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## Caring Sciences

# The five aspect meal model as a conceptual framework for children with a gastrostomy tube in paediatric care

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#### Abstract

*Background:* Cancer treatments may induce side effects and cause eating problems. A gastrostomy tube may be required in order to maintain and optimise the child's nutritional needs. Despite the use of a gastrostomy tube, it is important to maintain a natural and attractive mealtime for the child. The Five Aspect Meal Model is age neutral and originally designed to improve restaurant visits. Its five aspects conceptualise what is necessary to ensure a complete meal experience. To date, there is lack of knowledge to guided model development about mealtimes adapted to children and limited knowledge regarding mealtime experiences for children with a gastrostomy tube.

*Aim:* The aim was to investigate whether the Five Aspect Meal Model could be appropriate to be used for children with a gastrostomy tube in caring science and paediatric care.

*Methods:* The design followed steps retrieved from Renjith and colleagues. Seven interviews were performed with

the Five Aspect Meal Model as a base in the interview guide. The transcripts were analysed by using a qualitative directed content analysis with a deductive approach, which finally passed into a more inductive one.

*Findings:* All aspects of the Five Aspect Meal Model were represented in the interviews. There were also experiences related to the gastrostomy tube and the mealtimes that did not fit into any of the five predetermined categories. As a result, the modified version was developed, an adapted prescribing practice model that includes seven aspects, whereof bodily discomfort and time for change and acceptance are specific to children with a gastrostomy tube.

*Conclusion:* Based on children and their parent's experiences, the Five Aspect Meal Model has been developed and adapted into a modified version, which includes seven aspects. The modified version seems to be appropriate to use within caring science and paediatric care.

**Keywords:** cancer, children, gastrostomy tube, mealtime, nursing, nutrition.

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#### Introduction

Childhood cancer patients usually require a demanding course of treatment (1-3). Surgery, chemotherapy, radiation and stem cell transplantation (SCT) are possible measures that can be taken (4). Side effects such as

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Ulrika Mårtensson, Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, SE- 405 30, Gothenburg, Sweden. E-mail: ulrika.martensson@gu.se nausea, vomiting, mucositis, altered taste and altered smell, as well as lack of appetite, can result from the treatment (5, 6). The side effects can lead to eating problems (5–7) and cause malnutrition (6, 8–10), which can lead to impaired treatment as well as an increased risk of morbidity and mortality in childhood cancer (8, 10, 11).

The hospital environment (5, 7, 12), as well as other physical, social and psychological aspects, can affect the nutritional intake of children with cancer negatively (5–7, 12). In particular, older children commonly refuse to eat hospital food, sometimes in order to gain control (5, 12). The main reason is the taste and smell (5–7, 12),

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but improper sizes of portions (7) or poor presentation can also have negative effects (5–7). The cancer treatments may make it even more difficult to eat, which leads to the mealtime being demanding (6, 12, 13) and associated with negative feelings for the parents, for example frustration (6), stress and conflict (13).

During a cancer treatment, it is crucial to preserve equivalent nutrition (6, 14, 15) why nutritional support (10, 16, 17) and 'attractive' mealtimes are fundamental in paediatric care (5, 12). Enteral nutrition (EN) can be an option when there are feeding difficulties in cases of childhood cancer (8, 10, 17, 18). A nasogastric tube (NG-tube) or a gastrostomy tube (G-tube) can be used in order to administrate EN (8–10, 19).

To date, there is a lack of knowledge regarding guided model development about mealtimes adapted to children within paediatric care. There are also limited knowledge regarding how children with cancer and a G-tube experience mealtimes. The concept of the Five Aspect Meal model (FAMM) came originally from the Michelin Guide (20-22). The FAMM is an age neutral practice meal model, with the aim of improving meal experiences for guests visiting restaurants (20-22). It is uncertain whether the FAMM (20-22) can be used for children with a G-tube, or indeed, for children at all, since their expectations as well as the nature and 'ideals' of the mealtimes may be different to those of adults. Due to the lack of knowledge, the aim of our study was to determine whether the FAMM (20-22) 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.

#### Methods

#### Research design

The design of this study follow steps retrieved from and inspired by Renjith and his colleagues (23 p. 97), see Table 1. The steps have been used in order to create a structure during the process of investigating whether the FAMM (20–22) could be an appropriate model to be used for children with a G-tube. Three children and four of their parents in three families were interviewed. In total, seven semi-structured individual interviews were performed with the FAMM (20–22) as a base in the interview guide, see Table 2. The interviews lasting between 14–24 minutes for the children and between 22–69 minutes for the parents, see Table 2.

#### Step I: Identification of an appropriate conceptual model

The FAMM was originally designed to improve visits to commercial restaurants and describes what is necessary

 Table 1
 Application of the Five Aspect Meal Model (FAMM) (20–22)

 to the mealtimes of children with cancer and a gastrostomy tube (G-tube).

	Application of the Five Aspect Meal Model (FAMM)
Step I	Identification of an appropriate conceptual model
Step II	Overview of the selected conceptual model
Step III	Link the conceptual model concepts with study variables
Step IV	Analyse the relationship between study variables on the basis of the conceptual model
Step V	Applicability of the conceptual model

The steps in the table are retrieved from and inspired by Renjith and his colleagues (23 p. 97).

 Table 2
 Case description – data were collected at one of the six

 Childhood
 Oncology
 Centres in Sweden.

	Children (n = 3)	Parents of the children $(n = 4)$
Year of birth	2009-2012	
Diagnosis	Brain tumour, Rhabdomyosarcoma, Wilms' tumour	
Cancer treatment	Chemotherapy, Stem cell transplantation, Surgery	
Supportive care (nutrition)	Gastrostomy tube	
Interview guide	The Five Aspect Meal Model (FAMM) was used as the basis of the interview guide	The Five Aspect Meal Model (FAMM) was used as the basis of the interview guide
Interviews	Semi-structured interviews, conducted 2019, lasting between 14 and 24 minutes (n = 3)	Semi-structured interviews conducted 2019, lasting between 22 and 69 minutes (n = 4)

to facilitate a complete meal experience focusing on five aspects: the room, the meeting, the product, the management control system and the atmosphere (20–22). The model (20–22) has been debated in other meal models (24, 25) and also been used as a framework in research regarding the public sector (26) and elderly's experiences in hospital (27). The Swedish national Board of Health and Welfare (28–30) has in some of their official documents used the FAMM (20–22) in order to create presumptions for improved mealtimes and mealtime experiences. The National Food Agency (31) has developed their meal model on, for example the aspects in the FAMM (20–22).

#### Step II. Overview of the selected conceptual model

See Table 3.

### Step III: Link the conceptual model concepts with study variables

Children with cancer can undergo complications, for example granuloma, leakage, infections and inflammations due to G-tube surgery (8). One assumption is that these complications affect children's experience of mealtimes negatively. Given that the FAMM was originally developed to improve mealtimes at restaurants (20–22), the next step in this study was to investigate whether it could be used as a model in caring science and paediatric care for children with a G-tube.

### Step IV: Analyse the relationship between study variables on the basis of the conceptual model

The first author (UM) transcribed the audio recordings from each interview verbatim. The transcripts were

 Table 3
 Step II: Overview of the selected conceptual model and its five aspects, the Five Aspect Meal Model (FAMM) (20–22).

The room	The environment and factors regarding the room are highlighted as being crucial in terms of influencing the mealtime. The
	mealtime can be perceived dissimilar
	depending on where it is consumed and
	knowledge about the room is essential in
	order to meet individual requirements.
The meeting	This aspect refers to the interaction and the relations between the individuals involved in the mealtime. It requires knowledge and
	competence to meet and manage different
	kinds of individuals and their needs
The product	Food and drinks are declared as the most
	important factors in the model. The visual effect and the taste experience are also
	central elements in the mealtime. Therefore,
	in order to create appetising meals and an
	optimal mealtime experience, the individuals
	involved in preparing and serving the food
	need both theoretical and practical knowledge.
The management	This aspect describes administrative factors,
control system	work and processes that cannot be seen outwardly, but that all affect other aspects
	in the model.
The atmosphere	The atmosphere is described as an experience
	when an individual feels convenient and
	relaxed. Verbal communication is central, since it contributes to the atmosphere,
	which in turn creates the mealtime as a
	which in turn creates the meanine as a whole.
	WINE.

analysed using a qualitative directed content analysis approach (32) - a deductive analysis, which involved a line-by-line review of the transcripts. The target of this analysis - which also represents its strength - is to confirm or extend the existing theory (32). In the final step, a more inductive approach was used in order to create the category others (33). The analysis was based on four steps, see Table 4.

#### Step V: Applicability of the conceptual model

Researchers expect to base their work on a theory or a conceptual model. According to Risjord, a conceptual model can be seen as a tool in order to manage the research process, a way to elucidate perspectives that are of importance for the nurses (34). The FAMM (20–22) has been used in order to see if the model can be adapted to the mealtimes of children with cancer who use a G-tube. Risjord's requirements of a middle range theory will be used for evaluation of the model in this study (35). See Table 5.

#### Results

After completion of the analysis, all aspects in the FAMM (20–22) were represented. It also became apparent that the category 'Other aspects' was necessary, where from the two additional aspects was established. Based on children and their parent's experiences, the FAMM was developed and adapted into the M-FAMM, a prescribing practice model including seven aspects that needs to understand mealtimes for children with a G-tube. With the aspects, bodily discomfort and time for change and acceptance, specific added for children with a G-tube, the M-FAMM seems to be appropriate to use in caring science and paediatric care.

#### The room

Mealtimes occurred in different places and in different rooms, for example around a table, in bed or on the

 Table 4
 Steps in the analysis process inspired by Hsieh & Shannon (32)

	Steps in the analysis process
Step I	Codes were based on six predetermined categories, that is the Five Aspect Meal Model (FAMM) and 'Other aspects'.
Step II	The codes were sorted into categories of the Five Aspect Meal Model (FAMM) and 'Other aspects'.
Step III	The category 'Other aspects' was abstracted into subcategories.
Step IV	Credibility and dependability were assured by having all authors review each of the steps in the analysis.

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 Table 5
 Risjord' s criteria for analysis and evaluation according to his

 model (35) has been used for evaluation of the modified version of

 the Five Aspect Meal Model (M-FAMM) in this study.

	Pragmatic criteria of evaluation
Usefulness	The use of the modified model is appropriate to meet the mealtime needs of children with a gastrostomy tube.
Abstraction	The modified model is suitable to use for the target group of children at home as well as in hospital and in paediatric care.
Values	The performed deductive interviews resulted in the modified model that, according to our results, is suitable to chart and improve mealtimes for children living with a gastrostomy tube.
	Epistemic criteria of evaluation
Operationalisation	The modified model is structured and specific. In total it includes seven different aspects that in the future can be used as an instrument or a framework in paediatric care.
Precision	As a result of the deductive interviews, which in the final step passed to an inductive approach, the modified model includes seven aspects that all differs, there is a discrepancy between them and the areas is present.
Empirical Support	The modified model is supported by the empirical data that emerged during the qualitative interviews conducted with both children and their parents.
Theoretical support	The modified model is supported by a previous theoretical framework, that is the Michelin Guide. The Five Aspect Meal Model, which constitutes a base for the modified model, has also been used as a framework in other research areas.

couch, so adaptation and flexibility were required. The importance of habitually eating together around the kitchen table was emphasised. The kitchen environment was experienced as personal, warm and relaxed being described as an optimal place for the mealtimes. The children's condition sometimes involved severe issues regarding eating orally. As a result, an unwillingness to participate in the mealtimes arose. The children chose to spend time for G-tube feeding somewhere else, which created negative emotions for the parents: 'X did not want to join us around the table because x was not allowed to eat [orally]' (mother of child I).

The difference between the rooms at home and those in hospital and the impact of this at the children's mealtimes were highlighted. At hospital, the rooms were perceived as small, bare and uninspiring, something that could result in food rejection: 'X does not want the hospital food at all' (mother of child III). The fact that the children were isolated and had issues arising from their condition resulted in most mealtimes being spent in bed: 'You are usually in your room...you eat and do everything in bed' (mother of child III). The only alternative was a small table that was not attractive for the children and was not considered an option for them to sit there and eat.

#### The meeting

There was a desire to keep things as normal as possible, doing everything in the same way as had been done prior to the G-tube: 'It is important that x is participating in the meal even if x is not able to eat so much' (mother of child III). However, differences in opinion whether the child would join the family at the dinner table or not could sometimes result in disagreements between the parents, which affected the mealtimes negatively. The parents perceived negative emotions like frustration, stress and pressure in conjunction with the mealtimes, which in turn influenced the children. The parents felt responsible for making the mealtime as pleasurable as possible: 'We must be pushy in a manner that makes x positive, so that it does not feel like an obligation' (mother of child I). The parents tried to awake a desire for the children to participate rather than making the mealtimes into a coercive demand.

The parents constantly listened to their children's needs, while avoiding focusing on the nutritional intake: '...not trying to put so much emphasis on the food' (mother of child II). Nagging about the food created frustration and stress for the children, which resulted in anger and negative emotions since they were already aware of their need to eat.

The interaction between the child, parents and health care professionals could sometimes be problematic, which affected the moment of facing the food negatively. The experience of eating hospital food at mealtimes was neither advantageous nor optimal for the children: 'Food is rather a necessary evil there, hence if x were not forced to [eat], x would not' (mother of child 1). The children experienced a problematic situation when the hospital food came in to their rooms without having been prepared for it in some way of the health care professionals. This situation was hard to cope with, which resulted in stress, frustration and even more difficulty at mealtimes. Also, the fact that the mealtimes were often interrupted by health care professionals to perform medical procedures disturbed the children: 'At the hospital, it gets pretty tough...x is eating and gets interrupted in order to get some medicine or something at the same time' (father of child I). The parents sometimes experienced feelings of loneliness at mealtimes and lacked support from the health care professionals in terms of motivating the children to eat orally. The parents thought educational meals could create a more social and enjoyable situation for the children.

#### The product

The visual appearance of the food was highlighted as being important since it had a great significance for the child's mealtime. The parents felt that the hospital food was not presented in an appealing way, which resulted in negative consequences, leading to the children consuming no food, or much less than at home. All children agreed; they perceived the hospital food extremely negatively: 'The hospital serves disgusting food' (child I). The hospital food affected the children greatly and, most of the time, it was not possible to implement the mealtimes at all: 'I do not find the food at the hospital so nice. I do not even eat the food at the hospital' (child III). Every day of their treatment, the hospital food was hard to deal with. The mealtimes practically stopped and became associated with feelings of uneasiness for the whole family: 'X does not find the hospital food appetizing and I can actually understand that; it is not very appealing' (mother of child I).

#### The management control system

The parents highlighted that daily life revolved around food and nutritional intake, which is why requesting the children's favourite food, was important. Changes in taste and flavour contributed to the children's challenges with the oral intake. It required a lot of time, patience, and adaptation to purchase, prepare, adapt and cook food according to the children's requests: 'I was cooking different dishes, like five times a day, in order to find something that would work' (mother of child III). The hospital food was associated with feelings of frustration and discouragement for the whole family. Despite the possibility of choosing between several dishes, attempts to motivate the children to eat were problematic: 'They have that in the oncology ward, a wish list for foods, it does not matter, it is not working there' (mother of child III).

#### The atmosphere

Comfort, well-being and having similar routines as before the G-tube were emphasised as essential aspects. The mealtimes created opportunities to bond and created a sense of normality, thus an important feeling of connection around the dinner table. The children needed peace and quiet in order to manage the mealtimes. The environment at home created a sense of safety and an opportunity to socialise and relax: 'It is more relaxing to eat at home... then the whole family is there...and you can eat together' (child III). The importance of avoiding to focus on the food, and instead create cohesive mealtimes was highlighted, that is a social activity was promoted.

By contrast, the hospital environment and medical equipment had an adverse impact on the children's appetite and attempts to eat: 'It is very "stripped down"... a lot of appliances and there is an IV pole [drip stand]...it is not an environment that is optimal and enjoyable for having meals' (mother of child III). A large amount of food was served, which was remarkable for the parents since their children could not cope with it: 'Often the portions are quite large...surprising given that it is at an oncology ward' (mother of child III). However, the most prominent aspect that affected all the children greatly was the smell of the hospital food: 'I do not like the smell of the food' (child III). The smell was hard to cope with and the children refused to allow food into their rooms: 'X usually does not even want the tray in the room' (mother of child III).

Rather than resulting in a sense of hunger and stimulating the children's appetite, the smell of the food was associated with feelings of nausea and uneasiness: 'Just seeing the food tray makes x start to feel a bit nauseous and to think of its smell and the situation becomes tough' (mother of child III). The ability to support the children in the mealtimes became challenging for the parents since they also perceived the smell of the food as unpleasant and unappealing. The mealtimes practically ceased and became an abnormal event for the families. The smell of the hospital food affected the children so much that usually they could not manage to eat at all: 'That smell... when I smell it ... it smells disgusting...I do not want to eat it' (child III).

#### Bodily discomfort

All the children experienced nausea and vomiting due to their treatment. A NG-tube was used for a period before the G-tube, which resulted in additional bodily discomfort: 'The nasogastric tube always came up when I felt sick' (child III). The NG-tube exacerbated the problems with both nausea and vomiting, which resulted in unmanageable mealtimes: 'The nasogastric tube...x kept puking it up, so the situation was not sustainable' (mother of child II). The children felt some pain close to the G-tube insertion and other complications that occurred were, for example redness, tenderness, skin irritation and discomfort, which did not affect the mealtimes to the same extent as the nausea. After a while, the Gtube insertion resulted in decreased nausea and improved mealtimes for the children.

#### A time of change and acceptance

The severity of nausea and insufficient nutritional intake resulted in the children receiving a NG-tube in order to facilitate their mealtimes. The children experienced feelings of discomfort and uneasiness due to the NG-tube particularly in conjunction with feeling conspicuous and having a changed appearance, with their feelings of being different amplified: 'With it [the nasogastric tube], there used to be people just stopping and staring at me' (child II). This new vulnerability resulted in new situations with withdrawal and isolation: 'X did not want to go to school before because it [the nasogastric tube] was visible...x did not want to go out among people' (mother of child I).

The G-tube was seen as yet another intervention among many others in a chaotic and acute situation. Although the change to a G-tube resulted in an improved feeling of 'normality', the children also tried to hide the G-tube. However, it was a step in the right direction as the G-tube was more discreet. The parents described a new and strange period to cope with after the G-tube insertion, even though the new situation soon turned into some kind of normalcy. Time and the ability to manage the child's need of a G-tube were mentioned as being essential to the process: 'It was more awkward at the beginning...now we have got used to it' (mother of child I).

The G-tube insertion was the best option, but despite a sense of relief, most of the days still revolved around food and nutritional intake. Despite this, the parents felt secure in the knowledge that the intake of nutrition, fluids and medications was ensured: 'It helps a lot for us to know that x gets what x needs' (father of child I). It was important for the parents that the mealtimes took place in an atmosphere of comfort and well-being. One factor that facilitated this was that the G-tube resulted in less nagging and conflicts about the nutritional intake: 'You do not need to have these conflicts... you avoid all of the nagging about the food' (mother of child III). The Gtube was seen as something that simplified daily life, something great that made it possible to ensure the nutritional intake. The parents experienced the G-tube as something helpful and invaluable for their children's physical health and well-being: 'You can control that x does not lose even more weight... so for the sake of x's health, it is great' (mother of child I).

#### Discussion

The FAMM (20–22) and its perspective on the meal and the mealtime experience has been discussed (36) as well as the FAMM has been debated in other meal models (24, 25). Beyond this, has the National Board of Health and Welfare (28–30) as well as the National Food Agency (31) in Sweden used the model (20–22) in their official documents. The FAMM (20–22) has also been used as a framework in research within the public sector (26) and elderly's experiences in hospital (27). In this study, the FAMM (20–22) has been used in order to see if the model can be adapted to the mealtimes of children with cancer who use a G-tube.

In the case of childhood cancer, mealtimes may be demanding and problematic to varying degrees (6, 7, 13),

which can lead to the parents experiencing negatively feelings (6, 13, 37). Due to this, it is crucial to create an appealing mealtime for children with a G-tube. While there is currently limited knowledge regarding childhood cancer and the use of a G-tube, the M-FAMM (see Fig. 1) seems to be an appropriate way to determine how health care professionals in the paediatric care can meet children's needs with regard to mealtimes.

Every child has the right to the best health possible (38), why competence regarding children is essential (39, 40). The FAMM (20–22) was in this study, used as a framework to investigate what a mealtime means and may be experienced by children living with a G-tube. Based on the interviews conducted and the analysis performed, the FAMM (20–22) with the modifications described in the present study, seems to be a feasible tool for use with children with a G-tube, considering their mealtime needs both in hospital and at home. The M-FAMM may be one way of creating a structure within the paediatric care in order to investigate how to prepare, implement and improve the mealtimes of these children.

In childhood cancer, it is important to preserve equivalent nutrition (6, 14, 15), since malnutrition can increase the risk of a negative outcome (8, 11, 15). The results from this study showed that nausea, vomiting and altered smell were prominent aspects that adversely affected the mealtimes, in line with earlier research (5, 6), why it seems to be important for bodily aspects to be taken into consideration. Variations in the child's health generate also a progress of transition (41) and children with cancer experience several such transitions (42). Transitions are multifaceted processes, involve variations and are time consuming (41), which was the case in this study; receiving a NG-tube as well as undergoing a Gtube insertion involved a period of change and acceptance. The new situation required adaptation on the part of the whole family. The results from this study show that there is a need for more support and guidance after the G-tube insertion.

According to our results, sensitivity to the smell of the hospital food, as well as the amount of food and its appearance, also emerged as aspects that affected the children's mealtimes negatively. It has been proved that there is a link between smell and food intake (43). It is common for children to have negative opinions about hospital food and thus refuse to eat (5-7). In addition, the type of cancer treatment can affect the incidence of smell dysfunction in children with cancer (5, 12, 44). Despite this being well known, our results emphasise the need to discuss how the mealtimes are created for children with cancer in hospital. Organisational aspects at the hospital therefore seem to be of importance, for example it would appear that smaller portion sizes, a different appearance of the food, as well as food with a reduced smell, may all be factors that could improve the

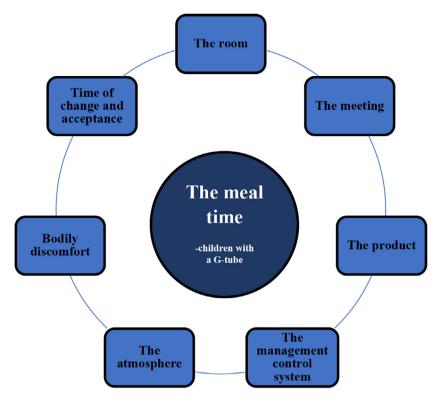


Figure 1 A modified version of FAMM (M-FAMM), adapted for children with a gastrostomy tube (G-tube).

mealtimes for these children. Customising the mealtimes is required in order to facilitate and optimise the nutritional intake.

The environment affects both choice of food, food consumption (43) and the experience of the mealtimes (20-22). The environment seems to be significant for recovering and achieving health (45, 46) as well as the contentment of the care (47). The environment can also facilitate social support, which in turn can affect the satisfaction of the family, as well as the child and his or her experience of the hospitalisation (45). It has been reported that the hospital environment (5, 7, 12, 37) as well as physical, social and psychological aspects, can affect the food intake negatively for children with cancer (5-7, 12, 37), and, indeed, the influence of such factors was borne out in this study. The hospital environment and the medical equipment around the child became a part of the mealtime, which had an adverse impact on the children's appetite and attempts to eat.

Psychosocial aspects related to the mealtimes may not always be given a high priority for children with cancer. There are probably many other urgent and more highly prioritised medical factors to be considered in the first acute phase of the treatment of these children. However, it is necessary to pay attention to children's needs in relation to the mealtime. Eating together is an aspect that can affect the nutritional intake (43, 48). When a child has cancer, usually daily situations regarding, for example nutrition, food and mealtimes are affected (7, 49), which creates stress for the parents (49). In order to achieve an optimal nutritional intake, the parents need information and education to manage their children's symptoms and nutritional problems (7).

#### Limitations

The FAMM (20–22) is just one meal model and it is important to highlight that other conceptual models pertaining meal situations do exist (24, 25), it should also be noted that broader perspective can be needed (24, 25, 36). A weakness of this study was that only three families were interviewed at one hospital unit. Further interviews would be valuable to strengthen the credibility and transferability of the data. However, in qualitative research, the number of interviews is not decisive for the quality of the results. Instead, the specific detailed experiences as well as the depth in the interviews may be seen as a strength. Some of the interviews were quite short since the younger children tended to present their stories concisely, which could be considered a limitation.

The interpretation of the data was strengthened by the fact that the content of all seven interviews, performed with both children and parents, confirmed each other. The experiences were conveyed in a thorough manner whereby the content became comprehensive and contributed to rich data. In turn, prerequisites for confirmative and truthful results emerged, which had a positive effect on the range and quality of the results. However, additional research is needed to confirm whether the M-FAMM can describe mealtimes appropriately for children with a G-tube.

#### Conclusion

This study presents an empirically grounded model, a new approach to meeting childhood cancer and nutritional needs. Based on children and their parent's experiences, the FAMM (20-22) has been developed and adapted into the M-FAMM, including seven aspects. Two aspects are specific to children with a G-tube, bodily discomfort and time for change and acceptance. Risjord's criteria for analysis and evaluation according to his model (35) have been used to evaluate the M-FAMM, which strengthen the model. The M-FAMM seems to be transferable and useful to achieve an optimal mealtime for children with a G-tube in paediatric care. It could enable opportunities to capture children's experiences regarding their G-tube and mealtimes, which would be of great benefit since positive experiences are essential to facilitate the treatment and recovery process.

#### **Clinical implications**

The M-FAMM could be used in paediatric care in order to chart and identify children's nutritional needs before and after they have received a G-tube. It is an important part of the recovery process to create an appealing mealtime environment, adapted to these children's specific conditions and needs. The use of the M-FAMM in paediatric care facilitates new interventions and guidelines in order to motivate and optimise mealtimes and nutritional intake in children with cancer. For example, in this study, the model detected a need to debate the food at Paediatric Oncology wards. The presentation of the food, the portions sizes, and the smell of the food were specific aspects that affected both nutritional intake and mealtimes negatively for the children. The results highlight a need to adapt the mealtime situations.

#### References

- Jibb LA, Croal L, Wang J, Yuan C, Foster J, Cheung V, et al. Children's experiences of cancer care: a systematic review and thematic synthesis of qualitative studies. *Oncol Nurs Forum*. 2018;45(4):527–44. https://doi.org/ 10.1188/18.ONF.527-544.
- 2 Cheng L, Liu F, Feng S, Wang Y, Gu Y, Kang Q. Symptom experience of

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#### **Conflicts of interests**

The authors declare that they have no conflicts of interests.

#### Authors' contributions

All authors were involved in the study design. The first author carried out the data collection. The first and the last author analysed the data, wrote the first draft and subsequently coordinated the writing of the drafts and the final version of the paper. All authors contributed to the review of all subsequent drafts of the paper, read, and approved the final version of the paper.

#### **Ethical approval**

The regional ethics committee in Gothenburg approved the study (approval number 937-17, approved 13/12/ 2017). Information about the study was given to the children and their parents both verbally and in writing. All participants gave their written consent to participate in the study. Those children that participated in this study lived with an acute life threatening and serious diagnosis. The families were therefore in different stages of crisis why a high degree of consideration and respect has been taken. Days, times and places of the interviews have been adapted with attention to the children's condition as well as examinations and treatments.

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children with cancer younger than eight years of age: an integrative review. *J Pain Sympt Manag.* 2019;58 (1):157–66. https://doi.org/10.1016/j. jpainsymman.2019.03.021.

- 3 Hooke MC, Linder LA. Symptoms in children receiving treatment for cancer – part I: fatigue, sleep disturbance, and Nausea/vomiting. J Pediatr Oncol Nurs. 2019;36(4):244–61. https://doi. org/10.1177/1043454219849576.
- 4 Alcoser PW, Rodgers C. Treatment strategies in childhood cancer. J Pediatr Nurs. 2003;18(2):103–12. https:// doi.org/10.1053/jpdn.2003.10.
- 5 Klanjsek P, Pajnkihar M. Causes of inadequate intake of nutrients during the treatment of children with chemotherapy. *Eur J Oncol Nurs.* 2016;23:24–33. https://doi.org/10. 1016/j.ejon.2016.03.003.

- 6 Beaulieu-Gagnon S, Bélanger V, Marcil V. Food habits during treatment of childhood cancer: a critical review. *Nutr Res Rev.* 2019;32 (2):265–28. https://doi.org/10.1017/ S0954422419000131.
- 7 Arpaci T, Toruner E, Altay N. Assessment of Nutritional problems in Pediatric patients with cancer and the Information Needs of their parents: A parental perspective. *Asia Pac J Oncol Nurs.* 2018;5(2):231–6.ISSN: 2347–5625.
- 8 McGrath K, Hardikar W. Gastrostomy tube use in children with cancer. *Pediatr Blood Cancer*. 2019;66(7): e27702. https://doi.org/10.1002/pbc. 27702.
- 9 Aarnivala H, Pokka T, Soininen R, Möttönen M, Harila-Saari A, Niinimäki R. Trends in age- and sex-adjusted body mass index and the prevalence of malnutrition in children with cancer over 42 months after diagnosis: a single-center cohort study. *Eur J Pediatrics*. 2020;179 (1):91–8. https://doi.org/10.1007/ s00431-019-03482-w.
- 10 Gaynor EPT, Sullivan PB. Nutritional status and nutritional management in children with cancer. *Arch Dis Child.* 2015;100:1169–72. https://doi.org/10. 1136/archdischild-2014-306941.
- Barr RD, Gomez-Almaguer D, Jaime-Perez JC, Ruiz-Arguelles GJ. Importance of nutrition in the treatment of leukemia in children and adolescents. *Arch Med Res.* 2016;47(8):585– 92. https://doi.org/10.1016/j.arcmed. 2016.11.013.
- 12 Skolin I, Wahlin YB, Broman DA, Koivisto Hursti UK, Vikström Larsson M, Hernell O. Altered food intake and taste perception in children with cancer after start of chemotherapy: perspectives of children, parents and nurses. *Support Care Cancer*. 2006;14 (4):369–78. https://doi.org/10.1007/ s00520-005-0904-6.
- 13 Fleming AKC, Cohen J, Murphy A, Wakefield EC, Cohn JR, Naumann LF. Parent feeding interactions and practices during childhood cancer treatment. A qualitative investigation. *Appetite*. 2015;89:219–25. https://doi. org/10.1016/j.appet.2014.12.225.
- 14 Montgomery K, Belongia M, Schulta C, Haddigan Mulberry M, Nugent ML, Simpson PM. Health care

providers perceptions of nutrition support in pediatric oncology and hematopoietic stem cell transplant patients. *J Pediatr Oncol Nurs*. 2016;33(4):265–72. https://doi.org/ 10.1177/1043454215616604.

- 15 Joffe L, Dwyer S, Glade Bender JL, Lindsay Frazier A, Ladas EJ. Nutritional status and Clinical Outcomes in Pediatric Patients with solid tumors: A systematic review of the literature. *Semin Oncol.* Elsevier. 2019;46:48–56. https://doi.org/10. 1053/j.seminoncol.2018.11.005.
- 16 Ward EJ, Henry LM, Friend AJ, Wilkins S, Phillips RS. Nutritional support in children and young people with cancer undergoing chemotherapy (Review). *Cochrane Library. Cochrane Database Syst Rev.* 2015;(8):CD003298. https://doi.org/ 10.1002/14651858.CD003298.pub3.
- 17 Baumgartner A, Bargetzi A, Zueger N, Bargetzi M, Medinger M, Bounoure L, et al. Revisiting nutritional support for allogenic hematologic stem cell transplantation a systemic review. *Bone Marrow Transpl.* 2017;52:506–13. https://doi.org/10. 1038/bmt.2016.310.
- 18 Gonzales F, Bruno B, Alarcón Fuentes M, De Berranger E, Guimber D, Behal H, et al. Better outcome with enteral rather than parenteral nutrition in children undergoing MAC allo-SCT. *Clin Nutr.* 2018;37: 2113–21. https://doi.org/10.1016/j.c lnu.2017.10.005.
- 19 Ricciuto A, Baird R, Sant'Anna A. A retrospective review of enteral nutrition support practices at a tertiary pediatric hospital: a comparison of prolonged nasogastric and gastrostomy tube feeding. *Clin Nutr.* 2015;34(4):652–8. https://doi.org/10. 1016/j.clnu.2014.07.007.
- 20 Gustafsson I-B. Culinary arts and meal science – a new scientific research discipline. *Food Service Technol.* 2004;4(1):9–20. https://doi.org/ 10.1111/j.1471-5740.2003.00083.x.
- 21 Gustafsson I-B, Öström Å, Johansson J, Mossberg L. The five aspects meal model: a tool for developing meal services in restaurants. *J Foodservice*. 2006;17(2):84–93. https://doi.org/10. 1111/j.1745-4506.2006.00023.x.
- 22 Edwards JSA, Gustafsson I-B. The five aspect Meal Model. *J Food*

*Service*. 2008;19(1):4–12. https://doi. org/10.1111/j.1745-4506.2007. 00075.x.

- 23 Renjith V, Pai MS, Cashalino F, George A, Pai A. Engel's model as a conceptual framework in nursing research: well-being and disability of patients with migraine. *Holist Nurs Pract.* 2016;30(2):96–101. https://doi. org/10.1097/HNP. 00000000000136.
- 24 Keller H, Carrier N, Duizer L, Lengyel C, Slaughter S, Steele C. Making the most of mealtimes (M3): Grounding mealtime interventions with a conceptual model. *J Am Med Directors Assoc.* 2014;15(3):158–61. https://doi.org/10.1016/j.jamda.2013. 12.001.
- 25 Justesen L, Overgaard SS. The hospitable meal model. *Hosp Soc.* 2017;7 (1):43–62. https://doi.org/10.1386/ hosp.7.1.43\_1.
- 26 Magnusson Sporre C, Jonsson IM, Pipping EM. Enjoy! Enhancing meals in the Swedish Public Sector. J Culinary Sci Technol. 2017;15(3):239–58. https://doi.org/10.1080/15428052. 2016.1238801.
- 27 Jonsson A, Nyberg M, Jonsson I-M, Öström Å. Older patients' perspectives on mealtimes in hospitals: a scoping review of qualitative studies. *Scand J Caring Sci.* 2020. Online ahead of print. https://doi.org/10. 1111/scs.12866.
- 28 National Board of Health and Welfare (Socialstyrelsen). Mat och måltider inom Hälso- och Sjukvården. Exempel från sjukvårdsverksamhet. (Food and meals in health care and hospital care. Examples from the health care sector). 2011. ISBN 978-91-86885-63-2. Received 2020-06-09 from: https://www.socia lstyrelsen.se/globalassets/sharepointdokument/artikelkatalog/ovrigt/2011-11-8.pdf.
- 29 National Board of Health and Welfare (Socialstyrelsen). Näring för god vård och omsorg – en vägledning för att förebygga och behandla undernäring (Nutrition for good health and social care – a guide to preventing and treating malnutrition). 2011. ISBN 978-91-86885-39-7. Received 2020-06-09 from: http://hkr.divaportal.org/smash/get/diva2:639755/ FULLTEXT01.pdf.

- 30 National Board of Health and Welfare (Socialstyrelsen). Måltidsmiljö inom särskilda boenden och dagverksamheter. Förslag till indikatorer. (Meal environment in special housing and day centers. Proposal of indicators). 2014. Received 2020-06-09 from: https://www.socialstyrelsen. se/globalassets/sharepoint-dokume nt/artikelkatalog/ovrigt/2014-8-8.pdf
- 31 National Food Agency. (Livsmedelsverket). Sjukhusmåltiden en viktig del av vården. (The hospital meal an important part of the care). 2015. ISBN: 978 91 7714 2294. Received 2020-06-09 from: https://docplayer.se/23719350-Sjukhusmaltiden-en-vik tig-del-av-varden.html.
- 32 Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res.* 2005;15 (9):1277–88. https://doi.org/10.1177/ 1049732305276687.
- 33 Graneheim UH, Lundgren B-M, Lundman B. Methodological challenges in qualitative content analysis: A discussion paper. *Nurse Educ Today.* 2017;56:29–34. https://doi. org/10.1016/j.nedt.2017.06.002.
- 34 Risjord M. Nursing knowledge science, practice, and philosophy. Chichester, West Sussex: Wiley – Blackwell; 2010.
- 35 Risjord M. Middle-range theories as models: New criteria for analysis and evaluation. *Nurs Philos*. 2019;20(1): e12225. p.n/a (10). https://doi.org/ 10.1111/nup.12225.
- 36 Meiselman HL. Dimensions of the meal. *J Foodservice*. 2008;19:13–21.

https://doi.org/10.1111/j.1745-4506. 2008.00076.x.

- 37 Skolin I, Koivisto Hursti U-K, Wahlin YB. Parents' perception of their child's food intake after the start of chemotherapy. J Pediatr Oncol Nurs. 2001;18(3):124–36. https://doi.org/ 10.1177/104345420101800305.
- 38 Unicef. (2020). Received 2020–04-26 from: https://www.unicef.org/ child-rights-convention/conventiontext.
- 39 Coyne I, Hallström I, Söderbäck M. Reframing the focus from a familycentered to a child centered care approach for children's health care. J Child Health Care. 2016;20(4):494– 502. https://doi.org/10.1177/ 1367493516642744.
- 40 Söderbäck M, Coyne I, Harder M. The importance of including both a child perspective and the child's perspective within health care settings to provide truly child-centered care. *J Child Health Care*. 2011;15(2):99– 106. https://doi.org/10.1177/ 1367493510397624.
- 41 Meleis AI, Sawyer LM, Im E-O, Hilfinger Messias DK, Schumacher K. Experiencing transitions: an emerging middle-range theory. *Adv Nurs Sci.* 2000;23(1):12–28.ISSN: 0161–9268.
- 42 Woodgate LR, Degner FL. Cancer symptoms transition periods of children and families. J Adv Nurs. 2004;46(4):358–68. https://doi.org/ 10.1111/j.1365-2648.2004.03002.x.
- 43 Stroebele N, De Castro JM. Effect of ambience of food intake and food choice. Nutrition. 2004;20(9):821–38.

https://doi.org/10.1016/j.nut.2004. 05.012.

- 44 Cohen J, Laing DG, Wilkes FJ, Chan GM, Cohn RJ. Taste and smell dysfunction in childhood cancer survivors. *Appetite*. 2014;75:135–40. https://doi.org/10.1016/j.appet.2014. 01.001.
- 45 Ulrich SR, Zimring C, Zhu X, DuBose J, Seo H-B, Choi Y-S, et al. A review of the Research literature on evidence-based healthcare design. *Health Environ Res Design J.* 2008;1 (3):61–125. https://doi.org/10.1177/ 193758670800100306.
- 46 Lambert V, Coad J, Hicks P, Glacken M. Young children's perspectives of ideal physical design features for hospital-built environments. *J Child Health Care*. 2014;18(1):57–71. https://doi.org/10.1177/ 1367493512473852.
- 47 Harris PB, McBride G, Ross C, Curtis L. A place to heal: environmental sources of satisfaction among hospital patients 1. *J Appl Soc Psychol*. 2002;32(6):1276–99. https://doi.org/ 10.1111/j.1559-1816.2002.tb01436. x.
- 48 Edwards JSA, Gustafsson I-B. The room and atmosphere as aspects of the meal: a review. J Foodservice. 2008;19(1):22–34. https://doi.org/10. 1111/j.1745-4506.2007.00077.x.
- 49 Kerr LMJ, Harrison MB, Medves J, Tranmer J. Supportive care needs of parents of children with cancer transition from diagnosis to treatment. *Oncol Nurs Forum*. 2004;31(6): e116–e126.EISSN: 1538–0688.