



Taste changes in children with cancer and hematopoietic stem cell transplant recipients

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Abstract

Background Objectives were to describe bothersome self-reported changes in taste in pediatric oncology and hematopoietic stem cell (HSCT) patients and to identify patient and treatment-related factors associated with bothersome taste changes.

Methods We prospectively enrolled children and adolescents with cancer or pediatric HSCT recipients 8–18 years of age from three groups: inpatients receiving cancer treatments; outpatients in maintenance therapy for acute lymphoblastic leukemia (ALL); and outpatients in survivorship. Bothersome changes in taste was self-reported using the Symptom Screening in Pediatrics Tool (SSPedi); nausea was self-reported using the Pediatric Nausea Assessment Tool (PeNAT).

Results Among the 502 children included, 226 (45.0%) reported bothersome taste changes and 48 (9.6%) reported severely bothersome taste changes. In multiple regression, factors independently associated with severely bothersome taste changes were: inpatients receiving cancer treatments vs outpatients in survivorship (odds ratio (OR) 12.28, 95% confidence interval (CI) 2.50–222.27), ALL in maintenance vs outpatients in survivorship (OR 7.43, 95% CI 1.06–147.77), current nausea (OR 1.59, 95% CI 1.04–2.42), vomiting (OR 2.18, 95% CI 1.06–4.38), and first language not English (OR 2.09, 95% CI 0.97–4.28).

Conclusions We found that 45% of children with cancer and pediatric HSCT recipients reported bothersome changes in taste and these were severely bothersome in 9.6% of children. Inpatients receiving cancer treatment, those experiencing more nausea and vomiting and children whose first language was not English were at greater risk of severely bothersome changes in taste. Future work should evaluate systematic symptom screening in clinical practice and identify interventions focused on addressing bothersome taste changes.

Keywords Symptom screening · Children · Taste changes · Oncology · Hematopoietic stem cell transplantation

Background

Improvement in survival for children with cancer have been, in part, attributable to the provision of intensive therapies. However, as a result, most children suffer and experience severe and distressing treatment-related symptoms [1]. In order to address symptom control, we developed the Symptom Screening in Pediatrics Tool (SSPedi) [2–4], a 15-item symptom screening

tool for children receiving cancer treatments. Using SSPedi, pediatric patients rate the degree to which they are bothered by each item on a 5-point Likert scale ranging from 0 (not at all bothered) to 4 (extremely bothered) [3, 5, 6]. In a multi-center study that included 502 children and adolescents 8–18 years of age with cancer or hematopoietic stem cell transplantation (HSCT) recipients, SSPedi was reliable, valid, and responsive to change [7].

In the SSPedi validation study, among the 302 inpatients, 298 (98.7%) reported having at least one symptom of any degree of bother (\geq score of 1) and 181 (59.9%) had at least one symptom scored as “a lot” or “extremely bothered” (score of 3 or 4) [1]. The most common symptoms of any degree of bother were feeling tired ($n = 271$, 89.7%), feeling more or less hungry than usual ($n = 233$, 77.2%), and changes in taste ($n = 182$, 60.3%). The most common severely bothersome

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symptoms were feeling tired ($n = 99$, 32.8%), feeling more or less hungry than usual ($n = 75$, 24.8%), hurt or pain ($n = 43$, 14.2%), and changes in taste ($n = 43$, 14.2%) [1]. Thus, in this initial descriptive study of symptom burden in pediatric cancer and HSCT patients, we identified that changes in taste was a common bothersome symptom.

While disorders of taste are highly prevalent in adults with cancer with estimates ranging from 38% [8] to 66% [9], less is known about changes in taste in children with cancer. In fact, during SSPedi development, items were initially identified by healthcare providers and a patient advocate using a nominal group technique and taste changes was not initially included in the tool [5]. However, in a subsequent study, parents of pediatric cancer patients identified changes in taste as a missing item. The importance of this symptom was confirmed by children with cancer during cognitive interviewing and thus, the item, “changes in taste” was subsequently added to SSPedi [3].

The objectives were to describe bothersome self-reported changes in taste in pediatric oncology and HSCT patients and to identify patient and treatment-related factors associated with bothersome taste changes.

Methods

This report is a sub-analysis of a primary study designed to evaluate the reliability, validity, and responsiveness of SSPedi [7].

Subjects We enrolled English-speaking children and adolescents 8–18 years of age with cancer or pediatric HSCT recipients. In order to evaluate the psychometric properties of SSPedi, three groups of respondents were enrolled: (1) inpatients receiving active treatment for cancer or undergoing HSCT and expected to be in hospital or in clinic 3 days later; (2) outpatients with non-relapsed acute lymphoblastic leukemia (ALL) during a routine clinic visit following at least 6 months of maintenance chemotherapy and clinically well with no procedure planned that day; and (3) outpatients in survivorship during a routine clinic visit at least 3 months after completion of cancer treatment that did not include HSCT and clinically well. Exclusion criteria were illness severity, cognitive disability, or visual impairment that precluded completion of SSPedi according to the primary healthcare team and inability to understand English.

Procedures There were nine participating sites in Canada and the USA (Appendix 1). Research Ethics Board approval was obtained from all participating sites and children and their parents provided informed consent and assent as appropriate.

For consenting participants, demographic information were obtained from the respondent and from the patient’s

health record. Children self-reported SSPedi on an iPad. Changes in taste is one of the 15 SSPedi items. We categorized bothersome changes in taste as none (not at all bothered, SSPedi score of 0), moderate (a little or medium bothered, SSPedi score of 1 or 2), and severe (a lot or extremely bothered, SSPedi score of 3 or 4).

For the purpose of construct validation, we also administered the Pediatric Nausea Assessment Tool (PeNAT) after administering SSPedi. PeNAT is a reliable and valid measure of current nausea severity in children and adolescents aged 4 to 18 years of age [10]. It consists of a script which focuses the child on the construct of nausea and a series of four horizontal faces representing increasing nausea severity from “no nausea at all” to “nauseated a whole lot.” We also asked whether the child vomited yesterday or today and the number of vomits during this time period.

Statistics To compare baseline demographics between the “none,” “moderate,” and “severe” bothersome taste changes groups, we used the Chi square test for categorical variables. To determine factors associated with any bothersome changes in taste and severely bothersome changes in taste, we conducted univariate and multiple logistic regression analysis. Collinearity was evaluated using the Spearman correlation coefficient. Factors significant in univariate analysis were evaluated in multiple regression. Statistical significance was considered a P value < 0.05 . Analyses were conducted using the SAS statistical program (SAS-PC, version 9.4; SAS Institute Inc., Cary, North Carolina).

Results

Details of enrollment have previously been described [7]. In brief, between November 11, 2014 and June 5, 2017, 624 children were assessed for eligibility. Among these potential participants, 61 were not eligible and 61 declined participation, thus leaving 502 children who were enrolled in the study. There were 302 inpatients receiving active cancer treatments, 64 outpatients with ALL in maintenance, and 136 outpatients in survivorship. In terms of bothersome changes in taste, 48 (9.6%) described severely bothersome changes, 178 (35.5%) described moderately bothersome changes, and 276 (55.0%) described no bothersome changes in taste. Table 1 presents demographic information of study participants stratified by no bothersome, moderately bothersome, and severely bothersome changes in taste. It illustrates that those with ALL and those in school were less likely to experience bothersome changes in taste, while those with acute myeloid leukemia (AML), those admitted to hospital and receiving cancer treatment, those whose reason for the clinic visit was chemotherapy, and those with more nausea and vomiting were more likely to experience bothersome changes in taste.

Table 1 Demographics of the study cohort by degree of bothersome taste changes (none, moderate, and severe) ($N = 502$)

Characteristic	Extent of bothersome changes in taste			P value
	None (SSPedi score 0) $N = 276$ n (%)	Moderate (SSPedi score 1 or 2) $N = 178$ n (%)	Severe (SSPedi score 3 or 4) $N = 48$ n (%)	
Patient characteristics				
Gender				0.365
Male	167 (60.5%)	107 (60.1%)	34 (70.8%)	
Female	109 (39.5%)	71 (39.9%)	14 (29.2%)	
Median age in years				0.152
8–10.99	93 (33.7%)	48 (27.0%)	9 (18.8%)	
11–14.99	100 (36.2%)	78 (43.8%)	24 (50.0%)	
15–18.99	83 (30.1%)	52 (29.2%)	15 (31.3%)	
Diagnosis				0.256
Leukemia	165 (60.0%)	98 (55.1%)	24 (50.0%)	
Lymphoma	37 (13.4%)	22 (12.4%)	8 (16.7%)	
Solid tumor	62 (22.5%)	50 (28.1%)	10 (20.8%)	
Brain tumor	8 (2.9%)	5 (2.8%)	5 (10.4%)	
Other	4 (1.4%)	3 (1.7%)	1 (2.1%)	
Diagnosis ALL				0.003
Yes	146 (52.9%)	68 (38.2%)	17 (35.4%)	
No	130 (47.1%)	110 (61.8%)	31 (64.6%)	
Diagnosis AML				0.032
Yes	15 (5.4%)	21 (11.8%)	6 (12.5%)	
No	261 (94.6%)	157 (88.2%)	42 (87.5%)	
Metastatic disease				0.357
Yes	47 (17.0%)	40 (22.5%)	9 (18.8%)	
No	227 (82.2%)	137 (77.0%)	39 (81.3%)	
Relapse				0.301
Yes	26 (9.4%)	21 (11.8%)	8 (16.7%)	
No	250 (90.6%)	157 (88.2%)	40 (83.3%)	
Stem cell transplantation				0.107
Yes	12 (4.3%)	15 (8.4%)	5 (10.4%)	
No	264 (95.7%)	163 (91.6%)	43 (89.6%)	
In school				0.0005
Yes	246 (89.1%)	151 (84.8%)	33 (68.8%)	
No	28 (10.1%)	27 (15.2%)	15 (31.3%)	
First language				0.051
English	238 (86.2%)	152 (85.4%)	35 (72.9%)	
Non-English	37 (13.4%)	26 (14.6%)	13 (27.1%)	
SSPedi group				< 0.0001
Inpatient	120 (43.5%)	139 (78.1%)	43 (89.6%)	
Outpatient ALL in maintenance	38 (13.8%)	22 (12.4%)	4 (8.3%)	
Outpatient in survivorship	118 (42.8%)	17 (9.6%)	1 (2.1%)	
Reason for visit chemotherapy				< 0.0001
Yes	120 (43.5%)	128 (71.9%)	39 (81.3%)	
No	156 (56.5%)	50 (28.1%)	9 (18.8%)	
Nausea now by PeNAT				< 0.0001
No nausea at all	241 (87.3%)	116 (65.2%)	26 (54.2%)	
A little bit nauseated	32 (11.6%)	48 (27.0%)	14 (29.2%)	

Table 1 (continued)

Characteristic	Extent of bothersome changes in taste			P value
	None (SSPedi score 0) N = 276 n (%)	Moderate (SSPedi score 1 or 2) N = 178 n (%)	Severe (SSPedi score 3 or 4) N = 48 n (%)	
Even more nauseated	3 (1.1%)	11 (6.2%)	6 (12.5%)	< 0.0001
Nauseated a whole lot	0 (0%)	3 (1.7%)	2 (4.2%)	
Vomited yesterday or today				
Yes	20 (7.2%)	34 (19.1%)	18 (37.5%)	< 0.0001
No	256 (92.8%)	144 (80.9%)	30 (62.5%)	
Parent characteristics				
Parent gender				0.830
Male	64 (23.2%)	44 (24.7%)	10 (20.8%)	0.673
Female	181 (65.6%)	109 (61.2%)	29 (60.4%)	
Married				0.673
Yes	195 (70.7%)	119 (66.9%)	34 (70.8%)	0.351
No	81 (29.3%)	59 (33.1%)	14 (29.2%)	
Parent works full time				0.351
Yes	140 (50.7%)	79 (44.4%)	21 (43.8%)	0.351
No	136 (49.3%)	99 (55.6%)	27 (56.3%)	

ALL acute lymphoblastic leukemia, AML acute myeloid leukemia, SSPedi Symptom Screening in Pediatrics Tool, PeNAT Pediatric Nausea Assessment Tool

When patient age was examined as a continuous variable, it was not associated with any bothersome taste changes (OR 1.04, 95% CI 0.98 to 1.10; $P=0.180$) or severely bothersome taste changes (OR 1.04, 95% CI 0.94 to 1.15; $P=0.411$). Table 2 shows that the following variables were significantly associated with a greater risk of any bothersome taste changes in univariate analysis: diagnosis of AML, HSCT recipient, SSPedi group (inpatient and outpatient ALL in maintenance vs. outpatient in survivorship), reason for clinic visit was chemotherapy, PeNAT nausea score, vomited yesterday or today, and number of vomiting episodes. Those with a lower risk of any bothersome taste changes were diagnosed with ALL and those in school.

Tables 3 shows that the following variables were significantly associated with a greater risk of severely bothersome taste changes in univariate analysis: first language not English, SSPedi group, reason for clinic visit was chemotherapy, PeNAT nausea score, vomited yesterday or today, and number of vomiting episodes.

In terms of multiple regression, there was moderate correlation between SSPedi group (inpatient, outpatient ALL in maintenance and outpatient in survivorship) and ALL diagnosis (Spearman correlation 0.42, $P<0.0001$) and reason for visit chemotherapy (Spearman correlation 0.62, $P<0.0001$) and thus, only SSPedi group was included. There was also a strong correlation between vomiting yesterday or today and number of vomits (Spearman correlation 0.99, $P<0.0001$) and thus, only vomiting yesterday or today was retained. Variables independently associated with a greater risk of any bothersome changes

in taste were SSPedi group (inpatient vs outpatient in survivorship OR 7.25, 95% CI 4.14 to 13.28; $P<0.0001$ and outpatient ALL in maintenance vs outpatient in survivorship OR 4.34, 95% CI 2.14 to 8.97; $P<0.0001$); and PeNAT nausea score (OR 2.35, 95% CI 1.59 to 3.60; $P<0.0001$) (Table 2). Variables independently associated with a greater risk of severely bothersome changes in taste were SSPedi group (inpatient vs outpatient in survivorship OR 12.28, 95% CI 2.50 to 222.27; $P=0.015$ and ALL in maintenance vs outpatient in survivors OR 7.43, 95% CI 1.06 to 147.77; $P=0.077$), PeNAT nausea score (OR 1.59, 95% CI 1.04 to 2.42; $P=0.031$), vomited yesterday or today (OR 2.18, 95% CI 1.06 to 4.38; $P=0.030$), and first language not English (OR 2.09, 95% CI 0.97 to 4.28; $P=0.0499$) (Table 3).

Discussion

In this study of children with cancer and pediatric HSCT recipients, we found that 45% reported any bothersome changes in taste and 9.6% reported severely bothersome changes in taste. We also found that inpatients receiving active cancer treatment and those experiencing more nausea were at greater risk of both any bothersome changes in taste and severely bothersome changes in taste. These findings are important as little is known about this symptom in pediatric cancer and HSCT recipients.

Table 2 Factors associated with any bothersome taste changes

Characteristic	Univariate analysis			Multivariable analysis		
	Odds ratio	95% CI	<i>P</i> value			
Patient characteristics						
Male gender	1.08	0.76 to 1.56	0.667			
Median age in years			0.067			
8–10.99	REF					
11–14.99	1.66	1.09 to 2.57	0.020			
15–18.99	1.32	0.83 to 2.09	0.241			
Diagnosis			0.652			
Leukemia	0.76	0.50 to 1.17	0.215			
Lymphoma	0.84	0.46 to 1.52	0.562			
Solid tumor	REF					
Brain tumor	1.29	0.48 to 3.60	0.614			
Other	1.03	0.24 to 4.55	0.964			
Diagnosis ALL	0.54	0.37 to 0.77	0.0007			
Diagnosis AML	2.36	1.24 to 4.66	0.011	1.76	0.85 to 3.74	0.133
Metastatic disease	1.35	0.86 to 2.10	0.193			
Relapse	1.42	0.81 to 2.49	0.225			
Stem cell transplantation	2.14	1.03 to 4.60	0.044	0.90	0.41 to 2.05	0.800
In school	0.50	0.30 to 0.83	0.008	1.06	0.60 to 1.88	0.844
First language not English	1.34	0.82 to 2.19	0.239			
SSPedi group			<0.0001			<0.0001
Inpatient	9.94	5.89 to 17.67	<0.0001	7.25	4.14 to 13.28	<0.0001
Outpatient ALL in maintenance	4.49	2.24 to 9.19	<0.0001	4.34	2.14 to 8.97	<0.0001
Outpatient in survivorship	REF			REF		
Reason for visit chemotherapy	3.68	2.53 to 5.41	<0.0001			
Nausea per increment by PeNAT	3.30	2.29 to 4.93	<0.0001	2.35	1.59 to 3.60	<0.0001
Vomited yesterday or today	3.83	2.24 to 6.77	<0.0001	1.64	0.90 to 3.09	0.114
Number of vomits	1.82	1.38 to 2.53	0.0001			
Parent characteristics						
Parent gender male	1.11	0.72 to 1.69	0.639			
Married	0.87	0.60 to 1.28	0.476			
Parent works full time	0.77	0.54 to 1.10	0.149			

ALL acute lymphoblastic leukemia, AML acute myeloid leukemia, SSPedi Symptom Screening in Pediatrics Tool, CI confidence interval, PeNAT Pediatric Nausea Assessment Tool

ALL diagnosis, reason for visit chemotherapy, and number of vomits not included in multivariable analysis due to collinearity with other included variables

In adults with head and neck cancer, significant changes in the ability to taste sweet, salty, sour, and bitter were documented following radiotherapy with impairment mainly involving the tastes of salty and bitter [11]. In qualitative studies of adult chemotherapy recipients, changes in taste were common and were associated with reduced food enjoyment [12]. Some studies have documented a high prevalence of distress and impact on daily life associated with taste changes [9], and a relationship between taste disorders and weight loss has been demonstrated [8]. These studies highlight the potential importance of changes in taste from the patient's perspective.

We found that bothersome changes in taste were more common among inpatients actively receiving treatments for cancer or undergoing HSCT when compared to outpatients with ALL in maintenance or outpatients in survivorship. Our finding is consistent with a study demonstrating that abnormalities in taste resolved after completion of chemotherapy [13]. However, the degree to which changes in taste are bothersome to children on treatment is novel and suggests identifying effective interventions to minimize this symptom should be a priority to optimize quality of life.

Table 3 Factors associated with severely bothersome taste changes

Characteristic	Univariate analysis			Multivariable analysis		
	Odds ratio	95% CI	<i>P</i> value			
Child characteristics						
Male gender	1.60	0.85 to 3.15	0.159			
Median age in years			0.184			
8–10.99	REF					
11–14.99	2.11	0.98 to 4.93	0.066			
15–18.99	1.74	0.75 to 4.27	0.206			
Diagnosis			0.126			
Leukemia	1.02	0.49 to 2.30	0.956			
Lymphoma	1.52	0.55 to 4.05	0.404			
Solid tumor	REF					
Brain tumor	4.31	1.19 to 14.26	0.019			
Other	1.60	0.08 to 10.37	0.674			
Diagnosis ALL	0.62	0.33 to 1.13	0.124			
Diagnosis AML	1.66	0.60 to 3.91	0.281			
Metastatic disease	0.97	0.43 to 1.98	0.929			
Relapse	1.73	0.72 to 3.75	0.188			
Stem cell transplantation	1.84	0.60 to 4.66	0.235			
In school	0.31	0.16 to 0.61	0.0005	0.53	0.26 to 1.12	0.086
First language not English	2.30	1.12 to 4.49	0.018	2.09	0.97 to 4.28	0.0499
SSPedi group			0.003			0.042
Inpatient	22.41	4.81 to 399.22	0.002	12.28	2.50 to 222.27	0.015
Outpatient ALL in maintenance	9.0	1.30 to 177.94	0.052	7.43	1.06 to 147.77	0.077
Outpatient in survivorship	REF			REF		
Reason for visit chemotherapy	3.60	1.78 to 8.08	0.0008			
Nausea per increment by PeNAT	2.30	1.55 to 3.39	<0.0001	1.59	1.04 to 2.42	0.031
Vomited yesterday or today	4.44	2.29 to 8.46	<0.0001	2.18	1.06 to 4.38	0.030
Number of vomits	1.38	1.13 to 1.69	0.001			
Parent characteristics						
Parent gender male	0.93	0.42 to 1.90	0.841			
Married	1.08	0.57 to 2.14	0.811			
Parent works full time	0.84	0.45 to 1.52	0.554			

ALL acute lymphoblastic leukemia, AML acute myeloid leukemia, SSPedi Symptom Screening in Pediatrics Tool, CI confidence interval, PeNAT Pediatric Nausea Assessment Tool

Reason for visit chemotherapy and number of vomits not included in multivariable analysis due to collinearity with other included variables

We found significant associations between taste changes and both nausea and vomiting. Little is known about the relationship between these symptoms but we hypothesize several potential explanations. First, the link may be related to specific chemotherapy causing nausea, vomiting, and changes in taste. For example, cisplatin is a highly emetogenic agent that has also been linked to taste changes [14, 15]. To compound matters, bitter tastes can induce nausea [16]. Therefore chemotherapy such as cisplatin may cause taste changes, which may in turn contribute to nausea. Second, it is possible that the physical effect of vomiting can affect the perception of taste. For example, patients with bulimia with frequent vomiting experience altered ability to perceive

certain tastes [17]. Third, nutritional deficiencies in patients with severe nausea and vomiting could cause alterations in taste [18].

All patients participating in our study spoke English and many were multi-lingual. We found that those whose first language was not English had a higher risk of severely bothersome taste changes. This finding may be spurious or may be associated with genetic or cultural factors. Race and ethnicity have been reported to be strong determinants of taste preference, notably for sweet taste [19]. Unfortunately, we did not collect race, ethnicity, or genetic information for this study. It is important to note that we cannot comment on the prevalence, severity, or type of bothersome changes in taste in children who do not speak English.

A strength of this study is that we measured changes in taste and severity of nausea from the child's perspective using validated tools. Another strength is that we enrolled children from multiple sites which improves the generalizability of our finding. However, our results should be interpreted in light of its limitations. First, we did not randomly sample from all children with cancer or undergoing HSCT. Instead, we sampled from subgroups selected for relevancy for psychometric evaluation. Since we enriched the sample with those expected to have fewer bothersome symptoms, we may have underestimated the prevalence of bothersome taste changes in pediatric oncology and HSCT patients. Second, our study did not clarify what patients mean when they report bothersome taste changes and whether changes in smell may have contributed to, or may have been misinterpreted as changes in taste [20]. It is also possible that bothersome changes in taste were actually changes in taste preference. Since nausea can induce taste aversions in children undergoing cancer treatment [21], this may be an explanation behind our observed association between taste changes and nausea (and vomiting). Finally, we do not know how changes in taste may have influenced body weight, appetite or oral intake. Future qualitative and quantitative studies could clarify these issues.

In summary, we found that 45% of children with cancer and pediatric HSCT recipients reported bothersome changes in taste and these were severely bothersome in 9.6% of children. Inpatients receiving cancer treatment, those experiencing more nausea and vomiting and children whose first language was not English, were at greater risk of severely bothersome changes in taste. Future work should evaluate systematic symptom screening in clinical practice and identify interventions focused on addressing bothersome taste changes.

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Compliance with ethical standards

Informed consent Child participants and their parents provided informed consent or assent as appropriate.

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

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