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Original article

Eating and feeding problems in children with cancer: Prevalence, related factors, and consequences

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SUMMARY

Background & aims: During treatment for cancer, children experience many side effects such as lack of appetite, nausea, and vomiting. As a result, ensuring adequate intake puts pressure on both the child and the parent. This study aims to determine the prevalence, causes and consequences of eating and feeding problems in children treated for cancer.

Methods: Parents of 85 children with cancer completed the Behavioral Pediatrics Feeding Assessment Scale (BPFAS) and symptoms, BMI, energy intake, feeding style, and parental distress were measured at 0, 3, 6 and 12 months after diagnosis.

Results: Parent-reports revealed that almost a quarter of the children experienced eating disorder: 15.7% experienced problems related to diminished intake and 8.6% related to excessive intake. Prevalence of feeding disorders related to parents' behavior was 21.1%. In children <8 years prevalence of eating and feeding disorders was significantly higher: 31% and 36% for child and parent behavior respectively. Younger age, poor pre-illness eating behavior, increase in symptoms and a demanding feeding style were associated with more eating problems. Excessive eating resulted in higher energy intake, however, no association was found between eating problems and nutritional status. Food refusal resulted in more parental distress.

Conclusions: Especially younger children with cancer are at risk for eating and feeding problems. In addition, poor pre-illness eating behavior, symptoms and a demanding feeding style aggravate eating problems. Therefore, interventions should focus at diminishing side effects of treatment and instructing parents to be less demanding regarding their child's eating behavior.

1. Introduction

Ensuring adequate nutrient intake in a child with cancer is a challenging task for parents and health care professionals. Lengthy treatments that include aggressive therapies, periods of enteral nutrition, and hospitalization can disrupt eating patterns and cause significant nutritional problems. Chemotherapy and radiation may cause multiple side effects such as appetite suppression, changes in taste and smell, nausea, vomiting, mucositis, gastrointestinal malabsorption, diarrhea, pain, and fatigue [1–5]. As a result of these side-effects, children may become reluctant to eat and develop food aversions due to negative experiences with food during this period.

Abbreviations: AYCE-R, About Your Child's Eating-Revised; BMI, Body Mass Index; BPFAS, Behavioral Parental Feeding Assessment Scale; CBF, Child Behavior Frequency; CBP, Child Behavior Problem; CF, Cystic Fibrosis; CEBQ, Child Eating Behavior Questionnaire; EGID, Eosinophilic Gastro Intestinal Disorders; GI, Gastro Intestinal; MSAS, Memorial Symptom Assessment Scale; PBF, Parent Behavior Frequency; PBP, Parent Behavior Problem; UMCG, University Medical Center Groningen.

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Contrarily, children receiving corticosteroid therapy experience insatiable appetite, graving, and binge eating [5–8].

A poor nutritional status (both under- and overnutrition) in children with cancer is linked to deleterious clinical outcomes such as more complications, higher relapse rates, lower survival rates and lower quality of life [9–11]. Knowing the importance of a good nutritional status, parents and health care professionals become concerned about the child's eating behavior [12]. Moreover, for many parents feeding is one of the few aspects in which they can contribute to their child's treatment. They feel responsible for their child's intake and may become too focused on the feeding, even using strategies to force a child to eat [2,5,12]. Consequently, a child's aversion to eating can increase [4]. On the other hand, some parents become more permissive and allow their child to eat whatever he/she wants in order to avoid conflicts and to improve their child's intake [6]. In both situations, the parent's concern about the treatment related side effects on their child's intake may create conflicts during mealtime interactions. Consequently, parents report frustration and increased stress trying to attempt their child to eat [2,13].

Beyond doubt, having a child with cancer affects family's mealtime: both eating behavior of the child and parental feeding behavior[1] become disrupted. So far, several studies examined eating and feeding behavior in children with cancer. Most studies were qualitative and concerned relatively small samples [2,4,13–15] These studies described the impact of the side effects of treatment on children's eating behavior [2,13–15], the conflicts during mealtime interactions [2,4,13–15] and the parental feelings of stress and helplessness [2,13,14]. Strikingly, data about the magnitude and prevalence of eating and feeding problems in this patient group are lacking. Additionally, it is important to differentiate between tolerable problems and problems of clinical significance, the so called eating and feeding disorders [16]. Therefore, quantitative research is needed in order to get a better impression of the prevalence of eating and feeding problems in children with cancer, and the causes and consequences of these problems.

This study focuses on the following research questions: 1) What is the prevalence of eating and feeding disorders (clinical significant problems) in children treated for cancer and does it change over time? 2) Is this eating behavior better or worse compared to children with other diseases? 3) Which factors (age, gender, pre-illness eating behavior, type of malignancy, symptoms, parental feeding style) are related to the child's eating behavior? 4) What are the consequences of eating behavior on energy intake, nutritional status of the child, and parental stress?

2. Methods

2.1. Participants

Participants of this study took part in the Pecannut (Pediatric Cancer & Nutrition) study of the University Medical Center Groningen (UMCG) in the Netherlands between September 2007 and December 2010. For more details about the Pecannut study see previous publications [17,18]. Eligible patients were between 1 and 18 years old, had no prior diagnosis of cancer, received treatment with curative intent, and had sufficient command of the Dutch language. Ethical approval was obtained from the Medical Ethics Committee of the UMCG, and parents and children aged ≥12 years gave their written consent. Measurements were performed at the time of diagnosis and at 3, 6, and 12 months after diagnosis.

2.2. Measures

2.2.1. Eating and feeding behavior

Parents' perception of mealtime behavior was assessed using the Behavioral Pediatrics Feeding Assessment Scale (BPFAS) [19]. The BPFAS is a 35-item parent-report questionnaire which examines child and parent behavior during mealtimes. The scale consists of 25 items focusing on child eating behavior (e.g. my child delays eating by talking) and 10 items focusing on feeding behavior describing parents' feelings and feeding strategies (e.g. I get anxious and/or frustrated when feeding my child). Items are phrased in both positive and negative directions (e.g. my child will try new foods; my child whines or cries at feeding times). For each item, parents reported how often the particular behavior occurred on a 5-point Likert scale from "1 = never" to "5 = always" and whether or not the parent considered the behavior as problematic (yes/no). The BPFAS generates four scores: Child Behavior-Frequency (CBF) and Parent Behavior-Frequency (PBF) reflecting how often the child and parent behaviors occur, and Child Behavior-Problems (CBP) and Parent Behavior-Problems (PBP) reflecting the number of behaviors the parents consider to be problematic. The BPFAS focuses on behavioral problems related to food refusal or poor nutritional intake [20] and has been used to asses eating and feeding behavior in children with medical problems such as Cystic Fibrosis (CF), diabetes, and gastrointestinal (GI) disorders [20–24]. However, children with cancer do not only demonstrate food refusal. Some children with brain tumors and children treated with corticosteroids experience insatiable appetite and binge eating and this behavior is problematic as well. Therefore, 5 items from the Child Eating Behavior Questionnaire (CEBQ) [25] describing excessive eating were added to the questionnaire resulting in 30 items describing the child's eating behavior.

Apart from the BPFAS, parents were asked to classify their child's pre-illness eating behavior as poor, moderate, or good.

Feeding style of the parents was measured with the Caregiver's Feeding Style Questionnaire (CFSQ) [26]. The CFSQ is composed of seven child-centered items representing the child's autonomy (e.g. reasoning, complimenting: I say something positive about the food the child is eating during dinner) and 12 parent-centered items representing external control of the parent (e.g. demands, threats: I say to my child "Hurry up and eat your food") measured on a 5-point Likert scale from "1 = never" to "5 = always." Parents' feeding style was classified along two dimensions: demandingness and responsiveness. Demandingness refers to the extent to which parents exert control over their child's eating whereas responsiveness refers to parents awareness of their child's needs showing acceptance, affection, and involvement [26,27]. Feeding style is considered to be a trait characteristic and a predictor of the child's eating behavior [27–29].

2.2.2. Symptoms

Symptom frequency was assessed using the Memorial Symptom Assessment Scale (MSAS) [30]. The MSAS consists of 30 items representing both physical (e.g. pain, vomiting) and psychological symptoms (e.g. feeling sad) experienced by children with cancer. Parents rated whether a symptom was present (=yes) or not (=no). Then sumscores were calculated.

2.2.3. Energy intake

Energy intake was measured using a 3-day food record filled in by parents and total energy intake was calculated using food

[1] Eating refers to the child's behavior to consume food; feeding refers to the parents' behavior to nourish their child.

calculation software (Eetmeter 2002, the Netherlands Nutrition Centre, the Netherlands). Percentage intake of individual energy requirement (using Schofield's formula [31]) was calculated.

2.2.4. Nutritional status

Nutritional status was expressed in BMI z-scores according to Dutch reference values [32]. Weight and height were measured using calibrated digital scales and recorded to the nearest 0.1 kg and 0.1 cm respectively [17].

2.2.5. Parental distress

Parental feeding distress was measured on a 5-point Likert scale, answers ranging from totally disagree to totally agree. The question the parents answered was "I become distressed when I feed my child".

2.3. Data analyses and statistics

In order to answer the first research question, sum scores of the four child and parent subscales of BPFAS (25 child focused + 10 parent focused items) were calculated and the following cut-off values were used to determine the prevalence of eating and feeding disorders: CBF>61, CBP>6, PBF>20, PBP>2 [16]. These cut-off values resulted in sensitivities and specificities between 79 and 87% [16]. The second research question was answered by comparison of the CBF-score of the current study with values presented in the literature referring to eating problems in children with other diseases and healthy controls. Since the BPFAS has predominantly been used with younger children, the scores of the children with cancer were divided into the age groups: < 8 years and ≥8 year to facilitate comparison with children suffering from other illnesses. Data of the 3 months measurement were tested against studies including the same age range. The 3 months measurement was considered to be the most representative, because all children received active treatment at that time.

Given the different eating behaviors presented in the BPFAS, factor analyses were performed for answering research questions three and four. The 25 items representing child-behavior of the BPFAS +5 items CEBQ were analyzed according to principal component factor analysis with oblimin rotation (given the interrelationships between the items of the BPFAS). The decision for the number of factors was based on eigenvalues greater than the 1.0, explained variance of at least 50%, parallel analysis, interpretability of the factors, and Cronbach's α of the factors.

Multilevel analyses (linear mixed models in SPSS) were used to determine which factors (age, gender, pre-illness eating behavior, diagnosis, symptoms, method of feeding, and parental feeding style) predicted the child's eating behavior (research question three). Independent variables were entered stepwise (both forward and backward). Final models were based on lowest −2 Log Likelihood.

To determine the consequences of the child's eating behavior for energy intake and nutritional status multilevel analyses were used with the factors of the BPFAS as predictor (research question four). Given the ordinal structure of parental feeding distress, REpeated measures Proportional Odds Logistic Regression (Repolr) in R was used to determine the predictors of parental distress. Considering the low numbers in the answer category 'totally agree', answer categories were merged. The final model, based on the lowest Quasi Likelihood Information, consisted of three categories (1. totally disagree, 2. disagree, and 3. tend to agree/agree/totally agree).

Table 1
Patient characteristics.

Characteristics	Number (n = 85)	%
Gender: female	44	(52.9)
Median age at diagnosis (range)	9.1	(1.7–17.7)
<8 years	37	(43.5)
≥8 years	48	(56.5)
Diagnosis:		
Hematological	*41*	*(48.2)*
Leukemia	31	(36.5)
ALL	26	(30.6)
AML/JML	5	(5.9)
Lymphoma	10	(11.8)
Solid tumors	*26*	*(30.6)*
Neuroblastoma	5	(5.9)
Wilms tumors	3	(3.5)
Bone tumors	7	(8.2)
Solid other	11	(12.9)
Brain tumors	*18*	*(21.2)*
Medulloblastoom	3	(3.5)
Astrocytoma/glioma	5	(5.9)
Craniopharyngioma	4	(4.7)
Other	6	(7.1)
Pre-illness eating behavior		
Poor	4	(4.7)
Moderate	15	(17.6)
Good	57	(67.1)
Missing	9	(10.6)
Tubefeeding[a]	38	(44.7)

[a] Tube feeding at any time during 12 months.

3. Results

3.1. Patients

Informed consent was obtained from 101 of 128 eligible patients (79% response rate). Reasons for non-participation included: too much burden (n = 17), child too ill (n = 2), lack of motivation (n = 8). Respondents who failed to return baseline questionnaires and those without data on eating and feeding behavior were excluded (n = 26). Eighty-five children (median age 9.1 years, min–max range 1.7–17.7) diagnosed with a hematological (48.2%), solid (30.6%) or brain malignancy (21.2%) participated (Table 1). Percentage children with a hematological malignancy was higher in the group participants than in the group non-participants (48.2% vs 27.3%) whereas percentage children with a brain malignancy was lower (21.2% vs 42.2%) (χ^2-test = 6.42, $P = 0.040$). Both groups did not differ in age or gender.

In total, 38 (44.7%) children received nasogastric tube feeding for several days or weeks at any given time during treatment. The percentage of children receiving tube feeding decreased over time from 27.4% at diagnosis till 10.0% after 12 months. At 12 months, 57.5% of the children had finished treatment.

3.2. Prevalence of eating and feeding disorders

On average, in 15.7% of the respondents the scores of CBF, and in 21.1% the scores of PBF exceeded the cut-off value (Table 2). These prevalence rates only represented problems scores related to poor nutritional intake. The items for excessive eating from the CEBQ were not included in these percentages, since no cut-off values are available. However, 8.6% of the respondents exceeded the sum score of 14 points (range 5–25), meaning that on average they scored *sometimes* to *always* on these items.

Prevalence of eating disorders (CBF) was higher in children <8 years than in children ≥8 years (χ^2-tests for all measurement times had *P*-values <0.005) and ranged from 29% at diagnosis to 37% 12

Table 2
Mean values BPFAS and prevalence eating & feeding disorder.

	all times			0 months			3 months			6 months			12 months		
	% disorder	Mean	SD	% disorder	Mean	SD	% disorder	Mean	SD	% disorder	Mean	SD	% disorder	Mean	SD
CBF	15.7	48.3	13.4	14.9	48.8	12.3	16.7	48.5	13.7	13.5	47.6	12.4	17.8	48.2	15.2
CBP	8.5	1.9	3.4	7.8	2.0	3.2	12.1	2.0	3.6	7.9	1.8	3.1	6.3	1.7	3.4
PBF	21.1	17.0	4.5	27.7	17.9	4.5	19.5	16.6	4.4	19.2	17.0	4.5	18.1	16.4	4.7
PBP	10.5	0.7	1.7	14.8	0.8	1.5	9.1	0.7	1.9	8.5	0.6	1.8	9.4	0.6	1.5

CBF = child behavior frequency (range 5–150); CBP = child behavior problem (range 0–25) PBF = parent behavior frequency (range 10–50); PBP=Parent Behavior Problem (range 0–10).

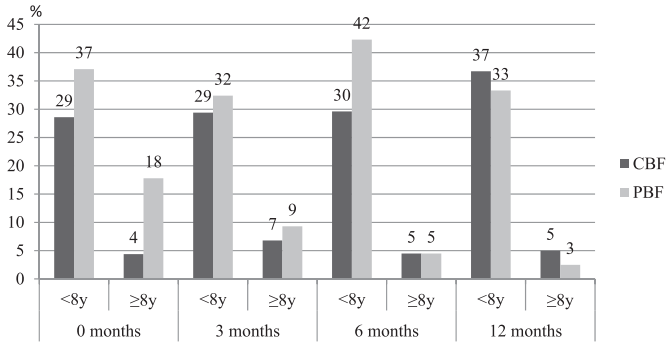

Fig. 1. Prevalence of eating disorder (CBF) and feeding disorder (PBF) for children <8 years (n = 37) and ≥8 years (n = 48). All percentages of children <8 years are statistically higher than percentages in children ≥8 years except for PBF at 0 months.

months later (Fig. 1). Similarly, the prevalence rates of PBF were significantly higher in the youngest group only at diagnosis the *P*-value of χ^2-test was non-significant ($P = 0.051$). Children with poor or moderate pre-illness eating behavior had higher frequencies of eating disorders (prevalence rates 42%–57%) during treatment than children with good pre-illness eating behavior (prevalence rates 4%–8%) (χ^2-tests for all measurement times had *P*-values <0.001).

Prevalence rates of problem scores were on average 8.5% for child behavior (CBP) and 10.5% for parent behavior (PBP) (Table 2).

3.2.1. Change over time

The mean scores of the CBF were around 48 and stable over time. The mean scores PBF decreased over time from 17.9 at diagnosis to 16.4 12 months later (paired t = 2.463, df = 67, $P = 0.016$) (Table 2). Both frequency scores and problem scores of child and parent behavior were related (range Pearson's R of frequency scores = 0.552 to 0.686, all P-values < 0.001; range Spearmans'rho of problem scores = 0.472 to 0.675, all P-values < 0.001.

3.3. Comparison of child eating behavior with other patient groups and healthy controls

CBF of children with cancer <8 years was comparable with CBF of children with CF and diabetes, was much lower than in children with feeding problems, and was significantly higher than in healthy controls (Table 3). Higher CBF score implies more eating problems. One study [24] assessed eating behavior in children with eosinophilic gastrointestinal disorders (EGID) and included children in the same age range as the Pecannut study. CBF score in children with cancer (mean = 48.5) was significantly lower than in children with EIGD (mean = 55.0) (95% CI differences 2.2–10.9) and higher than in healthy controls (mean = 40.5) (95% CI differences 4.4–11.5) (Table 3).

3.4. Related factors of child eating behavior

Factor analyses of CBF were performed for every measurement time. Only small differences in loadings occurred across time. Therefore, the final factor analysis was executed based on the 3 months data, since this time point was considered to be the best representation of therapy given that all respondents received anti-cancer treatment at this time. The factor analysis resulted in four subscales of eating behavior: *picky eating, excessive eating, food refusal, and texture & gastrointestinal (GI) problems* (Table 4). Cronbach's alpha's of the subscales were respectively 0.873, 0.878, 0.837, and 0.779. All items from the CEBQ loaded on the factor *excessive eating*.

Cronbach's α of the MSAS in the current study was 0.90.

The subscales 'poor' and 'moderate' of pre-illness eating behavior were merged into one group because of the low numbers. Multilevel analyses with the subscales of the BPFAS as dependent variable, revealed that age, pre-illness behavior and symptoms predicted *picky eating*; younger children, children with poor or moderate pre-illness eating behavior and children with more symptoms demonstrated *more picky eating* (Table 5). *Excessive eating* was predicted by age and method of feeding: younger children and children without tube feeding scored higher values on *excessive eating* (Table 5). Besides, *excessive eating* decreased over time with 0.02 points per month. *Food refusal* was predicted by pre-illness eating behavior, symptoms, tube feeding, and demandingness feeding style. A poor or moderate pre-illness eating behavior, more symptoms and a demandingness feeding style were associated with more *food refusal* and children without tube feeding demonstrated less *food refusal* (Table 5). *Food refusal* increased over time with 0.02 points monthly. Pre-illness behavior, symptoms, tube feeding, and demandingness were also predictors for *texture & GI problems*: children with poor or moderate pre-illness eating behavior and experiencing more symptoms or a demandingness feeding style scored higher on *texture & GI problems*; children without tube feeding scored lower. *Texture & GI problems* increased with 0.02 points monthly. No associations were found for gender or type of malignancy (hematological, solid of brain malignancy).

3.5. Consequences of child eating behavior

Children demonstrating *excessive eating* and children with *food refusal* had higher energy intakes (estimates 11.03 and 18.09 respectively, Table 6). None of the eating styles was found to be associated with zBMI (for detailed information of energy intake and nutritional status in this patient group see Brinksma [17,18]).

Parental distress was predicted by *excessive eating* and *food refusal*: excessive eating resulted in lower parental distress (odds ratio = 0.564, $P = 0.027$) and food refusal was associated with higher parental distress (odds ratio = 8.633, $P = 0.000$) (Table 7). Parental distress decreased over time (odds ratio = 0.898, $P = 0.006$).

Table 3
Comparisons of BPFAS scores across children with diseases and healthy controls.

Population	<8 years			1–18 years		
	CBF (SD)	n	t-value	CBF (95% CI)	n	95% CI differences mean
Cancer	54.8 (15.3)	34		48.5 (45.5–51.6)	85	
Feeding problems						
Marshall 2014	75.2 (12.1)	36	−6.2**			
Dovey 2013	72.4 (15.5)	64	−5.4**			
Dovey 2012	77.3 (11.5)	24	−6.4**			
Crist 2001	69.9 (12.6)	95	−5.2**			
Cystic fibrosis						
Crist 1994	54.7 (13.9)	21	0.02			
Diabetes						
Patton 2009	44.9 (9.3)	31	3.1**			
Patton 2006	50.5 (10.1)	85	1.8			
Powers 2002	50.0 (11.0)	40	1.6			
GI disorders						
WU 2012				55.0 (51.9–58.1)	92	2.2–10.9
Healthy controls						
Marshall 2014	49.7 (11.3)	54	1.8			
Dovey 2013	45.6 (12.6)	509	4.1**			
Crist 2001	46.6 (10.3)	96	3.4**			
Crist 1994	46.5 (12.3)	21	2.2*			
Powers 2002	45.8 (7.7)	40	3.3**			
Wu 2012				40.5 (38.6–42.3)	89	4.4–11.5

CBF = Child Behavior Frequency. Higher values of CBF represent more eating problems.
Mean values of CBF of children with diseases and healthy controls were tested (independent t-test or 95% CI of differences of the mean) with cancer as reference group.
*$P < 0.05$, **$P < 0.01$ two-tailed tested.

Table 4
Factor loadings BPFAS (3 months after diagnosis).

	Factor loadings			
	1	2	3	4
Factor 1: picky eating				
Eats starches	**.847**	0.060	−0.210	−0.112
Eats meat and/or fish	**.836**	0.047	−0.012	0.116
Eats vegetables	**.794**	−0.053	−0.136	−0.134
Eats fruit	**.723**	−0.131	0.156	0.057
Enjoys eating	**.648**	−0.067	0.007	0.360
Drinks milk	**.602**	−0.033	0.204	0.013
Will try new foods	**.533**	−0.091	−0.046	0.132
Has required nasogastric feeds	**.531**	−0.141	−0.205	0.190
Comes readily to mealtime	**.361**	−0.150	−0.045	0.142
Factor 2: excessive eating[a]				
If he/she got the chance, my child would always have food in his/her mouth	−0.002	**.913**	0.024	0.092
Is it was up to him/her, my child would eat virtually non-stop	0.012	**.908**	0.097	0.082
My child would eat too much if it were allowed.	−0.020	**.878**	0.138	0.060
Even when my child has eaten enough, he/she always finds a corner for his/her favorite food	−0.154	**.683**	−0.089	−0.042
My child is always asking for food.	−0.088	**.669**	−0.223	0.038
Factor 3: food refusal/disruptive behavior				
Tantrums at meals	−0.090	−0.022	**−.751**	0.137
Would rather drink than eat	0.326	−0.007	**−.743**	−0.087
Delays eating by talking	−0.227	−0.034	**−.727**	0.111
Has a poor appetite	0.277	−0.306	**−.586**	0.156
Refuses to eat meals but requests food immediately after meal	0.129	0.070	**−.576**	−0.070
Eats junck food snacks foods but will not eat at mealtime	0.220	0.120	**−.567**	−0.282
Whines or cries at feeding time	0.015	0.253	**−.546**	0.287
Tries to negotiate what he/she will eat and will not eat	−0.082	−0.070	**−.533**	0.251
Gets up from table during meal	0.030	0.122	**−.513**	−0.277
Takes longer than 20 min to finish meal	−0.016	−0.168	**−.463**	0.267
Lets food sit in his/her mouth and does not swallow it	0.002	−0.154	**−.441**	0.221
Factor 4: Texture and gastro-intestinal problems				
Has problems chewing foods	0.199	0.120	0.029	**.757**
Chokes or gags at mealtime	0.020	0.096	−0.104	**.747**
Vomits just before, at, or just after a meal	−0.003	−0.153	−0.115	**.607**
Eats only ground, strained, or soft food	0.226	0.061	0.031	**.573**
Spits out food	0.275	0.054	−0.245	**.399**
Eigenvalues	8.11	4.08	2.28	1.86
% of variance	27.04	13.58	7.61	6.19

Extraction Method: Principal Component Analysis.
Rotation Method: Oblimin with Kaiser Normalization.
Boldface indicates highest factor loadings.
[a] All items of this factor are from CEBQ (Wardle 2001).

Table 5
Parameter estimates factors BPFAS.

		Estimate	95% CI	P-value
Picky eating				
Intercept		2.42	2.17, 2.66	0.000
Age		−0.02	−0.04, −0.00	0.050
Pre-illness behavior before Dx	Poor/moderate	0.50	0.27, 0.73	0.000
	Good	0		
Symptoms		0.02	0.00, 0.03	0.000
Excessive eating				
Intercept		1.94	1.60, 2.28	0.000
Age		−0.04	−0.07, −0.01	0.014
Tube feeding	No	0.41	0.20, 0.63	0.000
	Yes	0		
Time[a]		−0.02	−0.03, −0.00	0.011
Food refusal				
Intercept		0.42	0.10, 0.73	0.009
Pre-illness behavior	Poor/moderate	0.30	0.11, 0.48	0.002
	Good	0		
Symptoms		0.02	0.01, 0.03	0.000
Tube feeding	No	−0.18	−0.32, −0.03	0.015
	Yes	0		
Demandingness		0.57	0.46, 0.67	0.000
Time[a]		0.02	0.01, 0.03	0.001
Texture & GI problems				
Intercept		0.32	−0.06, 0.69	0.097
Pre-illness behavior	Poor/moderate	0.25	0.02, 0.48	0.034
	Good	0		
Symptoms		0.03	0.01, 0.04	0.000
Tube feeding	No	−0.23	−0.40, −0.07	0.006
	Yes	0		
Demandingness		0.39	0.26, 0.51	0.000
Time[a]		0.02	0.01, 0.03	0.000

[a] Time is measured in months.

Table 6
Parameters estimates %energy intake.

%Energy intake	Estimate	95% CI	P-value
Intercept	48.57	26.80, 70.33	0.000
Excessive eating	11.03	4.39, 17.67	0.001
Food refusal	18.09	9.54, 26.65	0.000

Table 7
Parameter Estimates of Parental stress (repeated measures proportional odds logistic regression).

	Odds Ratio	P-value
Excessive eating	0.564	0.027
Food refusal	8.633	0.000
Time[a]	0.898	0.006

[a] Time is measured in months.

4. Discussion

4.1. Prevalence of eating and feeding disorders

This study demonstrated that during treatment 15.7% of the children experienced eating disorders related to food refusal and diminished intake, whereas another 8.6% experienced problems related to excessive intake. The problem of diminished intake was most prevalent in younger children; almost one in three children <8 years demonstrated this kind of eating problem. Parental feeding behavior was disturbed in one of 5 families for all ages and in 1 of 3 families with a child <8 years. Other research confirmed that younger children performed worse than older children whereas in healthy children no differences in BPFAS scores were found [24]. Likely, eating behavior of younger children is more severely affected by their illness. Although these behavioral problems are very well known in children treated for cancer [2,4,13,15,33], so far prevalence rates of eating and feeding disorders were lacking.

The magnitude of eating problems of children with cancer <8 years was comparable with eating problems of young children with the chronic diseases CF and diabetes [20,23,34]. However, they performed worse than healthy controls. Children with the primary diagnosis of feeding problems had the worst scores on eating behavior. Comparison in the age range 1–18 years showed similar results: children with cancer performed worse than healthy controls but better than children with EGID [24]. The magnitude of eating problems in children with cancer was comparable with eating problems in children with chronic diseases. It was expected that, due to the side effects of treatment (i.a. nausea, taste and smell alterations), they would experience more eating problems. Likely, item scores between children with cancer, CF or diabetes differed (e.g. higher frequencies on 'vomiting' and 'poor appetite'). On the other hand, a large proportion of the cancer patients received tube feeding and this might have lowered the scores on other items compensating for higher sum scores of BPFAS. Obviously, in children with cancer and EGID the seriousness of symptoms played a major role, whereas in children with CF, diabetes, and feeding problems, behavioral and environmental factors might have provoked eating problems. For future studies, it would be interesting to look at the mechanisms that elicited eating feeding problems in the different patient groups.

Contrary to the current findings, Gerhardt [35] found no significant differences in mealtime interaction between children with cancer and controls using the AYCE-R, nor did Gerhardt find associations with age or treatment factors. Probably the inclusion of only older children (8–15 years) prevented them from finding significant results.

Even though CBF scores were stable over time, scores of the subscale *excessive eating* decreased, whereas *food refusal* and *texture & GI problems* increased over time. Especially the increase of *food refusal* and *texture & GI problems* is worrisome and unexpected, given that for most children the frequency of symptoms diminished over time and that after 12 months more than half of the children had finished treatment. Such disturbed behavior might have been provoked by side-effects of treatment and maintained by a demanding feeding style of the parents. However, no interaction effect between time and demandingness was found to confirm this hypothesis.

4.2. Related factors of child eating behavior

Pre-illness eating behavior and symptoms were the main factors affecting eating behavior and were associated with *picky eating, food refusal and texture & GI problems*. Likely, poor pre-illness eating behavior continued during cancer treatment or even worsened. In future studies it would be interesting to measure eating behavior at diagnosis twice: once concurrent and once retrospectively in order to determine deterioration of eating behavior during treatment. For clinical practice assessment of pre-illness eating behavior at diagnosis is recommended in order to identify children at risk for feeding problems in due time.

It is not surprising that side effects like taste and smell alterations, nausea, vomiting and mucositis immediately affect a child's appetite. Also in qualitative studies, parents mentioned side effects of treatment as one of the main causes of eating problems [2,13]. So, adequate symptom management to reduce the impact of side effects can add a significant contribution at improving eating behavior.

Age was negatively associated with *picky eating*: younger children were more picky. A plausible explanation is that young children are in the midst of establishing routine eating patterns and expanding their nutritional repertoire [35]. Their eating pattern is still in development and consequently more vulnerable for the impact of illness. Younger children demonstrated more *excessive eating*. Possibly, their eating behavior is more driven by primary internal needs and less sensible for parental interference.

Tube feeding was also associated with the child's feeding style; children receiving tube feeding demonstrated more *food refusal* and *texture and GI problems*. It was expected that tube feeding would diminish the pressure to eat and improve the child's eating behavior. Unfortunately, sample size was too small to conduct sub analyses with predictors for feeding style in children with or without tube feeding.

The demandingness feeding style was associated with *food refusal* and *texture and GI problems*; the more demanding and controlling the parental feeding style, the more problematic the eating behavior of the child. Given the parents' concern about their child's intake, it is obvious they do their utmost to improve the intake and put pressure on them. Fleming [2] described that some parents used verbal pressure or threaten to increase the intake. So far, the relationships between parental feeding style and the child's eating behavior has been studied in pre-school and obese children and in families with low incomes [27,29,36,37]. Generally, the authoritative style (high responsiveness, high demandingness) showed to be the most beneficial regarding dietary quality and BMI [29,36,38,39]. However, whether the same applies in sick children is not known. This study suggests that parents could better be more tolerant and compliant regarding their child's eating behavior than being demanding and strict.

4.3. Consequences of child eating behavior

None of the eating styles was associated with diminished energy intake nor was an association found with BMI. This is a positive finding: disturbances in eating behavior during treatment had no serious consequences for the child's nutritional status. Naturally, the fact that almost 45% of the children received tube feeding at any time during treatment, prevented them from becoming malnourished. One might conclude that regarding energy intake and nutritional status feeding problems were adequately treated. Results from previous research about the relationship between eating behavior and intake is contradictory [20,34,40]. Possibly, the difficulty to collect reliable dietary intake data plays a role.

It is obvious that *excessive eating* contributed to a higher energy intake, whereas the positive contribution of *food refusal* to energy intake seems paradoxical. However, children demonstrating *food refusal* received more often tube feeding. Apparently, the administration of tube feeding contributed to higher energy intake in children with this type of eating behavior.

Disturbed eating behavior was associated with parental distress. *Food refusal* using strategies to delay eating, tantrum, crying and negotiating is very distressing for parents. The few studies on eating behavior in children with cancer have established high levels of parental distress and reported worries, anxiety, sad feelings [13], distress [14], and disagreement between parents regarding the management of their child's behavior [2]. Strikingly, parents were not concerned about *excessive eating* of their child. Earlier data in survivors of childhood cancer confirmed that parents were the least worried about their child's risk for overweight [41]. This is especially of concern considering the increase of BMI during treatment [17] and the high prevalence of overweight in survivors of childhood cancer [42,43].

Strengths of the current study were the relatively large sample size, the wide age-range, the longitudinal measurements during the first year after diagnosis, and the investigation of antecedents ánd consequences of eating problems. However, several limitations should be noted. The study relied on parent-report. Parents' appraisal on eating and feeding behavior is influenced by their own emotions and feelings and might differ from more objective measures. Therefore, future studies could benefit from child-report or observational data-collection. Furthermore, comparisons of eating behavior with children with other diseases and controls were based on the literature. Concurrent data collection in different groups of the same age would be preferable.

In conclusion, during cancer treatment particularly young children are at risk: with one in three exhibiting eating disorders. This is especially worrisome, since eating habits develop at young age and the negative food experiences during cancer treatment might directly shape the child's future eating behavior. Assessment of pre-illness behavior at diagnosis is needed to identify children at risk for eating problems in due time. Adequate management of treatment related side-effects like nausea, taste and smell alterations, and mucositis is important in order to prevent these problems. Additionally, educational interventions can learn parents to cope with their child's eating behavior and to become more tolerant and permissive. Finally, further research is recommended to determine whether eating and feeding problems during treatment have consequences for future mealtime behavior.

Statement of authorship

The authors' responsibilities were as follows: AB participated in study design, collected data, conducted data analysis, and drafted the manuscript. ES participated in study design, collected data, participated in interpretation of data. IIJ participated in interpretation of data, helped to draft the manuscript. JGMB performed statistical analyses, participated in interpretation of data. WJET participated in study design, supervised its execution, helped to draft the manuscript. All authors read and approved the final manuscript.

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Conflicts of Interest

The authors have declared no conflict of interest.

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