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Changes in taste among pediatric patients with cancer and hematopoietic stem cell transplantation recipients

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Abstract

Purpose Changes in taste is a common bothersome symptom in children receiving cancer treatments. However, little is known about how pediatric cancer patients experience this symptom. The objective was to describe how children receiving cancer treatments experience taste alterations and the approaches they use to address the issue.

Methods In this qualitative study, we included English-speaking children 4–18 years of age with cancer or hematopoietic stem cell transplantation recipients who were actively receiving cancer treatment or who had completed therapy. Using a semi-structured questionnaire, we asked questions about the experience of altered taste sensation. We asked about its characteristics, impacts and identified coping strategies.

Results We included 50 children. Children experienced changes in taste in a heterogeneous fashion although commonly described food as tasting "different", "not right" or "funny". While change in food preferences due to taste alterations was common, specific choices varied. Many found changes started with treatment initiation or mid-way through treatment, and some found that symptoms persisted up to 9 months following treatment completion. Actions taken to address taste changes were sucking on candy, brushing teeth and modifying food choices.

Conclusions The experience of changes in taste was common yet highly variable in its presentation and resultant changes in food preferences. Taste changes did not always resolve soon after treatment completion. Future research should identify ways to manage this symptom in pediatric cancer patients.

Keywords Children · Cancer · Hematopoietic stem cell transplantation · Symptoms · SSPedi · Taste

Introduction

Most children with cancer survive [1], in part, related to the administration of intensive therapies. However, these treatments result in severe and bothersome symptoms for the majority of children [2]. In a prior study of 302 inpatients, nearly all (98.7%) reported having at least one symptom of any degree of bother (score ≥ 1 on a 0 to 4 scale) and 181 (59.9%) had at least one symptom scored as "a lot bothered" or "extremely bothered" (score of 3 or 4) at enrollment [3]. We found that changes in taste was the third most common symptom of any degree of bother (182/302, 60.3%) and also the third most common severely bothersome symptom (43/302, 14.2%) [2]. That study enrolled children without cancer undergoing hematopoietic stem cell transplantation (HSCT) because conditioning regimens include intensive chemotherapy expected to result in severe symptoms.

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Changes in taste can include dysgeusia (abnormal taste), hypogeusia (diminished taste) or ageusia (complete lack of taste sensation) [4]. In adult cancer patients, changes in taste has been associated with reduced food enjoyment [5]. In this population, studies have documented a high prevalence of distress and impact on daily life associated with taste changes [6]. A relationship between taste disorders and decreased caloric intake has been observed [7], resulting in weight loss [6] and vitamin deficiencies [8].

However, much less is known about how pediatric cancer patients experience changes in taste, nor is much known about the strategies they use to manage the symptom. This symptom is important in pediatric cancer not only because of its prevalence and degree of bother, but also because it may have other consequences. In one qualitative study of 22 children with cancer-receiving chemotherapy, altered taste was considered the main reason for eating difficulties [9]. Consequently, the objective was to describe how children receiving cancer treatments experience taste alterations, and the approaches they use to cope with the issue.

Materials and methods

This qualitative study consisted of a single semi-structured interview. The study was approved by the Research Ethics Board at The Hospital for Sick Children and all participants and their guardians provided informed consent or assent as appropriate.

Subjects

We included English-speaking children 4–18 years of age with cancer or hematopoietic stem cell transplantation (HSCT) recipients who were actively receiving cancer treatment or who had completed therapy within any time frame. We excluded those whose illness severity, cognitive disability or visual impairment precluded utilization of SSPedi or mini-SSPedi according to the primary healthcare team.

Procedures

Potential respondents were approached in the inpatient or outpatient setting. Sampling was consecutive and, given expected differences by age, we enrolled patients into the following age cohorts: 4–7, 8–10, 11–14 and 15–18 years. Demographic information was obtained from the respondent, respondent's guardian and from the patient's health record. Additional data collection was decided a priori based upon previous literature and included the following: receipt of cisplatin [10] or vincristine [11] in the 3 months prior to interview, head and neck radiation [12] and HSCT [13]. Based upon our previous study [14], we also asked about current mouth sores or mucositis and presence of nausea or vomiting in the previous 7 days (both recorded as none, mild, moderate or severe). For those who had completed treatment, we recorded time from the last treatment.

Interviews were conducted in person by trained research personnel. First, participants completed a paper version of Symptom Screening in Pediatrics Tool (SSPedi) (age 8–18) [3] or mini-SSPedi (age 4–7) [15]. Both measures include 15 symptoms and ask children to indicate how much each symptom bothered them. SSPedi has a recall period of yesterday or today and uses a 5-point Likert scale while mini-SSPedi has a recall period of today and a 3-point Likert scale to account for developmental differences between the age groups. SSPedi is reliable, valid and responsive to change [3]. Mini-SSPedi is understandable and easy to complete for children 4–7 years of age [15]. Then, using a semi-structured questionnaire (Online Resource 1), we asked each patient about their experience with altered taste sensation. We asked about its characteristics, impacts and identified coping strategies. In this study, coping was defined as strategies used by children to either reduce taste changes or to make them less bothersome. Parents and guardians were not specifically probed but if they provided comments, these were noted and included in the analysis. The interview was audio-recorded and transcribed.

Analysis

Qualitative interview data were analyzed using the constant comparative technique derived from grounded theory methods [16]. Data were coded into common categories based on similar content by two investigators working independently; in other words, all transcripts were double coded. Any new categories that emerged during the process were compared with previous categories. The investigators then translated codes into higher level categories by analyzing and grouping similar codes into broader conceptual categories, using the constant comparative method, eventually reducing these categories into a set of higher level themes [17]. Where coding was discrepant, a third team member was consulted. A total of 10 meetings were required before finalizing the code book. We planned to enroll 10 to 30 participants in each of the four age groups and enrolled patients in groups of five until saturation was achieved per age category, defined as no new themes identified in a round of five interviews [18].

Results

Figure 1 illustrates the flow diagram of patient identification and selection. In total, 73 children were assessed for eligibility, 14 did not meet eligibility and nine declined participation, thus leaving 50 who were interviewed when

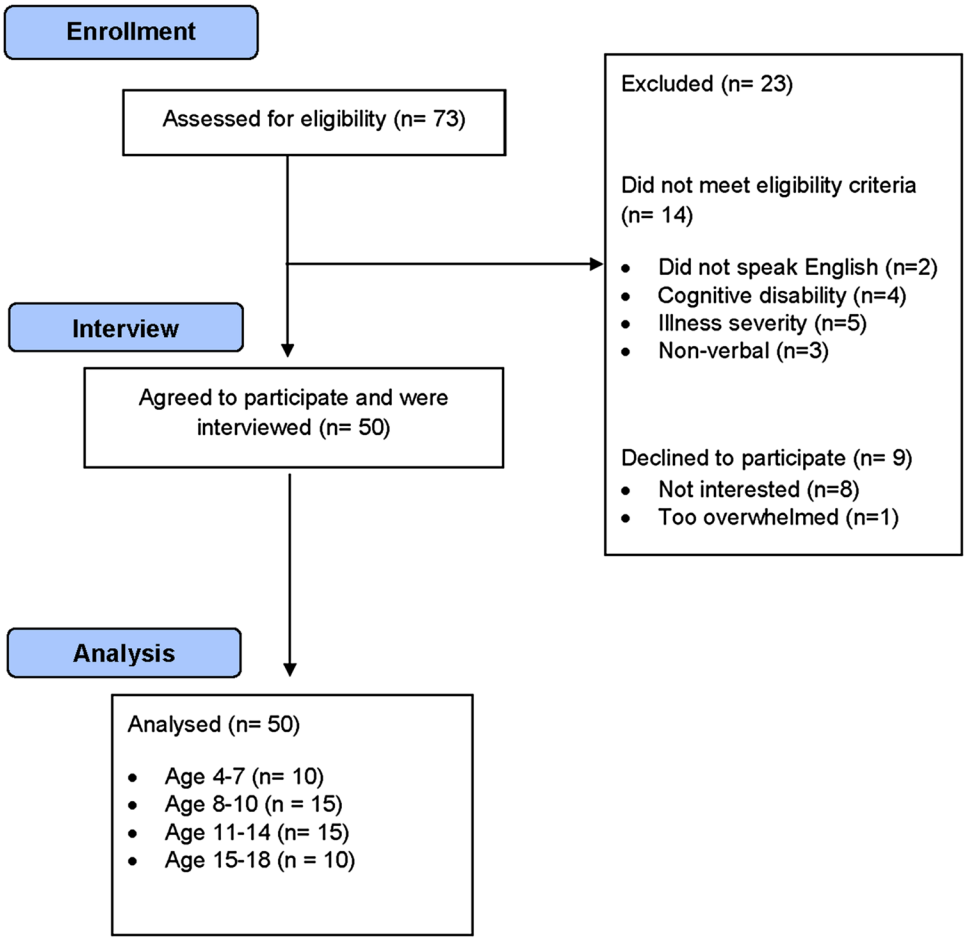

Fig. 1 Flow diagram of child identification and enrollment

saturation was reached in each age category. The number in each age group were: 4–7 years ($n=10$), 8–10 years ($n=15$), 11–14 years ($n=15$) and 15–18 years ($n=10$).

Table 1 describes the demographics of the 50 participants; 33 (66%) were male. Of the nine patients who had received radiation, seven received radiation therapy specifically to the head and neck region (not as part of total body irradiation). In terms of exposure to specific chemotherapy in the previous 3 months, three (6%) had received cisplatin and 26 (52%) had received vincristine. The SSPedi scores of the 40 participants 8–18 years of age indicated that 16 (40%) experienced changes in taste that were mildly to severely bothersome and, of these, seven (18%) described severely bothersome changes in taste on the day of the interview or the day before. Among the 10 children aged 4–7 years, two (20%) described bothersome changes in taste using mini-SSPedi on the day of the interview.

Table 2 describes the patients' experiences with changes in taste (Fig. 2). The number of times each theme was identified is indicated in the table. Heterogeneous experiences were described although the most common experience was that food tasted "different", "not right" or "funny". Some noted that food tasted blander but others noted that flavors were more extreme than before cancer treatment or HSCT. Food tasting metallic, bitter or sour were specifically noted. While change in food preferences due to taste alteration was common, alternative food choices varied.

Table 3 identifies cancer treatments and symptoms that patients associated with changes in taste. While medications in general were noted to be associated with changes in taste, dexamethasone specifically was noted to make food taste better.

Table 4 describes themes related to timing of changes in taste, which also were relatively heterogeneous with some describing fluctuations in the symptom while others described the symptom being more constant. One participant noted that changes in taste started before treatment began while many noted it started with treatment

Table 1 Demographics of the study Cohort ($N=50$)

Characteristic	*n* (%)
Patient characteristics	
Male	33 (66)
Age in years	
4–7	10 (20)
8–10	15 (30)
11–14	15 (30)
15–18	10 (20)
Diagnosis	
Leukemia	26 (52)
Lymphoma	6 (12)
Solid tumor	8 (16)
Brain tumor	3 (6)
Other	7 (14)
Metastatic disease	9 (18)
Relapse	8 (16)
In school	31 (62)
First language english	41 (82)
Cancer treatments	
Hematopoietic stem cell transplantation	16 (32)
Radiotherapy	9 (18)
Surgery	14 (28)
Receiving active treatment at interview	34 (68)
Cisplatin past 3 months	3 (6)
Vincristine past 3 months	26 (52)
Current status	
Reason for visit chemotherapy or transplant	29 (58)
Nausea or vomiting in the past 7 days	
None	29 (58)
Mild	11 (22)
Moderate	8 (16)
Severe	2 (4)
Mucositis in the past 7 days	
None	47 (94)
Mild	0 (0)
Moderate	2 (4)
Severe	1 (2)

initiation or during treatment. In terms of timing of resolution, of the 12 patients who had completed treatment who had experienced changes in taste at any point, three described that it resolved after treatment completion. The remaining nine patients off treatment continued to experience changes in taste at the time of the interviews, conducted as distally as 5 months following HSCT and 9 months following chemotherapy completion. A further three patients receiving active therapy for relapsed disease at the time of the interview noted symptom resolution upon initial completion of treatment. Five other patients reported that changes in taste resolved while receiving active treatment.

Approaches used to manage changes in taste are described in Table 5. Specific interventions included sucking on candy and brushing teeth. Other interventions focused on trying different food or specific food choices.

Discussion

In this qualitative study, we described the experience of changes in taste from the perspective of children receiving cancer treatments. Children experienced this symptom in a heterogeneous fashion although commonly described food as tasting "different", "not right" or "funny". While change in food preferences due to taste alterations was common, specific food choices varied. Many children found changes started with treatment initiation or mid-way through treatment and, for some, persisted up to 9 months following treatment completion. Actions taken by children to address taste changes included sucking on candy, brushing teeth and modifying food choices.

Much more is known about changes in taste in adults compared to children [5, 19]. Dysgeusia is highly prevalent in adults with cancer, with estimates ranging from 38 [20] to 66% [6]. In adults with head and neck cancer undergoing radiotherapy, changes in the ability to taste sweet, salty, sour and bitter were documented following radiotherapy with impairment mainly with tasting of salt and bitter [21]. In contrast to this report, children with cancer and HSCT recipients do not appear to experience just a diminishment of taste sensation but also reported heightened or exaggerated taste sensation.

Coping strategies described among adult patients included frequent oral hygiene, systematic testing of foods and acceptance of change [22]. While use of candy has been described as a coping strategy in adults [23, 24], its use was prominent in our study. Our study also suggested that changes in taste did not always resolve soon after completion of treatment. This finding is in contrast to those described in adult patients where abnormalities in taste typically resolve 3 months after completion of chemotherapy [25].

The mechanism of changes in taste is not clear. In a study that evaluated sweet, bitter or salt tastes among 11 children with acute leukemia undergoing transplantation compared to 20 healthy children, only minor changes in

Table 2 Experience of changes in taste

Theme	*n*	Example quotation
General		
Food tastes "different", "not right", or "funny"	15	"I still notice that it's different sometimes—especially with spices. You don't get like whatever it is, like vegetables with spice or something, I don't taste it as much now. They taste different to me."
		"It tastes like chocolate, but like weird chocolate. I can't really describe it."
		"But now he doesn't like milk anymore because it tastes funny." (P)
Food tastes bland	13	"I feel like my taste buds aren't extracting all the flavors kind of? It seems like bland or flavorless."
		"Hot chocolate is a good one, you don't taste as much chocolate as I used to. It's more like, watery. I just notice it tastes more like water."
Food tastes not as good or "bad"	7	"I wouldn't even eat them if someone paid me. Would you eat garbage if someone paid you?"
		"A bad taste and the worst thing you've ever ate."
		"I can't take it. It tasted horrible."
Extreme flavors	6	"And stuff like pepperoni, which she would eat before transplant, now is too spicy." (P)
		"French fries can usually taste, like even if there's a little bit of salt on them. I wasn't really eating French fries at all because they tasted way too salty."
		"Chocolate tastes different. Like they taste really chocolate-y."
Metallic	6	"Metal-y. If you have a handful of coins and you drop it you know that metal-y smell? That's what it kind of tasted like."
Bitter	3	"Like a bitter taste."
Sour	1	"Yeah, because I have the taste in my mouth and then the water combined with the taste, sometimes it tastes like a bit sour."
Changes in food preference		
Prefer less sweet	10	"My buds changed because sweet is not as tasty anymore."
Prefer more salty	8	"After transplant they told me that maybe I was gonna like, I would like more of salty foods. And it has been like that. I don't eat a lot of sweet foods."
Prefer home-cooked	6	"He used to love eating out all the time and now he doesn't. No outside food. He likes the home cooked meal, he prefers that." (P)
		"I know what changed. I hate all restaurant food now."
Prefer less spicy	6	"It was a burger with Sriracha sauce on it and I couldn't eat it and normally I'd be able to eat that."
		"I feel like I need to take it a little bit easier when eating the spicy foods."
Prefer less meat	4	"Probably just the meat. He used to eat a ton of breakfast sausages and different things and now it's kind of like…remember you used to love having stuffed sausage and egg and he's like nope, just the egg. Meat is definitely a big one." (P)
Prefer less salty	4	"I wasn't really eating French fries at all because they tasted way too salty."
Prefer more sweet	3	"I started to like sweet foods more than salty foods. Especially peaches."
Prefer more bland	3	"Well at the beginning in the induction chemotherapy, there was a time when he would really go for bland things like Jell-O and bland vegetables." (P)
		"We got the food from the hospital and most of those have a plain taste so he didn't complain." (P)
Prefer greasy foods	3	"Right now he craves greasy foods. Now he wants MacDonald's." (P)
Prefer more flavorful	2	"Like foods with a lot of flavor in it. So peaches are very sweet. And sausages, there's a lot of salt. There's a lot of flavor in that as well so I liked that kind of food."
Prefer vegetables	2	"Cucumbers. Sometimes I'm just like, I need the cukes."
		"Before we would tell him to eat salad now since his treatments started in December he actually asks for salad." (P)

n refers to the number of times a theme was identified, *(P)* refers to parent/guardian comments

taste thresholds were demonstrated [26]. The authors concluded that alterations in taste thresholds do not account for changes in taste reported by patients. However, a second study suggested more taste alterations compared to healthy controls with higher thresholds for bitter and more taste-recognition errors [9].

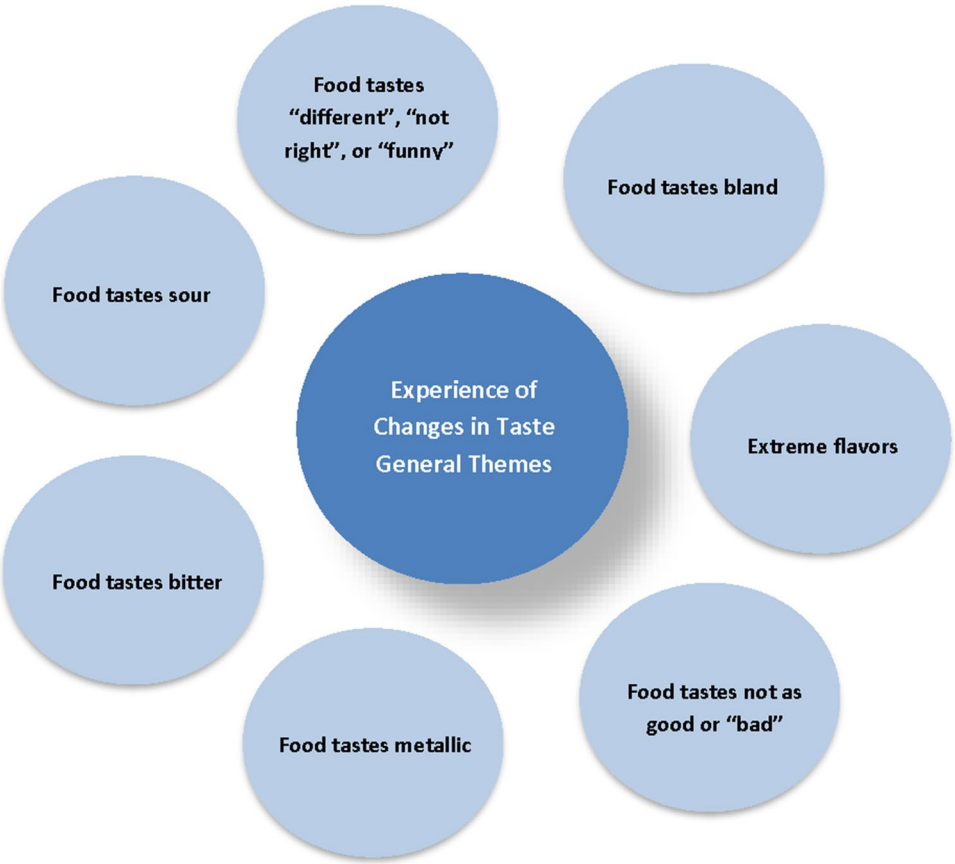

Fig. 2 General themes observed in changes in taste

Table 3 Associations with changes in taste

Theme	*n*	Example quotation
Treatment		
With medication	17	"Some of the medicines made my mouth taste different, which made the food taste different."
		"It tastes better with dex. When you're on the dex, when you're on the steroid everything tastes 1000× better."
With saline flush of central line	5	"Through the IV, when they flush saline you can taste it."
		"Salty was during the flush of his port, he felt the really salty taste."
Symptoms		
Nausea and vomiting	7	"If I felt nauseous it would taste different and then obviously I wouldn't want to eat."
		"Because [vomiting] just makes it taste even badder."
Thrush	2	"Thrush. Because of all the food that's collecting on my tongue, not the food but the thrush from not eating. That has a bad taste because it's a bunch of bacteria."

n refers to the number of times a theme was identified, *(P)* refers to parent/guardian comments

The strengths of our study are its focus on an understudied but important issue in pediatric cancer patients and its qualitative design, which allowed initial exploration of the issue. However, our findings must be interpreted in light of their limitations. These include conduct of the study at a single center and only among English-speaking participants, which reduce the generalizability of our results. It is possible that experiences with taste changes differs in other regions and among different non-English speaking cultures. Another limitation is that we did not specifically

Table 4 Timing of changes in taste

Theme	*n*	Example quotation
When started		
With start of treatment	16	"I think at the beginning of the treatment, stuff started to taste different."
Mid-way through treatment	11	"It tasted okay September even though I was on chemo. It tasted good to the end of September, it tasted good for about few days, but then I realized a big change."
During transplant	6	"The sensitivity came with the chemotherapy, but my taste going away came with the bone marrow transplant."
		"After transplant everything was spicy."
		"Once he had the transplant that's when all of his favorite foods were no longer favorite foods." (P)
Before diagnosis	1	"It was definitely around when I was just getting sick in general."
Changes over time		
Constant	7	While receiving treatment: "Even when I have a break from chemo, sometimes I have a month break the taste is still the same."
Differs with each chemotherapy cycle	7	"I remember like two or three cycles ago, I had pasta with something and it tasted just the same as it did before. But now probably if I'd had it today it would taste different."
		"I think it was like each treatment was different."
On and off	7	"Today, he doesn't even want hardboiled egg, before he liked hardboiled egg, even in the hospital he ate hardboiled egg, but this week? No, he doesn't want egg." (P)
		"Yeah, it goes on and off, but the first year was rough."
Resolution		
No resolution—constant	19 on treatment 9 off treatment	"It never really 100% goes back to the way it was."
Resolved with treatment completion	5	"It came back to what it was like before, but it came back slowly. That pretty much lasted the whole time I was in treatment."
		"They lasted until the end of treatment. He had chemo every week and it lasted right up until the end of treatment and once he started to get better then foods started to taste better." (P)
		"She had her transplant February and since probably mid-April she was able to taste better." (P)
Resolved within few months of onset but still on active treatment	5	"About a week or so. Actually no, I'd say about 2 or 3 weeks that it lasted, not that long."
		"Yea, but it was only for the first couple of months of treatment like now I'm pretty much fine."

HSCT hematopoietic stem cell transplantation, *n* refers to the number of times a theme was identified, *(P)* refers to parent/guardian comments

probe guardians for their input and they may have provided additional important information had this occurred. However, we did include their comments when spontaneously provided, which may also be another limitation since they may not have reflected the opinions of their child.

Future efforts should determine the association between specific changes in taste and specific treatments, the consequences of changes of taste and whether the experience differs in different populations. It will also be important to determine if implementation of systematic symptom screening and development of a clinical practice guideline for taste changes can reduce its impact and improve patient quality of life. Finally, this work could lead to the development of a scale to measure changes in taste, which would allow identification of patients at higher risk of taste changes. These studies would need to include a control group.

In conclusion, the experience of changes in taste is common yet is highly variable in its presentation and resultant changes in food preferences. Taste changes did not always resolve soon after treatment completion. Actions taken to address taste changes were sucking on candy, brushing teeth and modifying food choices. Future research should identify ways to manage this symptom in pediatric cancer patients.

Table 5 Approaches to management of changes in taste

Theme	*n*	Example quotation
Eat foods with stronger flavors	6	"And she was eating the hot Cheetos. Because everything else didn't have a taste."
		"Stronger flavored food helped."
Drink more	5	"I usually just keep on drinking my water."
Eat foods that are liked	5	"Just eat food I like really, that's why my mom always wants me to go to the grocery store she's like 'pick out what you want to eat'."
		"Even the favorite stuff, like we would go out of our way to okay, we know he likes this let's bring it."
Consulted with dietician	5	"I told my parents and the dietician."
Nothing tried	4	"It's kind of to be expected so just hang in there and wait."
Suck on candy	3	See he asks for a candy because he has this taste at the back of his mouth." (P)
		"Whenever you had to take your medicine you would take sour candies." (P)
Try different food	3	"So, I just try it. Don't like it, don't like it."
		"Just keep trying different stuff."
Eat bland food	2	"Bagels with cream cheese, it had to be… I feel here it was always very plain. It had to be."
Brush teeth	2	"Not brushing my teeth makes it worse."
		"[brush teeth] once or twice a day. At home twice a day and in the hospital once a day."

n refers to the number of times a theme was identified, *(P)* refers to parent/guardian comments

Author contributions LS conceptualized and designed the study, drafted the initial manuscript and reviewed and revised the manuscript. RL and EV designed the data collection instruments and coordinated data collection. RL collected data, RL and EP reviewed data, drafted the initial manuscript and reviewed and revised the manuscript. VT and SP collected data, reviewed data and reviewed and revised the manuscript. GG, TS, DT, EV, SZ and LD revised the initial data collection instruments and critically reviewed the manuscript for important intellectual content.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval This study obtained research ethics approval by The Hospital for Sick Children's Research Ethics Board (#100060182). All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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