave the author of the thesis an overall picture of how meals and mealtime situations were experienced before and after a G-tube insertion in children with malignant disorders, but they also provided an understanding that the FAMM needed to be modified into the M-FAMM to effectively function in this group of children within paediatric nursing care.

7.2 Study II: From functioning meals to the requirement of a G-tube

The findings of Study II resulted in four thematic patterns: '*struggling with nutritional intake*', '*the paradox of using an aid*', '*being different*' and '*challenges of public mealtimes*'. In this case, a drastic negative change of food consumption became devastating for the older child. Prior well-functioning mealtime situations disappeared and were replaced by meals which focused solely on the child's nutritional needs. The prior food-loving child, who had had no barriers to eating, underwent a physical impairment. As a result, the focus changed and the older child's need of food became central.

As a result, a transformation occurred: mealtime situations became associated with troublesome occasions. The pressure to eat caused uncomfortable mealtime situations. Several efforts were made to end this negative process; however, the child's condition required a change, and this was why the situation ended up in the need for feeding tube. The placement of the NG tube became an overwhelming intervention for the older child.

The feeding tube contributed to a further sense of discrepancy, which was especially challenging to manage in a sensitive phase of life. This was also the case for the parents. For instance, the older child was affected due to other persons' reactions, and this was a reason why the G-tube insertion was welcomed and at this time and seen as a better option. However, this intervention also caused public attention, and the physical discrepancy compared with others remained a major issue. However, the older child successively and partially regained her self-image, which facilitated the process to introduce the G-tube as a more natural part of daily life.

Meals, an experience that the older child had managed independently all of her life, became a basic need that required additional assistance. The NG tube insertion contributed to overwhelming feelings. The G-tube was later seen as an indispensable tool, an intervention that enabled an improvement of the older child's condition, but it also contributed to less number of stressful mealtime situations. However, although the G-tube positively changed meals, it contributed also to a transformation of routines, both at home as well as in school. This occurred since the older child mostly chose not to eat orally or participate in ordinary mealtime situations, independent of context. As a result, tube feeding became a separate activity, not associated with mealtime situations or the school context. The G-tube enabled other choices, which gave the older child an opportunity to recapture and master her meals. In conclusion, Study II emphasised how pain and treatment-related side effects can contribute to problematic meals, mealtime situations and a long-term need of a feeding tube in an older child with CP. Study II also enabled the child-centred meal model M-FAMM to be further used in another context.

7.3 Study III: Children's experiences of pain after a G-tube insertion

The qualitative findings of Study III involved four themes: '*time of uncertainty*', '*need of support*', '*side effects as a challenge*' and '*a supportive solution*'. The findings demonstrated that a G-tube insertion is a procedure that might cause anxiety and fear for the children, but also afterwards can result in intense pain. Experiences of pain after the surgery contributed to discouragement in the children initially associated the G-tube. This occurred since the ordinary routines with the care became uncomfortable and associated with discomfort. The parents shared experiences of being unprepared for the children's pain and how and why they struggled to manage with daily activities. Both children and parents felt a need for being seen and confirmed by the paediatric care team. However, later on, a stabilisation developed, and that made it possible to also grasp the benefits of the intervention. Later on, some of the children experienced some complications linked to the G-tube; however, these were not described as affecting meals or mealtime situations. Instead, they were associated with another new aspect to be considered: at this time, the G-tube had become an intervention the families described as invaluable to manage the child's daily life.

The quantitative findings of Study III, i.e. the children's reported pain experiences, were described and presented in relation to the G-tube, mainly after the postsurgery phase. The results indicated that experiences of pain associated with the G-tube were unusual. The children's experiences of pain arose sporadically in a majority of cases after they had undergone the recovery process. The findings indicated that the occasions of pain linked to the G-tube were mostly associated with *skin pain* (11 of 16) and *pressing or squeezing* (10 of 16), but also emerged because of the *hose or balloon* (5 of 16). Minor complications such as red skin could cause *discomfort* for some of the children (9 of 16); however, only one child (1 of 16) experienced *sleep disturbance* because of the G-tube. In conclusion, the insertion of a G-tube seems to be an applicable nutritional intervention also in children who have undergone HSCT within paediatric oncology care.

In Study III, the usefulness of the aspect *bodily discomfort* in the M-FAMM (developed in Study I and used in Study II) was further evaluated.

7.4 Study IV: Hospitalised children's experiences of meals and a G-tube

The main findings of Study IV gave a description of hospitalised children's mealtime experiences and involved four themes: '*changed prerequisites*', '*a troublesome sensory dimension*', '*aggravating obstacles*' and '*solving the unmanageable*'.

The majority of the children were isolated due to their condition, and this was one reason why the mealtime environment became a challenging aspect. The room and its limited space, but also the presence of, for instance, medical equipment, limited the possibilities to establish appealing mealtime situations. This, but also the child's condition, resulted in most meals being presented in bed. The need for care and treatment, also during meals, resulted in that members of the paediatric care team needing to disturb the children, an aspect that could end up in decreased food consumption. At the same time, all children struggled with sensorial impressions, all of which were difficult to manage. These experiences were associated with the hospital food (e.g. smell/taste/visibility), but also with perceived side effects (e.g. altered smell/taste/mucositis), which strengthened and triggered feelings of discomfort (e.g. nausea/vomiting), with devastating consequences and causing unmanageable mealtime situations as a result.

Consequently, troublesome mealtime situations became the norm. Pressure to eat contributed to experiences of having failed for all parties involved. This resulted in the children experiencing the G-tube as an alleviation. However, the parents struggled to maintain the child's oral intake, for instance by offering them familiarly food. They required a longer period to determine the G-tube's benefits, while the children saw it as a long-awaited opportunity, with a decreased pressure in conjunction to meals. The G-tube insertion involved several advantages, but disadvantages were also experienced. The parents saw the G-tube as a technical assistance, with changed mealtime situations within the family as a result. It was no longer a matter of course that the child became included in the ordinary meals as previously, so the child per se ended up being of secondary importance compared with their nutritional needs.

In conclusion, the findings of Study IV demonstrated that children within paediatric oncology care struggle with several aspects in conjunction to meals and mealtime situations during their hospitalisation. The G-tube is experienced as a solution to unappealing mealtime situations; however, the families need support to manage those challenges that may occur, but also to resume a sense of familiarity in the mealtime situations.

Study IV contributed to the understanding that the M-FAMM (developed in Study I and used in Study II and Study III) could be further used in a broader sample of children. The findings confirmed that this child-centred meal model was functional to use within a hospital context where children with a G-tube received oncology care and treatment.

7.5 Summary of the findings

The meaning of the mealtime environment was an aspect emphasised independently of the children's context (Study I, II and IV), however, of being of noticeable importance during a long-term hospitalisation. According to the findings (Study I and IV), the mealtime environment within paediatric oncology care requires special attention, and this was discussed in relation to these children's needs.

The findings demonstrated that the expectations and pressure to eat orally resulted in struggling mealtime situations for children, especially before the G-tube insertion (Study I, II and IV). The oral food intake was aggravated due to several aspects, which contributed to devastating consequences for the child in mealtime situations. Those children who had undergone oncology treatments and HSCT experienced, for instance, multiple negative *sensorial challenges* because of the hospital food and/or perceived side effects (Study I and IV). Negative sensorial impressions reinforced each other and caused an unmanageable situation, but contributed also to strong feelings and reactions that had to be dealt with several times a day. Sensorial challenges seemed not be linked to the G-tube, and remained an issue during the child's whole treatment and hospital stay. Consequently, a feeling of having failed and a sense of inadequacy were common. Thus, the G-tube became a helpful intervention, but also contributed to new challenges. Thus, the paediatric care team needed to be aware of and give attention to psychosocial aspects that may affect the child in conjunction with mealtime situations. According to the findings, the hospital food per se needs to become a focus within paediatric oncology care and a revision needs to be considered. Also, sensorial challenges in conjunction with meals need further attention to improve the children's mealtime situations (Study I and IV).

Experiences of pain and discomfort were present for most children initially after the G-tube insertion, which contributed to discomfort related to tube care. *Pain and discomfort* could also occur occasionally due to minor complications (Study III) or as a result of tube feeding being done too rapidly (Study IV). Postsurgical pain and discomfort after a G-tube insertion need attention within paediatric oncology care. According to the findings (Study III), there need to be adequate methods of pain assessment to prevent pain and/or relieve the pain adequately after a minor invasive procedure such as a G-tube insertion.

A life-saver, but also a stigma due to visual and social alterations – this description summarises both children and their parents' experiences of the G-tube as an intervention with two different sides. The G-tube was seen as a valuable tool since the meeting the need for nutrition could be ensured, independent of the child's condition (Study I, II and IV). However, the G-tube (but also the NG tube) involved a stigma, which resulted in challenges due to its insertion. The findings indicated that the families need further support and appropriate strategies to manage those challenges that the feeding tubes can contribute to, especially after insertion (Study I and II).

The findings demonstrated that *changed meals and eating habits* became a common consequence after the G-tube insertion, and this affected the whole family (Study I, II and IV). The tube feeding was seen as a separate activity and consequently not naturally integrated as a part of ordinary meals and mealtime situations, which is a reason why these activities often do not occur simultaneously (Study I, II, and IV). The tube feeding was associated with a medical procedure the families were not comfortable with including it in the mealtime situations. As a result, the tube feeding was done at different times and places, with changed eating habits as a result (Study I, II and IV). The findings (study I, II and IV) demonstrated that the families need further support to integrate the tube feeding as an obvious part of the ordinary mealtime situations with the purpose to recapture positive and functional meals for the whole family.

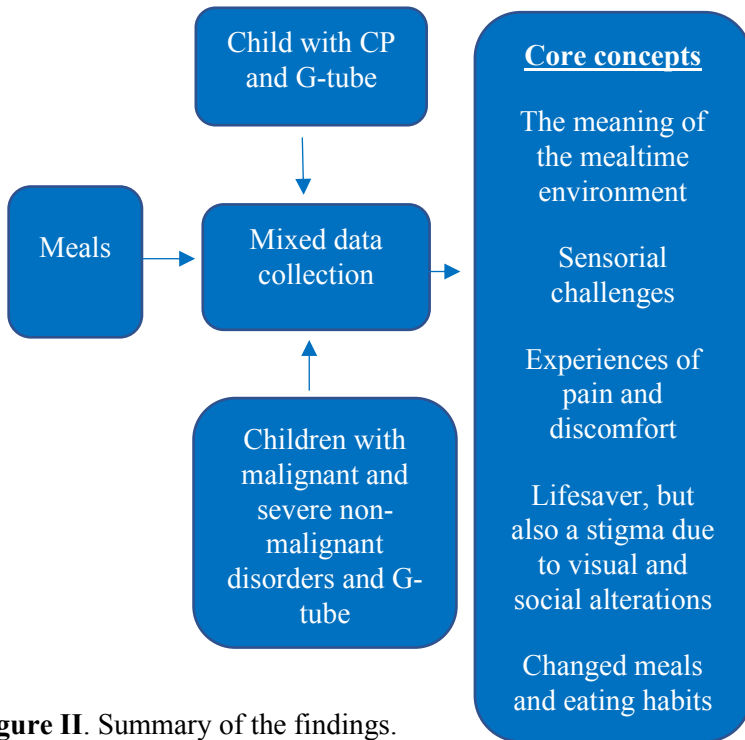


Figure II. Summary of the findings.

The findings of the studies included in this thesis demonstrated that the FAMM was not a suitable meal model to use more broadly within caring science. Consequently, a modification was required with the purpose to adapt the model to better suit children with a G-tube. This is why the M-FAMM was developed (see Figure III).

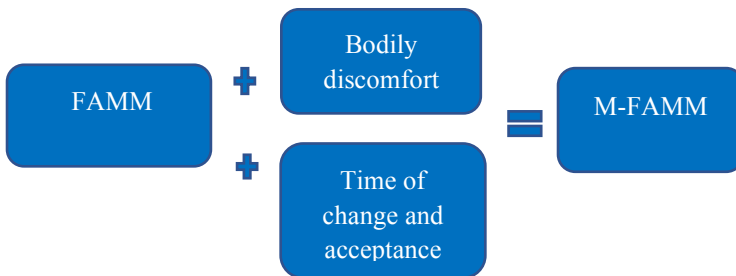


Figure III. Overview of the development of the M-FAMM.

Through the studies included in the thesis, the M-FAMM was used in different contexts, i.e. both within the paediatric oncology care as well as within the habilitation centre. The process contributed to the M-FAMM becoming a child-centred meal model suitable to use within caring science. To clarify that the model has been used within this context, the M-FAMM has been renamed as Mealtimes in Long-Term Child Conditions and Disability (MICCAD) (see Figure IV).

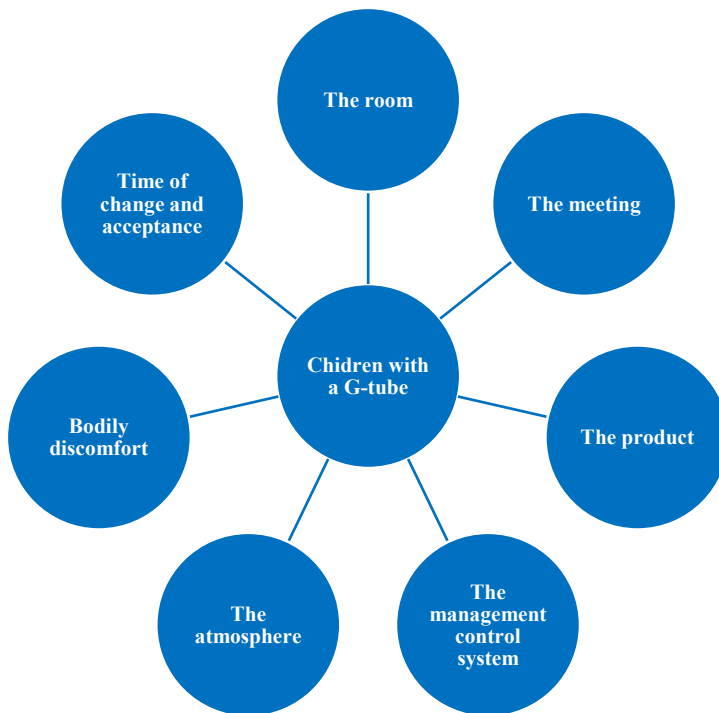


Figure IV. Overview of the MICCAD.

8. DISCUSSION

The overall aim of this thesis was to describe children and their parents' experiences of mealtime situations before and after a G-tube insertion and to develop a child-centred meal model focusing on mealtime situations and their environmental aspects. The question of whether the overall aim with the study has been fulfilled can be answered by those descriptions of the findings in the included studies. By exploring the children and their parents' experiences in Studies I–IV, this thesis has contributed to an overall description and comprehensive knowledge of mealtime situations before and after a G-tube insertion. As a start, the findings of Study I contributed to the development of a new child-centred meal model. This model, first named M-FAMM and later renamed MICCAD, was used throughout the research process (Studies II, III and IV). The summary of the findings in the thesis serves as a basis for the discussion provided below.

8.1 Results discussion

The results discussion is based on the core concepts presented in the summary of the findings: '*the meaning of the mealtime environment*', '*sensorial challenges*', '*experiences of pain and discomfort*', '*a lifesaver, but also a stigma due to visual and social alterations*' and '*changed meals and eating habits*', (see Figure II).

8.1.1 The meaning of the mealtime environment

The children included in Studies I, III and IV were hospitalised due to a life-threatening disorder, and some of them were also isolated, which proved to be a contextual change that was unexpectedly challenging to manage. It has been emphasised that the disorder and its physical effects may influence the child's experiences of environmental aspects during a hospitalisation (144). This is why feelings of lonesomeness can occur when a child becomes transferred into a hospital context (145), and this corresponded with those experiences the children in Study IV shared. Seclusion, i.e. in reference to a room or a bed along with the hospitalisation can be experienced as inconvenient and bothersome (146). In this thesis (Study IV), some of the children expressed that the hospital isolation made them miss siblings and family, why the mealtime situations also became affected, with a sense of emptiness as a result.

The hospital environment and its aspects contributed to deteriorated mealtime situations for the children described in this thesis (Studies I and IV). This is in line with prior research, where the child's hospitalisation and its contextual challenges have been emphasised as a contributing cause to deteriorated food consumption (147, 148). The finding of this thesis (Studies I and IV) demonstrated that the mealtime environment involved a concern for the hospitalised children. The presence of various pieces of advanced medical equipment, but also the sight of drip stands and medications resulted in decreased food intake and unappealing mealtime situations. These findings correspond with previous research, highlighting the negative effect of medications present in respect to meals (13). This aspect has also been discussed in respect to hospitalised adults, where contextual aspects adversely affected food consumption and meals (149, 150). Another aspect that deteriorated meals and mealtime situations for the children described in this thesis (Studies I and IV) was the recurrent interruptions that occurred because of necessary care and treatment. It has been demonstrated that the complex functions of a hospital room contribute to several events at once and why disturbances can occur during mealtime situations (109). Repeated distractions during meals may contribute to negative consequences, which is well-known with respect to the care of adults (151, 152); therefore, according to the findings documented in this thesis (Studies I and IV), such distractions must be addressed in paediatric oncology care. Hospital meals need to be integrated as a central part of the care (10, 153). However, aggravating circumstances exist as meals can be experienced as a subordinate aspect compared with other medical interventions (13), which has also been emphasized within the care of the elderly (154). Also, hospitalised children may require an environment adapted to their requests (155, 156), especially since this constitutes an important part of the child's ability to heal (95).

8.1.2 Sensorial challenges

Sensorial impressions affect the meal and consequently the mealtime experience (21, 23). This was clearly demonstrated in Studies I and IV, where those children who had undergone oncology treatments and HSCT experienced the hospital food as a repulsive and unpalatable aspect of the meal. It is well-known and has been previously noted that hospital food constitutes an awkward and unmanageable aspect to manage for hospitalised children within paediatric oncology care (59, 145, 147, 148). Sensory issues, such as smell and taste, are highlighted as especially problematic aspects (59, 148), which are findings in line with those experiences the children in Studies I and IV shared. According to the findings of Studies I and IV, the hospital food and its smells caused strong reactions in the children, and this was a reason why

offered dishes were seldom allowed to be brought in the room, with non-existing meals as a result. The negative effect of smells has earlier been pointed out in children with malignant disorders (13, 157). One explanation could be those sensorial alterations oncology treatments and HSCT may cause regarding the sense of smell (58, 158). However, the children in Studies I and IV also found the taste of hospital food as problematic. It is well-known that alterations in taste also occur in children who undergo oncology treatments and HSCT (57, 58, 159), and that this has a negative impact on meals has been highlighted (57, 59). These findings correspond with experiences shared in Study IV, where previously familiar food became distasteful and consequently a disappointment.

The importance of appealing meals has been emphasised in the care of adults (150, 160). The findings of Studies I and IV demonstrated that children within paediatric oncology care experience challenging meals due to the appearance of hospital food. This is in line with prior research that pointed out that the food's appearance can have an impact at the hospitalised child's food consumption (59, 148). The findings of Studies I and IV also indicated that children within paediatric oncology care were sensitive to the amounts of food offered. In fact, the presentation of large portions contributed to unappealing meals. Knowledge exists about these aspects. Research conducted both within paediatric oncology care (148) as well as in hospitalised adults (150) has underlined how large amounts of food can negatively impact meals (148, 150). A reduced appetite combined with a large portion food can be devastating for the mealtime experience (10). According to the findings of Studies I and IV, hospital food and the children's sensorial challenges linked to the meals require further attention, and possible interventions need to be identified. This needs to be done to improve mealtime situations for children within paediatric oncology care.

However, in Sweden, food and meals served in hospitals are regulated by laws such as the Health Care Act (142), the Patient Act (161), the Patient Safety Act (162), the Law of Public Procurement (163) and other regulations and guidelines (10, 164-166). Existing guidelines for hospital meals in Sweden advocate for nutritional care, i.e. food, meals and nutrition adapted to the specific patient and their needs, such as a flexibility in presenting more preferable and appetising dishes (10), also emphasised in other research (167). The findings described in this thesis (Studies I and IV) showed that children struggled to manage several aspects related to the hospital food. It is well-known that children within paediatric oncology care seldom experience longings for food (13). This is why recommended approaches and adaptations (10) are needed and require further attention.

However, it is not clear whether the negative impact of the hospital food discussed in Studies I and IV were caused by the hospital food, the children's treatment-related side effects or a combination of these. Regardless of the causes, it is necessary for the paediatric care team to reflect upon not only these children's sensorial challenges, but also their experiences linked to the hospital food. Thus, possible interventions, such as a revision of the hospital food, need to be taken into account. The value of food and meals as a part of paediatric oncology care needs to be further researched. This is the case since it has been emphasised that the value of this crucial activity can differ among the members of the paediatric care team as well as with among children who have undergone oncology care and treatment (13).

Meals need attention, and this is why '*zero hunger*' is stressed in the United Nations Agenda for Sustainable Development 2030, thus underlining the importance of adequate nourishment and the need for the best possible and most nourishing meals (168, 169). The need for attention in this area has also been highlighted in prior research as aspects such as '*health*' and '*sustainability*' also can be linked to hospital food and the patient's nutritional intake (170). According to the findings (Studies I, II and IV) described in this thesis, meals and mealtime situations are important for children with long-term conditions and disabilities. These findings can be linked to other research, where the mealtime situations were also seen as meaningful events also during a hospitalisation (171). Nonetheless, children can experience that the paediatric care team does not take their issues regarding food and meals seriously (13). This is alarming not only since the ability to receive appropriately composed meals constitutes an essential part of the process to achieve healthiness (172), but also due to the fact that nutritional alterations may be challenging to implement in hospital settings (173).

8.1.3 Pain and discomfort

The findings (Studies I–IV) demonstrated that pain and bodily discomfort due to the G-tube and/or meals influenced most children at some point and to some degree. Study III indicated that the planned surgery, in this case the G-tube insertion, caused the children uncomfortable feelings. It has been pointed out that concerns prior a G-tube insertion can occur (174). The children in Study III experienced insecurity despite the information they had received from the paediatric care team. Thus, adapted presurgery advices can make a difference (175). Study III indicated that those children who have undergone an HSCT can experience pain to a great extent after G-tube insertion. This pain seemed to be unsuspected, which contributed to overwhelming feelings and reactions for both children and parents. It has been emphasised that those who undergo

oncology therapies and HSCT are frequently affected by pain (176, 177), just as those who live with CP (178, 179). It is of greatest importance to be aware that interventions (e.g. a G-tube insertion) can cause the child further negative consequences of pain (180) with the risk of unnecessary suffering (181). For the children in Study III, the pain became bothersome to manage, especially during required care-related procedures. It is well-known that pain in younger people is not always treated sufficiently or appropriately within the care (181, 182), which was confirmed by the findings in Study III. This is why postsurgery guidance to relieve pain needs to be further emphasised (123, 182, 183). Pain can also be one cause of impaired nutritional consumption during oncology therapies and HSCT, thus affecting meals negatively (6, 147).

Nevertheless, pain and its treatment also contributed to negative consequences for the older child in Study II, with adversely affected meals as a result. Pain may constitute an everyday obstacle for children with CP (184). This is why the paediatric care team also needs to possess knowledge of the complexity of giving young people with CP and pain adequate support (185). In addition, it is important to be aware that medications given to relieve pain also might have negative effects (182), and special attention is needed in those cases where food intake and meals can be negatively affected.

8.1.4 A lifesaver, but also a stigma due to visual and social alterations

All children included in this thesis had received a G-tube, something that involved a change for the families. The findings of Studies I–IV emphasised that the G-tube resulted in an improvement of meals for the children. Most parents, as shown in Studies I, II and IV, described the G-tube in terms of an intervention their child could not have been without during this period in life. The G-tube had become an assurance, a valuable intervention, which helped their child both nutritionally and physically. This knowledge gave the parents a respite, a sense of control in a chaotic phase. The advantages of the G-tube, which are also linked to its great effects on the child's condition, have previously been described (14, 84). According to the findings of Studies I, II and IV, most children and parents experienced that the G-tube contributed to reduced pressure during meals and mealtime situations. This is in line with previous research. To enable tube feeding can also result in reduced requirements of oral food consumption with more manageable meals and mealtime situations as a result (186, 187).

However, the feeding tubes also involved some disadvantages for the families (Studies I and II), where both children and parents experienced that the nutritional intervention was associated with a stigma. Both the NG tube as well as the G-tube involved unexpected and unwanted public attention, which caused the child to have unpleasant feelings of discomfort (Studies I and II). The NG tube's visibility was an aspect that children in Studies I and II struggled with on a daily basis. It is well-known that an altered appearance caused by the NG tube can affect the child negatively (78, 93).

However, the presence of a G-tube can also contribute to attention (84, 188). This became especially pronouncedly in Study II, where the G-tube involved an additional experience of discrepancy for the older child. This is in line with prior research, underlining that a G-tube can contribute to a strengthened experience of difference (84, 189). The child in Study II struggled with her feelings of inequality in the here and now since the presence of the G-tube affected her social activities. This finding can be related to the knowledge that it is important for children with disabilities to maintain a sense of normalcy (190). In addition to these findings, prior research has indicated that discrepancies in appearance can be experienced as challenging for children within the paediatric oncology care even later on (93).

8.1.5 Changed meals and eating habits

The findings of Studies I, II and IV demonstrated that meals and mealtime situations could be conducted and managed differently after the G-tube insertion. For most children, the G-tube represented a possibility to use a more relaxed approach, while some parents experienced severities in terms of managing the mealtime situations. This is in line with prior research, emphasising that the complexity of tube feeding may contribute to noticeable challenges in daily life (188). According to the findings of Studies II and IV, the G-tube could result in changed mealtime routines for the family since the G-tube meant that the child's sense of belonging or participation in the family meals did not continue to be natural or prioritised as earlier. This is why the dependency on EN can contribute to a sense of being left out (14, 85). The parents described in Studies II and IV did not experience the tube feeding as a natural part of the mealtime situations. Instead, it became a separate activity, another technical assistance, usually not performed in conjunction with the family meals. These findings are strengthened by previous research which found that EN is mostly not integrated as a natural part of the meals (14, 82). This is why the paediatric care team needs to offer appropriate guidance (83, 188).

8.1.6 The MICCAD

The M-FAMM, later renamed as the MICCAD (see Figure IV), involves a CCC approach (87, 88) linked to children with a G-tube with long-term conditions (malignant and severe non-malignant disorders) and disabilities (CP). The MICCAD was developed (Study I) and used (Studies II, III and IV) in different contexts, and in a range of ages (1–18 years of age) during the research process, which can be seen as a strength. It was important to include children of different ages due their diverse ways expressing and conveying needs related to G-tube use and mealtime situations. The MICCAD is, to the best of our knowledge, the first meal model specifically modified for children with a G-tube with the aim of developing and explaining the mealtime situation. From a CCC approach (87, 88), where both the child's perspective and the parents' complementary child perspective is taken into account, is an additional strength. Other meal models exist and have been developed for use within healthcare, but these are aimed to be used in the case of adults and the elderly (99, 100), or patients in general (10). The MICCAD stands in contrast to existing meal models (99, 100) in regard to children's specific needs in cases of long-term condition and disability, as it considers aspects such as '*bodily discomfort*' and '*time of change and acceptance*'. These aspects consider, for instance, treatment-related side effects and complications that impact the child's mealtime situations, but also emphasise time as a decisive aspect for the families' ability to adapt to an everyday life with a G-tube.

Children have the right to their own meal model, one adapted to their specific needs, not to adults or the elderly, which is why the MICCAD is unique and can help address the complexity of the mealtime situations in paediatric care. The MICCAD involves an opportunity to highlight the experiences and needs of different groups of children with the purpose of improving their mealtime experiences in different contexts. Thus, better prerequisites can be created to prevent feeding difficulties and negative experiences regarding meals and mealtime situations, which further can contribute to a reduced need of hospital stay and fewer charges with lower costs. However, the meal model needs to be further used in larger samples and broader contexts of children. The model has been tested for content validity (120), but this still requires further validation. By using the MICCAD further, a validation could be obtained and the model strengthened.

9. METHODOLOGICAL CONSIDERATIONS

Different groups of children with either a long-term condition (Studies I, III and IV) or a disability (Study II), and their parents were examined in this thesis. The data collection in Studies III and IV were conducted during the children's complete healthcare process and involved the use of interpreters. During 2020, both inclusion and data collection were negatively affected because of COVID-19 and its restrictions. These challenges contributed to a number of methodological considerations which are discussed below.

9.1 Considerations during the data collection

This data collection was considered as a unique opportunity to give voice to children's experiences, which can be seen as an ethical responsibility as well as a strength. Conducting data collection over a long-term period of healthcare (Studies III and IV) involved parallel processes, which can be seen as both a strength and a weakness.

One strength has been the opportunity to follow the children over the course of several years, and this has provided rich data with a high degree of reliability. Another strength has been the possibility to develop relationships with the children and their families, which later on enabled the author to be involved in different stages of the disorders as well as in palliative care. Knowledge regarding meals and mealtime situations in children who live with a G-tube and receive palliative care remains insufficient, which is why this type of research needs to be stressed. However, a weakness with gathering data during a longer period of time is that the study design cannot be redone, and this can consequently influence the findings. Few studies have previously included children with a G-tube focusing on mealtime situations. Consequently, this approach was chosen to obtain rich data and a perspective on how to improve meals and mealtime situations for children living with a G-tube.

To include children with wide a range of ages in the research was a challenge during the data collection, since all had different presumptions. The children in the study ranged from 1 to 18 years of age; however, the children who participated by themselves in the data collection were from 6 to 14 years of age. It is well-known that those who live with, for instance, a long-term illness may undergo a faster development, which contributes to a further dimension in their ability to grasp situations (191). However, used approaches must be

revised to fit specific child's requirements (192). This is why the use of techniques specifically adapted for the child are appropriate (88, 193). Depending on the child, information and questions were modified during the data collection of Studies I–IV. Pictorial support was available and used when it was determined to be relevant. Furthermore, the child's own G-tube acted as a valuable support for the child in conjunction with the interviews. All of these strategies can be seen as a strength. However, further adaptations and alternative methods could be used, especially for children of younger ages. This is an aspect that could have affected the children's ability to share their experiences, thus influencing the findings of the studies discussed in this thesis. Nevertheless, the variety of ages of included children can be seen as a strength, contributing to various and broader dimensions of the research topic.

To include families from various contexts and cultures (Studies III and IV) required, in some cases, the need for interpreters during the data collection, which was a challenge due to its complexity. It is well-known that the use of interpreters involves a further responsibility for the researcher (194). For instance, the data collection with severely ill children may be a challenge for the interpreter (195). In terms of this thesis, this aspect was not experienced as problematic, which depended on how the interpreters were used to translate within the paediatric oncology care. To employ interpreters during the data collection was a time-consuming process, an aspect which has been emphasised as a reason why interpreters are not always effectively used (136).

It was not possible to use a single interpreter or the same interpreter during the data collection. This could be seen as a weakness, an aspect that could have affected the findings (Studies III and IV) negatively. According to prior research, the use of one person that interprets is recommended during the process (196). On the other hand, a longitudinal collaboration with one participant can also be problematic for the person who does the interpretation according to prior research (197). Nevertheless, the decision to use several interpreters made it possible to include a larger number of participants from different cultures, which was seen as a strength.

In Sweden, an authorised interpreter refers to a protected title where the interpreter has completed a certain degree of education (198). Not all the interpreters were authorised as to their competence in medical terminology, which is a limitation. To use an interpreter that possesses adequate linguistic competence is noted as an important aspect, affecting the quality of the translation (197, 199). Consequently, to use someone who makes an interpretation involves a risk that the information were not exactly or correctly obtained (135). This is an aspect which could result in an incomplete data

collection, which can be seen as a limitation. This is why the researcher also has accountability in this regard and needs experience in having conversations with those who translate (199). The author of the thesis had a previous practical experience of using interpreters within a habilitation centre, which in this case can be seen as a strength.

To include children with life-threatening disorders as well as disabilities involved multiple challenges, but also ethical dilemmas. That means that flexibility, courage and an ethical sensitivity were required. Several aspects that were not possible to effectively deal with affected the data collection. Included children within the paediatric oncology care all underwent demanding treatments or HSCT, while the majority were extremely at risk of infections. The majority of these children suffered from severe side effects, which negatively affected their general comfort. Thus, the possibility to conduct interviews was dependent on the child's daily condition, which could fluctuate from one day to another. Acute investigations, treatments or procedures could be necessary. This is why planned interviews were often postponed.

The need of protecting and supporting the children but also their negative replies regarding their child's condition could make the parents unable to participate in the planned interviews. This is another reason why they were often postponed. In some cases, children passed over to a palliative phase which could seriously affect the family's participation. Some of the children included in the study did not survive. In conclusion, the data collection was difficult to perform as planned. The regular times and intervals planned could not be adhered to, with fewer and unequal measurement points as a result. This could have influenced the findings of Studies III and IV, which can be seen as a limitation.

The parents sometimes felt a responsibility to protect their children and consequently acted as safeguards. This can be one strategy for the parents to manage a severe situation (200). In addition, members of the paediatric care team want to protect vulnerable individuals (201). It is well-known that gatekeepers can be present within the paediatric care (126). This is why research about children with disorders that require oncology treatments can be especially challenging (201, 202). In the data collection (Studies III and IV), gatekeepers may have influenced the researcher's ability to collect data. Consequently, the number of interviews and included families may have decreased, which may have affected the findings of Studies III and IV.

In the research for this thesis, both qualitative and quantitative methods (118, 120, 125, 127, 128, 131, 134) were used to explore children's experiences regarding mealtimes before and after a G-tube insertion. A variety of study designs enabled a broader perspective into the research questions because of the triangulation of the data. Furthermore, it was a strength to use various research methods during research education for a doctoral student. However, a limitation with these choices could be that the author's ability to fully focus on and achieve a deepened knowledge concerning one rather than a few specific methods was an issue.

9.2 COVID-19

During the spring of 2020, the COVID-19 pandemic paralysed the world. The pandemic affected all areas in society; however, hospitals suffered enormous consequences. The number of treatments and surgeries was minimised to the most necessary, and the ability to visit children at the hospital ward became non-existent. Data collection became severely limited, negatively affected and delayed because of COVID-19 restrictions.

As a result, it was not possible to maintain and continue with face-to-face meetings or the same contact with the key nurses at the paediatric oncology ward. Both these aspects affected the inclusion of families, but also the data collection of Studies III and IV. A transition to a digital approach was necessary to continue the remaining data collection (203). Consequently, face-to-face interviews were replaced by digital interviews via phone, facetime, Skype or Zoom. The transition to a digital approach involved challenges, especially since some of the younger children also chose to cancel their participation for this reason.

Having digital interviews with those participants who required an interpreter was also more difficult. The additional dimension to digitally balance three components became a challenge and required knowledge, awareness and flexibility. The pandemic and the digital approach also made it more difficult to recruit new participants, which is why the recruitment process was completed in advance. However, the digital interviews facilitated children at a high risk of infections to participate in an easier way. The ability to set up and conduct digital interviews was also facilitated because it was easier to set aside time to deal with all the aspects involved for parents.

10. CONCLUSIONS

This thesis provides a deeper knowledge and understanding of children and their parents' mealtime experiences before and after a G-tube insertion.

The findings confirm that children with long-term conditions and disabilities during a hospitalisation but also in the home environment experience troublesome meals and mealtime situations both before and after a G-tube insertion. The hospitalisation entails a challenging mealtime environment. Isolation at small rooms, repeated interruptions because of care and treatment, but also the presence of medical equipment (e.g. medications and drip stands) during mealtime situations adversely affected food consumption. Hospital food and sensorial challenges along with treatment-related side effects constitute a main concern for children during care and treatment. Smell, taste, appearance and portion sizes of hospital food contribute to challenging and troublesome mealtime situations. Bothersome side effects, such as nausea and vomiting, but also changed taste and smell exacerbate negative experiences of hospital food, resulting in reduced food intake. The meals focusing solely on ensuring the child's nutritional needs are another reason why these situations become associated with stress and pressure for both the children and their parents.

The G-tube insertion can for these children be frightening and painful, but it also involves immediate relief since the pressure to eat orally decreases. The G-tube can contribute to a sense of parental failure, but the intervention creates a sense of security since meals are facilitated. However, physical and psychosocial challenges can occur. Minor complications such as redness and granuloma tissues are common, but these seem not to affect the child during meals. An existing stigma in the society contributes to a sense of difference, as a changed appearance strengthens the experience of being ill and disabled.

Mealtime situations and eating habits undergo a change after the G-tube insertion. Tube feeding is associated with medical and technical methodology, where the child's nutritional intake is central, and thus it is mostly employed on different occasions than ordinary mealtime situations. Thus, community and shared family mealtime situations become de-prioritised, and thus the child risks experiencing a sense of exclusion. The paediatric care team needs knowledge and awareness to meet, support and offer these families appropriate strategies to recapture a positive feeling in respect to meals and mealtime situations in daily life.

11. CLINICAL IMPLICATIONS

According to the findings documented in this thesis, meals and mealtime situations before and after a G-tube insertion, but also the G-tube itself, involve several challenges for the child and the family. It is important that the paediatric care team achieve an enhanced awareness and deepened knowledge regarding children and their experiences of mealtime situations and G-tubes. Thus, the findings presented here could be used to inform and guide the hospital management, members of the paediatric oncology care team and the involved kitchen staff, but also members within the paediatric care team at habilitation centres.

The existing mealtime environment and hospital food constituted main concerns for the children during the oncology care and treatment, and this is why these aspects need attention. The paediatric oncology care needs to take into consideration whether the environment and the hospital food need to undergo eventual revisions or adjustments to meet these children's longings. The hospital food needs to be discussed and reflected upon in relation to existing routines, recommendations and national guidelines. Moreover, sensorial aspects such as smell, taste, colour, appearance, and portion size need to be more thoroughly investigated.

The findings related here could function as a basis and a support in these discussions, but also as the impetus for the development of new documents and guidelines within the area of hospital food, meals and mealtime environmental aspects. The children's need of sensorial improvements is another area that according to the findings require further attention. Opportunities to receive sensorial training, but also involvement in, for instance, preparation of meals, cooking and baking at the ward need to be considered as possible learning activities for all children.

Children experience the G-tube insertion as a significant concern. To improve children and the families' degree of knowledge and understanding within this area, the findings of these studies could be used as a basis to better inform families prior G-tube insertion. Thus, this could create the best possible presumptions about accepting and effectively managing the procedure.

The families experienced several challenges after the G-tube insertion. The findings could lead to the development of supportive material for the families prior to discharge as the importance of integrating tube feeding as a part of family mealtime situations was repeatedly shown in the data. By using the findings, the families can achieve support, an enhanced understanding and thus the best possible methods to include the child and recapture positive mealtime situations in daily life.

As it investigated families within paediatric oncology care and habilitation in similar situations, i.e. where the child received a G-tube due to a troublesome oral intake, this thesis could act as a basis for discussions. The findings could also be used to develop information, documents and a basis for education regarding meals and mealtime situations of those families in need of support.

The findings of these studies could serve as a basis for further education with the aim of educating nursing students as well as paediatric nurse students at a university level.

12. FUTURE PERSPECTIVES

This thesis contributed to a new meal model specifically adapted for children with a G-tube: the MICCAD. Based on the findings, I believe this model needs to be further used to confirm its validity. A continuation of Study II could be the next step, i.e. to elucidate the impact of mealtime experiences in a broader sample of children with disabilities and their parents before and after a G-tube insertion. The equivalent of Study III described in this thesis could also be relevant to perform in a sample of children with disabilities.

The findings suggest that a further validation of MICCAD is required, since the purpose is to implement the model in the contexts of paediatric oncology care and habilitation centres. This is why further research is needed regarding to what extent the MICCAD can be used, and which effects the model could generate after an evaluation is performed in these contexts. Research also needs to be conducted regarding if and how children's meals, mealtime situations and mealtime environment may be affected by the implementation of the MICCAD as well as an evaluation of the interventions applied. The findings also indicate that research in other areas within paediatric care could be of immense value.

The intention is also to develop the MICCAD further. By adapting the model to a digital approach, its usefulness could be facilitated. To enable the paediatric care team to use the MICCAD via an app could improve their ability to further use the model. To add to and complement the model with pictorial support, the included aspects in the MICCAD could be illustrated and thus be made more accessible. These aspects could facilitate the paediatric care team's ability to use the model, for instance, with younger children and children within habilitation centres. Translating the model into other languages could facilitate the paediatric care team's possibilities to use the model with children and parents who do not have a mastery of Swedish.

The findings indicate that research could be valuable to perform with additional participants such as the paediatric care team in the paediatric oncology care and habilitation centres to obtain a broader perspective on meals as a part of the nutritional care and treatment.

The MICCAD can also be used as a tool in future research. It can be used to find further interventions and improve those shortages and deficiencies regarding meals and mealtime experiences.

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