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Original Research

Symptom documentation and intervention provision for symptom control in children receiving cancer treatments



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KEYWORDS

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Abstract **Background:** Objectives were to describe the proportion of bothersome symptoms self-reported using the Symptom Screening in Pediatrics Tool (SSPedi) documented in the medical records and associated with an intervention.

Methods: Eligible respondents were inpatients aged 8–18 years receiving cancer treatments and expected to be in hospital or clinic three days later. Children self-reported symptom bother using SSPedi. We evaluated symptom documentation and interventions in the medical records proximal to SSPedi administration.

Results: There were 168 children included. Symptoms rated as at least ‘a lot’ bother were documented in the medical record less than 60% of the time for 12 of 15 symptoms. Of these symptoms, the most infrequently documented symptoms were problems with thinking or remembering things (0%), changes in how your body or face look (4.8%), changes in taste (7.7%) and tingly or numb hands or feet (11.1%). Intervention provision for symptoms rated as ‘a lot’ bother occurred less than 60% of the time for 10 of 15 symptoms. Of these symptoms, the most infrequently treated were thinking or remembering things (0%), changes in how your body or face look (0%), tingly or numb hands or feet (0%), changes in taste (0%), diarrhoea (0%) and feeling tired (1.6%).

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Conclusions: Documentation of symptoms and intervention provision were generally infrequent. Symptoms that were almost never documented or treated included problems with cognition, body image, taste changes and peripheral neuropathy. Future efforts should incorporate symptom screening into routine care and facilitate symptom management by improving access to evidence-based clinical practice guidelines.

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1. Background

Children receiving cancer treatments experience a high burden of bothersome symptoms, which negatively impacts on quality of life [1–3]. Active symptom screening is important as children may not complain about symptoms and health-care professionals may fail to ask about them [4,5]. To facilitate symptom screening for children receiving cancer treatments, we developed an instrument called the Symptom Screening in Pediatrics Tool (SSPedi) [5–7]. SSPedi asks how bothersome 15 symptoms were yesterday or today and allows children to provide additional symptoms as free text [5–7]. SSPedi is reliable, valid and responsive to change in children and adolescents aged 8–18 years and is shown as [Appendix 1](#) [8].

Our early experience with SSPedi administration has shown that among inpatients receiving cancer treatments, 98.7% reported at least one bothersome symptom (at least ‘a little’) and 59.9% reported at least one severely bothersome symptom (‘a lot’ or ‘extremely bothered’) [9]. This finding suggests a sizeable gap between current symptom burden and optimal symptom management. Reasons for this gap may include lack of awareness of these symptoms by health-care professionals and failure to provide interventions for symptom control [10]. Evaluating the degree to which bothersome symptoms are acknowledged by health-care professionals and interventions provided could, thus, suggest where efforts are required.

Consequently, objectives were to describe the proportion of bothersome symptoms self-reported using SSPedi that were documented in the medical records and were associated with an intervention.

2. Methods

2.1. Patients

Patients included in this study were enrolled in a previous study of SSPedi validation at the Hospital for Sick Children (SickKids) [8]. Patients from that study included in this analysis were paediatric patients aged 8–18 years receiving active cancer treatment, admitted to hospital and expected to be in hospital or in clinic three days later. We excluded those with illness severity,

cognitive disability or visual impairment that precluded completion of SSPedi as per the primary health-care team and respondents who could not understand English. Child and adolescent participants in this cohort completed SSPedi at enrolment and a second time 3 ± 1 days after the first assessment. The purpose of the second assessment in the original study was to evaluate test–retest reliability and responsiveness. Parents were also included to evaluate interrater reliability and completed SSPedi once at enrolment; their participation was optional. No health-care professionals were involved in the previous study.

2.2. Procedures

Research ethics board approval was obtained from SickKids, and participants/guardians provided informed consent or assent as appropriate. We approached potential respondents in the inpatient setting. For consenting patients and parents, demographic information were obtained in person and from the patient’s medical records. Paediatric respondents were invited to complete SSPedi on an iPad by themselves. Parent respondents also rated their child’s symptoms using SSPedi on an iPad without discussion with the child.

To identify symptom documentation and administration of interventions for symptoms in the medical records, the study team created an initial list of terms considered sufficient for symptom documentation and appropriate as interventions. It is important to note that the list of interventions was not restricted to those shown to be effective in trials but, rather, included all interventions that could reasonably be administered for a given symptom. Both pharmacological and non-pharmacological interventions were included. Then, four abstractors independently evaluated five cases and identified missing symptoms and interventions from the list. The four abstractors also compared agreement and developed standard operating procedures for abstraction and adjudication. Adjudication of these items was conducted through in-person study committee meetings with two investigators (L.L.D. and L.S.) who made decisions by consensus. The same process was followed if potential new synonyms or interventions were identified upon subsequent chart review. Examples of synonyms and interventions can be found in [Appendix 2](#).

Upon establishing the standard operating procedure for abstracting symptom documentation and interventions for symptom control, the medical records of children included in the study were reviewed independently by two trained abstractors. All medical record documentation, including all health-care professionals' progress notes and consultations, medication administration records and nursing flow charts, were reviewed. An initial abstractor completed the first round of data abstraction. All the data elements were then confirmed by a second abstractor (S.H. or D.T.). To provide a conservative estimate of symptom documentation and interventions provided, we allowed a wider window for symptom documentation and intervention provision than only the date SSPedi was completed. We recorded documentation of symptoms if it occurred up to two calendar days before SSPedi administration (accounting for at least the SSPedi recall period of 'yesterday or today') and interventions if they occurred up to two days before or two calendar days after SSPedi administration (accounting for at least the SSPedi recall period and allowing for a delay between symptom identification and intervention provision).

2.3. Statistics

We described symptom documentation and interventions for symptom control for symptoms that were rated as at least 'medium' bother and for symptoms that were rated as at least 'a lot' bother. We described symptom documentation and interventions separately for child self-report and parent proxy-report SSPedi. To describe agreement between respondent report of at least 'medium' bother and medical records documentation, we removed respondents who rated that symptom as 'a little' bother. In other words, the analysis of agreement between respondent reports of at least 'medium' bother only included respondents who reported 'not at all bothered' and those who reported at least 'medium' bother. Similarly, for the analysis of agreement between respondents who rated a symptom as at least 'a lot' bother, respondents who rated that symptom as 'a little' or 'medium' bother were removed. Agreement was described using the kappa statistic and 95% confidence intervals (CIs), and agreement was defined as slight (0%–20%), fair (21%–40%), moderate (41%–60%), substantial (61%–80%) or almost perfect (81%–100%) [11].

If any agreed upon intervention was administered within the adjudication window, irrespective of reason for administration, we considered the intervention to have been given for that symptom. However, we also separately described if interventions were administered to address a given symptom as documented in the medical records. Analyses were conducted using the SAS statistical program (SAS-PC, version 9.4; SAS Institute Inc, Cary, North Carolina).

3. Results

Between 11th November 2014 and 5th June 2017, 259 children were recruited for the primary SSPedi validation study at SickKids. Of these participants, 168 were inpatients and consequently included in this analysis. Fig. 1 illustrates the flow diagram of patient identification and enrolment. Among the 168 enrolled children, 159 provided a second SSPedi assessment. Table 1 illustrates the demographic characteristics of the children. The median age of the 168 children was 13.1 (range 8.0–18.2) years. The median total SSPedi scores (interquartile range [IQR]) on days 1 and 4 by child self-report were 14 [8,23] and 9 [6,19], respectively.

Of the 168 enrolled inpatient children, 145 (86.3%) of their parents or guardians were eligible and agreed to provide proxy-report SSPedi scores. Of the 145 participating guardians, 49 (33.8%) were male and the median age was 44.6 (range 19.1–69.2) years. There were 110 (75.9%) guardian respondents who had at least college or university level education and 90 (62.1%) were working full time. The median total SSPedi scores (IQR) by parent proxy-report on day 1 was 16 [12,24].

Table 2 describes symptom documentation in the medical records for children who self-reported at least 'medium' bother and who self-reported at least 'a lot' bother for each of the 15 symptoms included in SSPedi. For 12 of the 15 symptoms measured, symptoms reported as at least 'a lot' bother were documented in the medical records less than 60% of the time. The most infrequently documented symptoms reported as at least 'a lot' bother were problems with thinking or remembering things (0%), changes in how your body or face look (4.8%), changes in taste (7.7%) and tingly or numb hands or feet (11.1%). Only two symptoms reported as at least 'a lot' bother were documented at least 80% of the time, namely hurt or pain (92.6%) and throwing up or feeling like you might throw up (92.6%). Agreement between symptom documentation and child self-report of symptoms reported as at least 'a lot' bother was generally poor except for throwing up or feeling like you might throw up (kappa = 0.63), mouth sores (kappa = 0.49), headache (kappa = 0.42) and scared or worried (kappa = 0.41). For 13 of the 15 symptoms measured, symptoms reported as at least 'medium' bother were documented in the medical records less than 60% of the time. Two symptoms reported as at least 'medium' bother were documented at least 80% of the time, namely hurt or pain (92.6%) and throwing up or feeling like you might throw up (87.5%).

The proportion of bothersome symptoms documented and agreement with medical records were similar when comparing child self-report and parent proxy-report of symptoms of at least 'medium' bother. When comparing child self-report and parent proxy-report of symptoms of at least 'a lot' bother, 61.1%

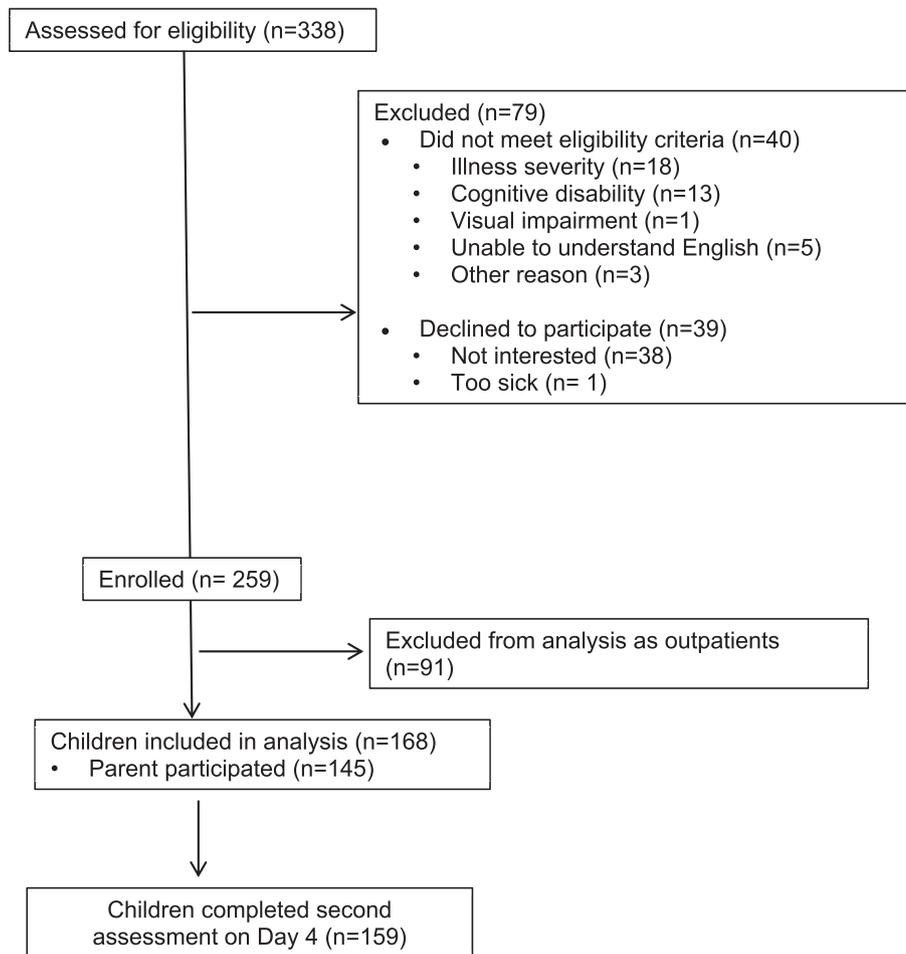


Fig. 1. Flow diagram of child and parent identification and enrolment.

children who reported at least ‘a lot’ bother by mouth sores had this symptom documented in the medical records in comparison to 84.6% parents ($P = 0.237$ by Fisher’s exact test). Kappa scores between mouth sores reported as at least ‘a lot’ bother and documentation in the medical records for children and parents were 0.49 and 0.69, respectively. A similar pattern was seen

with those who reported at least ‘a lot’ bother by headache.

Table 3 describes intervention provision for children who self-reported at least ‘medium’ bother and who self-reported at least ‘a lot’ bother for each of the 15 symptoms included in SSPedi. Intervention provision for symptoms reported as at least ‘a lot’ bother occurred less than 60% of the time for 10 of 15 symptoms. Almost none of the children and adolescents received an intervention for the following six symptoms that they had reported as at least ‘a lot’ bother: thinking or remembering things (0%), changes in how your body or face look (0%), tingly or numb hands or feet (0%), changes in taste (0%), diarrhoea (0%) and feeling tired (1.6%). Intervention provision was most common for hurt or pain (96.3%), headache (89.5%), throwing up or feeling like you might throw up (88.9%) and constipation (84.2%). When evaluating child self-report of symptoms reported as at least ‘medium’ bother, 10 of the 15 symptoms measured were also treated less than 60% of the time. Intervention provision was similar when comparing child self-reported and parent proxy-reported symptoms of at least ‘medium’ and ‘a lot’ bother except for mouth sores in which interventions

Table 1
Demographics of child participants.

Characteristic	Child self-report N=168
Male (%)	102 (60.7%)
Median age in years (range)	
8–10	46 (27.4%)
11–14	76 (45.2%)
15–18	46 (27.4%)
Diagnosis (%)	
Leukemia/lymphoma	74 (44.0%)
Solid tumour	48 (28.6%)
Brain tumour	8 (4.8%)
Other	7 (4.2%)
Metastatic disease (%)	29 (17.3%)
Relapse (%)	24 (14.3%)
Stem cell transplantation (%)	20 (11.9%)
In school (%)	139 (82.7%)
English as the first language	134 (79.8%)

Table 2
Agreement between symptom documentation and child and parent report of symptom bother.

Symptom	Child self-report at least 'medium' bother		Child self-report at least 'a lot' bother		Parent proxy-report at least 'medium' bother		Parent proxy-report at least 'a lot' bother	
	Documented	Kappa ^a (95% CI)	Documented	Kappa ^a (95% CI)	Documented	Kappa ^a (95% CI)	Documented	Kappa ^a (95% CI)
Disappointed or sad	10/39 (25.6%)	0.21 (0.04–0.38) N = 105	5/17 (29.4%)	0.26 (0.00–0.51) N = 83	15/61 (24.6%)	0.12 (0.01–0.23) N = 89	14/30 (46.7%)	0.39 (0.18–0.60) N = 58
Scared or worried	14/37 (37.8%)	0.32 (0.13–0.50) N = 110	8/16 (50.0%)	0.41 (0.17–0.66) N = 89	21/60 (35.0%)	0.25 (0.13–0.37) N = 92	13/27 (48.1%)	0.47 (0.26–0.67) N = 59
Cranky or angry	5/50 (10.0%)	0.08 (0.00–0.18) N = 118	3/25 (12.0%)	0.12 (0.00–0.30) N = 93	5/53 (9.4%)	0.09 (0.01–0.16) N = 99	2/21 (9.5%)	0.13 (0.00–0.29) N = 67
Problems with thinking or remembering	0/23 (0%)	0.00 (0.00–0.01) N = 122	0/8 (0%)	0.00 (0.00–0.01) N = 107	0/20 (0%)	0.00 (0.00–0.02) N = 110	0/4 (0%)	0.00 (0.00–0.01) N = 94
Changes in how your body or face look	2/47 (4.3%)	0.05 (0.00–0.13) N = 129	1/21 (4.8%)	0.07 (0.00–0.21) N = 103	1/41 (2.4%)	0.03 (0.00–0.08) N = 95	1/16 (6.3%)	0.09 (0.00–0.26) N = 70
Feeling tired	19/105 (18.1%)	0.03 (0.00–0.08) N = 120	14/64 (21.9%)	0.07 (0.00–0.15) N = 79	17/111 (15.3%)	0.00 (0.00–0.04) N = 117	11/60 (18.3%)	0.00 (0.00–0.07) N = 66
Mouth sores	20/34 (58.8%)	0.52 (0.35–0.69) N = 144	11/18 (61.1%)	0.49 (0.28–0.70) N = 128	16/22 (72.7%)	0.67 (0.49–0.84) N = 121	11/13 (84.6%)	0.69 (0.49–0.89) N = 112
Headache	25/50 (50.0%)	0.40 (0.24–0.56) N = 118	10/19 (52.6%)	0.42 (0.19–0.65) N = 87	18/30 (60.0%)	0.54 (0.36–0.73) N = 98	9/12 (75.0%)	0.60 (0.36–0.84) N = 80
Hurt or pain	50/54 (92.6%)	0.48 (0.33–0.62) N = 119	25/27 (92.6%)	0.39 (0.23–0.54) N = 92	52/55 (95.5%)	0.63 (0.48–0.77) N = 104	24/24 (100.0%)	0.58 (0.41–0.74) N = 73
Tingly or numb hand or feet	3/15 (20.0%)	0.31 (0.04–0.58) N = 131	1/9 (11.1%)	0.19 (0.00–0.51) N = 125	1/13 (7.7%)	0.07 (0.00–0.28) N = 125	0/4 (0%)	0.00 (0.00–0.00) N = 116
Throwing up or feeling like you might throw up	42/48 (87.5%)	0.65 (0.51–0.79) N = 115	25/27 (92.6%)	0.63 (0.48–0.79) N = 94	34/39 (87.2%)	0.50 (0.35–0.66) N = 107	16/18 (88.9%)	0.40 (0.23–0.58) N = 86
Feeling more or less hungry than you usually do	7/79 (8.9%)	0.02 (0.00–0.09) N = 115	6/45 (13.3%)	0.07 (0.00–0.18) N = 81	6/75 (8.0%)	0.04 (0.00–0.09) N = 113	3/41 (7.3%)	0.05 (0.00–0.14) N = 79
Changes in taste	3/55 (5.5%)	0.06 (0.00–0.12) N = 117	2/26 (7.7%)	0.11 (0.00–0.24) N = 88	2/47 (4.3%)	0.05 (0.00–0.11) N = 102	1/24 (4.2%)	0.06 (0.00–0.17) N = 79
Constipation	8/44 (18.2%)	0.08 (0.00–0.23) N = 139	4/19 (21.1%)	0.10 (0.00–0.31) N = 114	13/39 (33.3%)	0.32 (0.15–0.50) N = 114	11/21 (52.4%)	0.52 (0.31–0.74) N = 96
Diarrhoea	8/36 (22.2%)	0.28 (0.11–0.44) N = 133	6/21 (28.6%)	0.37 (0.14–0.60) N = 118	9/27 (33.3%)	0.42 (0.22–0.62) N = 122	4/10 (40.0%)	0.50 (0.19–0.82) N = 105

CI, confidence interval.

^a Removes respondents who reported 'a little' bother (for analysis of at least 'medium' bother) and those who reported 'a little' or 'medium' bother (for analysis of 'a lot' or 'extremely bothered').

Table 3
Agreement between interventions given and patient and parent report of symptom bother.

Symptom	Child self-report at least 'medium' bother		Child self-report at least 'a lot' bother		Parent proxy-report at least 'medium' bother		Parent proxy-report at least 'a lot' bother	
	Intervention given	Given for symptom ^a	Intervention given	Given for symptom ^a	Intervention given	Given for symptom ^a	Intervention given	Given for symptom ^a
Disappointed or sad	8/39 (20.5%)	4/8 (50.0%)	2/17 (11.8%)	1/2 (50.0%)	6/61 (9.8%)	1/6 (16.7%)	5/30 (16.7%)	1/5 (20.0%)
Scared or worried	21/37 (56.8%)	5/21 (23.8%)	9/16 (56.3%)	5/9 (55.6%)	25/60 (41.7%)	6/25 (24.0%)	14/27 (51.9%)	5/14 (35.7%)
Cranky or angry	9/50 (18.0%)	0/9 (0%)	5/25 (20.0%)	0/5 (0%)	9/53 (17.0%)	0/9 (0%)	3/21 (14.3%)	0/3 (0%)
Problems with thinking or remembering	0/23 (0%)	NA	0/8 (0%)	NA	0/20 (0%)	NA	0/4 (0%)	NA
Changes in how your body or face look	0/47 (0%)	NA	0/21 (0%)	NA	0/41 (0%)	NA	0/16 (0%)	NA
Feeling tired	1/105 (1.0%)	0/1 (0%)	1/64 (1.6%)	0/1 (0%)	1/111 (0.9%)	0/1 (0%)	1/60 (1.7%)	0/1 (0%)
Mouth sores	22/34 (64.7%)	16/22 (72.7%)	11/18 (61.1%)	8/11 (72.7%)	16/22 (72.7%)	13/16 (81.3%)	11/13 (84.6%)	11/11 (100.0%)
Headache	44/50 (88.0%)	21/44 (47.7%)	17/19 (89.5%)	10/17 (58.8%)	28/30 (93.3%)	16/28 (57.1%)	12/12 (100.0%)	8/12 (66.7%)
Hurt or pain	53/54 (98.1%)	49/53 (92.5%)	26/27 (96.3%)	23/26 (88.5%)	54/55 (98.2%)	49/54 (90.7%)	24/24 (100.0%)	24/24 (100.0%)
Tingly or numb hand or feet	1/15 (6.7%)	0/1 (0%)	0/9 (0%)	NA	0/13 (0%)	NA	0/4 (0%)	NA
Throwing up or feeling like you might throw up	44/48 (91.7%)	39/44 (88.6%)	24/27 (88.9%)	22/24 (91.7%)	37/39 (94.9%)	34/37 (91.9%)	17/18 (94.4%)	14/17 (82.4%)
Feeling more or less hungry than you usually do	3/79 (3.8%)	2/3 (66.7%)	2/45 (4.4%)	1/2 (50.0%)	5/75 (6.7%)	1/5 (20.0%)	1/41 (2.4%)	0/1 (0%)
Changes in taste	2/55 (3.6%)	0/2 (0%)	0/26 (0%)	NA	2/47 (4.3%)	0/2 (0%)	0/24 (0%)	NA
Constipation	33/44 (75.0%)	13/33 (39.4%)	16/19 (84.2%)	6/16 (37.5%)	31/39 (79.5%)	20/31 (64.5%)	19/21 (90.5%)	15/19 (78.9%)
Diarrhoea	1/36 (2.8%)	1/1 (100%)	0/21 (0%)	NA	0/27 (0%)	NA	0/10 (0%)	NA

NA, not applicable.

^a Among those provided an intervention, was the intervention provided for the reported symptom.

occurred 84.6% of the time when parents reported at least ‘a lot’ bother compared with 61.1% when children reported at least ‘a lot’ bother.

Table 3 also shows that even when interventions were provided, they were often not prescribed specifically for that symptom. In terms of evaluating the number of children who did not receive an intervention for a symptom self-reported as at least ‘a lot’ bothersome, the greatest numbers of untreated children were observed for feeling tired ($n = 63$), feeling more or less hungry ($n = 43$), changes in taste ($n = 26$), changes in how your body or face look ($n = 21$), diarrhoea ($n = 21$) and cranky or angry ($n = 20$).

Appendix 3 illustrates documentation of symptoms and intervention provision for self-reported symptoms during the second SSPedi assessment. Similar to the initial SSPedi assessment, 12 symptoms self-reported as at least ‘a lot’ bother were documented in the medical record less than 60% of the time and 10 symptoms self-reported as at least ‘a lot’ bother were associated with an intervention less than 60% of the time.

4. Discussion

We found that symptoms reported as moderately (at least ‘medium’) and severely (at least ‘a lot’) bothersome by paediatric patients receiving cancer treatments were, in general, poorly documented in the medical record. Most moderately and severely bothersome symptoms were not associated with an intervention, and even when interventions were provided, they often were not given specifically for that symptom. This pattern was observed in both the first SSPedi administration and the second SSPedi administration 3 ± 1 days later. Severely bothersome symptoms that were almost never documented or treated included problems with cognition, body image, changes in taste and peripheral neuropathy. The largest number of untreated children was observed for fatigue, changes in hunger, dysgeusia, changes in appearance and diarrhoea. Understanding both the proportion and the absolute number of untreated children is important to guide education, guideline development and policy change.

Although there are a paucity of studies that evaluate medical documentation and intervention provision against self-reported symptoms in children receiving cancer treatments, such data are available from studies of adult cancer patients [12–18]. Concordant with our results, these studies also found substantial disagreement between symptoms reported by patients and documentation by clinicians [12–19]. Furthermore, in studies where the same tool was used to measure symptom severity by patient self-report and clinician proxy-report, disagreement has also been demonstrated [17,19]. One study examined how often the documentation of a symptom in medical records was associated

with pharmacological intervention and found highest agreement for nausea, constipation and pain [14]. This finding is concordant with our study in which the symptoms most often associated with an intervention were pain, nausea and vomiting, and constipation.

Overall, we found that the highest rates of symptom documentation and intervention provision were for pain and hurt. A similar pattern was seen in a study of adult palliative cancer patients, where despite finding considerable discrepancy between self-reported symptoms and medical records documentation as a whole, pain was documented by physicians almost every time it was experienced by patients [15]. These findings may be related to local and international efforts to improve pain documentation and pain control [20–22] and suggest that, with targeted efforts, these aspects of care can be improved. However, despite high rates of documentation and intervention provision, 27/168 (16.1%) of the cohort still reported severely bothersome pain at the first SSPedi assessment. Thus, these findings suggest that improving pain control cannot be achieved solely by improving provider awareness or provision of any intervention but, rather, will likely require better preventative and treatment strategies.

We also found high rates of symptom documentation and intervention provision for nausea and vomiting. One of the important limitations of SSPedi is that it contains some items with two concepts, which is consistent with the screening nature of the tool. However, this aspect also means that we do not know if children with nausea without vomiting also had high rates of medical documentation and intervention provision. More specific symptom assessment tools such as the Paediatric Nausea Assessment Tool would be required to disentangle the two concepts [23].

A number of reasons may contribute to the low rates of symptom documentation and intervention provision for problems with thinking or remembering things, changes in how your body or face look, changes in taste and tingly or numb hands or feet. As primarily subjective experiences, these symptoms may be more difficult for a child to explain. In addition, there is not necessarily a visual indication when a child is experiencing these symptoms, reducing the possibility that healthcare professionals will be prompted to ask about them. We noted that documentation and intervention may be better when parents proxy-reported at least ‘a lot’ bother due to mouth sores compared with when children self-reported at least ‘a lot’ bother. As mouth sores may be observed by parents, it is possible that they are more vocal about their existence, leading to more documentation and intervention provision. However, we evaluated 15 symptoms, and this observation may also be a chance finding.

It is important to note that we developed our intervention list based upon what practitioners may prescribe for symptoms and not from evidence-based clinical

practice guidelines for symptom management. In other words, we have described a conservative estimate of intervention provision, and some interventions may have been ineffective or given with no intention of addressing the symptom of interest. However, one of the challenges we face is the absence of clinical practice guidelines for many symptoms. This deficiency has been identified and is being addressed by an international group of paediatric cancer supportive care guideline developers named the International Paediatric Oncology Guideline Network (iPOG) [24,25].

Even if a clinical practice guideline is available for symptom management, it is not easy for health-care professionals to be aware of them or to access them during their routine clinical workflow. To bridge this gap, we have created Supportive care Prioritization, Assessment and Recommendations for Kids (SPARK), a website devoted to enabling use of SSPedi and providing easy access to supportive care clinical practice guidelines for symptom prevention and management [26]. The guideline portal of SPARK will be freely available in the near future.

Strengths of this study are the rigorous and standardized approach to measuring symptom documentation and intervention provision for symptom control in a cohort of children who provided self-reported symptom scores using a validated tool, including the use of two data abstractors to improve data quality. However, this study is limited as it included children treated only at a single institution. A second limitation is that we allowed a wide range of interventions to be counted as intervention provision and considered symptom documentation and intervention provision to be adequate, if given within a large window. Thus, our estimates of documentation and intervention provision are almost certainly too high. Third, we know from our previous work that older children are more likely to have at least one severely bothersome symptom and to have higher total symptom scores compared with younger children [9]. We do not know, however, whether poor symptom documentation or lack of interventions to manage symptoms differ by age group. Fourth, we do not know how cultural differences in reporting symptoms due to stoicism or lack of understanding may affect symptom documentation and interventions for symptom management. These factors should be evaluated in future research. The final limitation is that some interventions such as consultant services may occur intermittently and a visit may have occurred outside our adjudication window.

In summary, documentation of symptoms and provision of interventions were generally infrequent. Severely bothersome symptoms that were almost never documented or treated included problems with cognition, body image, changes in taste and peripheral neuropathy. There is a substantial need for health-care professionals to actively seek information from patients

and parents regarding subjective symptoms, improve symptom documentation and increase intervention provision for symptom control to improve quality of life for paediatric oncology patients. Future efforts should incorporate symptom screening into routine care and facilitate symptom management by improving access to evidence-based clinical practice guidelines.

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Conflict of interest statement

None declared.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ejca.2019.01.002>.

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