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Symptoms Affecting Children With Malignancies During the Last Month of Life: A Nationwide Follow-up

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ABSTRACT

OBJECTIVE. In a population-based nationwide survey, we aimed to study symptoms in children with malignancies during the last month of their lives. Understanding which symptoms affect children in the terminal phase of disease is crucial to improve palliative care.

METHODS. We attempted to contact all parents in Sweden who had lost a child to cancer during a 6-year period. The parents were asked, through an anonymous postal questionnaire, about symptoms that affected the child's sense of well-being during the last month of life.

RESULTS. Information was supplied by 449 (80%) of 561 eligible parents. The symptoms most frequently reported with high or moderate impact on the child's well-being were: physical fatigue (86%), reduced mobility (76%), pain (73%), and decreased appetite (71%). Irrespective of the specific malignancy, physical fatigue was the most frequently reported symptom, and pain was among the 3 most frequently reported. Children who died at 9 to 15 years of age were reported to be moderately or severely affected, by a number of symptoms, significantly more often than other children. The gender of the reporting parent had no significant bearing on any of the symptoms reported.

CONCLUSIONS. The most frequently reported symptoms in children with malignancies to be aware of and possibly address during the terminal phase are physical fatigue, reduced mobility, pain, and decreased appetite. Children aged 9 to 15 years are reported to be moderately or severely affected by more symptoms than children in other age groups. Mothers and fathers report a similar prevalence of symptoms.

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Key Words
cancer, children, age, symptoms

Abbreviations
RR—relative risk
CI—confidence interval

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DESPITE ADVANCES IN cancer treatment, cancer is one of the leading causes of death in children,[1] and for children beyond cure, we must focus on making their final time as free from suffering as possible. Palliative care for children with malignancies has improved, for example, in meeting the special needs of the children and their families.[2] Nevertheless, it is possible that further improvements can be made, and research into pediatric palliative care may help to achieve this goal. In this study, we have investigated which symptoms affect terminally ill children with cancer with regard to age and type of malignancy. This information may be valuable for the improvement of future palliative care.

The most frequently recognized symptom in the terminally ill child has been pain, and many studies have identified pain and pain relief as one of the main concerns for the child and his or her family.[3–7] However, there are many other symptoms that contribute to the suffering of the child and for which we need to find better treatment.[8–13] We have analyzed the symptoms that moderately or severely affected the sense of well-being of children with malignancies during the last month of their lives as reported by the parents in a population-based, nationwide study. In addition, we studied differences in symptom prevalence with regard to the type of malignancy and the age of the child. This information may be of importance to further improve the palliative care of terminally ill children, to minimize the child's suffering, and to improve the final time for both the child and his or her family.

PATIENTS AND METHODS

We identified 368 children in Sweden, who had been diagnosed with a malignancy before the age of 17 (between 1970 and 1997) and who died as a result of this malignancy before the age of 25 (1992–1997). The children were identified through the Swedish National Cause of Death Register, which is linked to the Swedish Cancer Register. The children's parents, defined as the guardian of the child at the time of diagnosis, were identified in the Swedish Population Register by their social security number. To be eligible for the study the parents had to (1) be born in one of the Nordic countries, (2) have a nonconfidential telephone number, and (3) understand Swedish. Before contacting the parents, permission was required from the child's former physician. Permission was granted for all families.

A total of 561 bereaved parents met the criteria. Between August and October 2001, these mothers and fathers were sent an introductory letter explaining the objectives of the study and an invitation to participate. After obtaining informed consent from the parents by telephone, the questionnaires were sent out to the mothers and fathers separately. To safeguard parental anonymity, the parents were asked to return the uncoded questionnaire separately from a coded card that notified the investigators that the questionnaire had been returned. Ten days after the questionnaire was sent out, a thank-you-and-reminder card was mailed. The parents who did not return the notifying card were telephoned by an interviewer. The study was approved by the Ethical Committee at the Karolinska Institutet.

The questionnaire was developed on the basis of a literature review, 7 successive in-depth interviews with bereaved parents, and our clinical and epidemiologic experience in the field. A face-validity evaluation was performed including 15 separate bereaved parents to ensure that the questionnaire was correctly understood. In a pilot study addressing 22 bereaved parents, means for data collection were tested leading to modifications of the questionnaire. The questionnaire included 129 questions concerning both the child's medical and nursing care and the mental health of the parents before the child's disease, as well as 4 to 9 years after the death of the child. We have recently reported data on talking about death with children, anxiety and depression in bereaved parents, and the parents' perception of the questionnaire.[14–16]

In the present study, we analyzed 19 symptoms that may occur in children with a malignancy during the last month of their lives. The symptoms were: pain, poor appetite, weight loss, nausea, vomiting, difficulties in swallowing, physical fatigue, shortness of breath, paralysis, anxiety, depression, reduced mobility, impaired speech, sleepiness (daytime), disturbed sleep due to anxiety, disturbed sleep due to pain, troublesome swellings/edema, urinary problems, and constipation. The parents were asked to rate the symptoms on a 5-point scale depending on the effect of each symptom on the child's well-being: not applicable, none, low, moderate, or severe.

Data from the questionnaires were entered manually. The reliability of the coding was tested by recoding of randomly chosen questions. Analyses were conducted using the SPSS 10.0-11.5 (SPSS Inc, Chicago, IL) and SAS (SAS Institute, Inc, Cary, NC) programs. The symptoms studied were analyzed with regard to the reported effect on the child's sense of well-being. The results were also analyzed with regard to the diagnosis, age at the time of death, and the gender of the parents. These results are presented as relative risks (RRs) with an associated 95% confidence interval (CI). The parents of children with leukemia were used as a reference category when comparing diagnoses and the youngest group of children (0–4 years old) were chosen as a reference category for the analysis of symptoms with regard to the age of the children.

RESULTS

Subjects

The questionnaire was answered by 449 (80%) of the 561 eligible parents. Of the 449 participating parents, 191 (43%) were fathers and 251 (56%) were mothers, 7 (2%) parents did not state their gender; 438 (98%) were biological parents of the affected child (Table 1). Of the 449 responding parents, 413 answered both the questions on the prevalence of symptoms in the child and the type of malignancy. Similarly, 409 parents answered both the questions on the prevalence of symptoms and the age of the child at death. The majority of the parents had lost their child as a result of leukemia/lymphoma (149 of 449 [33%]), brain tumor (157 of 449 [35%]), or sarcoma/neuroblastoma (93 of 449 [21%]), and the rest were parents of children with less common cancer diagnoses (46 of 449 [10%]). Of the parents in this study, 132 of 449 (29%) had a child who died at age 0–4 years, 95 of 449 (21%) at 5–8 years, 103 of 449 (23%) at 9–15 years, and 106 of 449 (24%) had a child that was older than 16 years at the time of death.

TABLE 1 **Characteristics of the Parents Answering the Questionnaire and Their Children**

	n (%)
Parent	
Biological parent	438 (98)
Nonbiological parent	9 (2)
Not stated	2 (<1)
Gender	
Male	191 (43)
Female	251 (56)
Not stated	7 (2)
Parent's age at the time of child's diagnosis	
<30 y	66 (15)
30–39 y	232 (52)
40 y or older	146 (32)
Not stated	5 (1)
No. of children at the time of child's diagnosis	
1	82 (18)
2	192 (43)
3	116 (26)
≥4	54 (12)
Not stated	5 (1)
Age of child at diagnosis	
0–4 y	191 (42)
5–8 y	90 (20)
9–15 y	135 (30)
16–24 y	26 (6)
Not stated	7 (2)
Age of child at the time of death	
0–4 y	132 (29)
5–8 y	95 (21)
9–15 y	103 (23)
16–24 y	106 (24)
Not stated	13 (3)
Type of malignancy	
Leukemia/lymphoma	149 (33)
Leukemia	129
Lymphoma	20
Brain tumor	157 (35)
Sarcoma/neuroblastoma	93 (21)
Osteosarcoma	36
Soft tissue sarcoma	17
Neuroblastoma	40
Other malignancy	46 (10)
Not stated	4 (1)

Symptoms

The symptoms most frequently reported to have had high or moderate impact on the child's well-being were: physical fatigue (86%; mothers 85% and fathers 88%), reduced mobility (76%; mothers, 74%, and fathers, 78%), pain (73%; mothers, 73%, and fathers, 75%), and poor appetite (71%; mothers, 73%, and fathers, 69%) (Fig 1). These symptoms, as well as weight loss, vomiting, and sleepiness during the day, were all symptoms that more than half of the parents reported as having had a moderate or high impact on the child's well-being. We found no significant differences, calculating relative risks and 95% confidence interval, with regard to the gender of the parents in how any of the 19 symptoms studied were reported to have affected the children.

Diagnoses

Irrespective of the diagnosis of the child (leukemia/lymphoma, brain tumor, sarcoma/neuroblastoma, or other), physical fatigue was the symptom that most parents reported as having a high or moderate impact on the child's well-being during the last month of life. Similarly, independent of the diagnosis, pain was among the top 3 symptoms reported to have affected the child most frequently (Fig 2).

We found that parents of children with brain tumors reported that their children were significantly less troubled by pain (RR: 0.9; 95% CI: 0.7–1.0), poor appetite (RR: 0.7; 0.5–0.8), weight loss (RR: 0.7; 0.6–0.9), and edema (RR: 0.6; 0.5–0.8) than parents of children with leukemia/lymphoma (Table 2).

In contrast, difficulties in swallowing, paralysis, reduced mobility, impaired speech, and constipation were more often reported to affect the sense of well-being moderately or severely in children with brain tumors compared with children with leukemia/lymphoma. The highest relative risks for children with brain tumors were reported for paralysis (RR: 5.2; 95% CI: 3.1–8.5), impaired speech (RR: 3.0; 2.1–4.3), and constipation (RR: 1.8; 1.3–2.5). Parents of children with sarcoma/neuroblastoma reported that their children were more affected by paralysis (RR: 2.0; 1.0–3.7) and constipation (RR: 1.8; 1.2–2.6) than parents with children with leukemia/lymphoma (Table 2).

The Age of the Child

Significant differences were found in the reported level of suffering from the various symptoms in relation to the

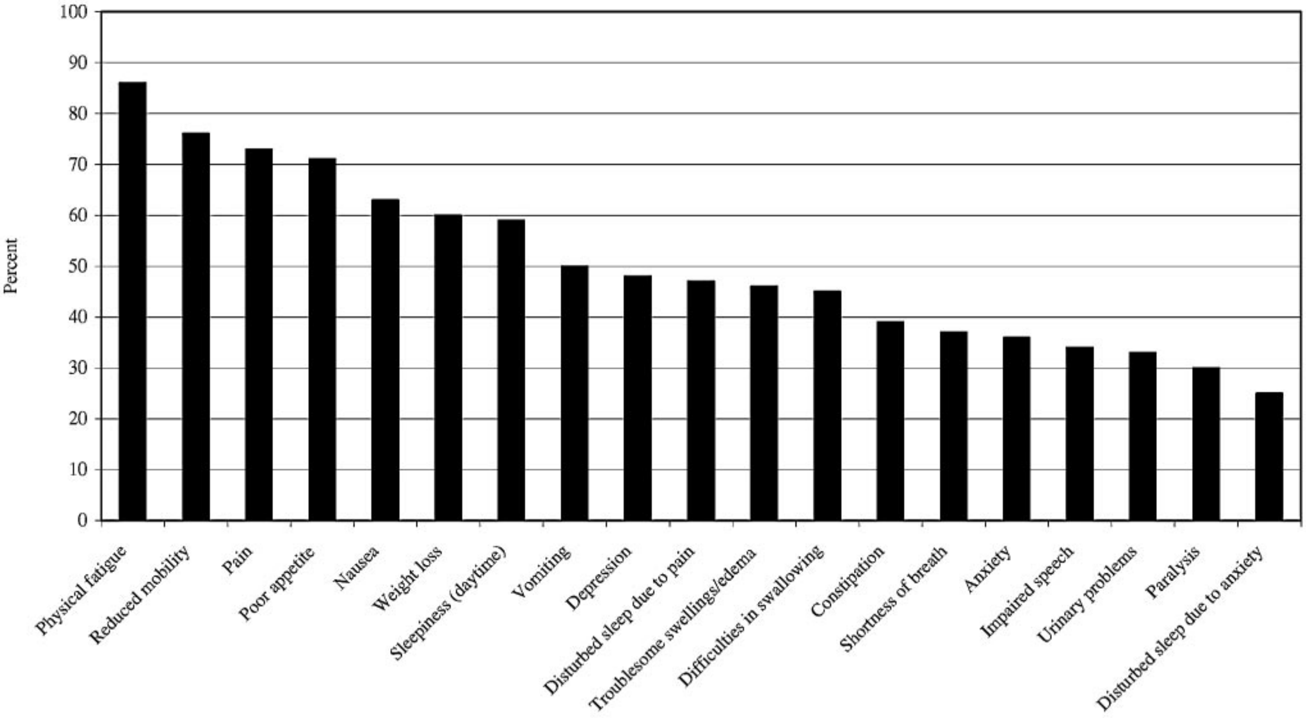

FIGURE 1
The frequency of 19 symptoms in children with cancer reported to have affected the children to a high or moderate degree during the last month of life. (No statistically significant differences were found with regard to the gender of the parents.)

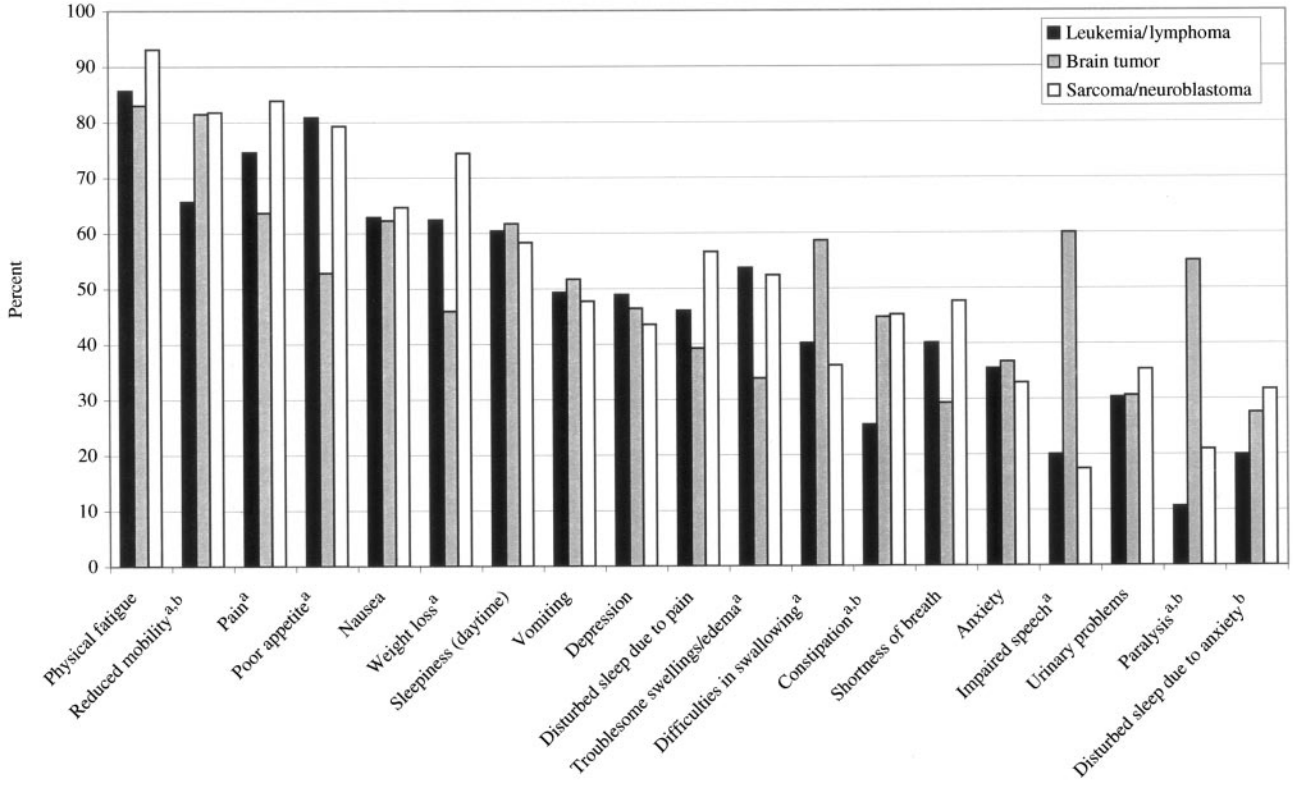

FIGURE 2
Overview of the frequency with which various symptoms moderately or severely affect the well-being of children with cancer during their last month of life with respect to various types of malignancies. [a] Statistically significant difference between children with leukemia/lymphoma and children with brain tumors; [b] statistically significant difference between children with leukemia/lymphoma and children with sarcoma/neuroblastoma.

TABLE 2 **RRs and CIs for Being Moderately or Severely Affected by a Specific Symptom During the Last Month of Life in Children With Various Solid Tumors as Compared With Children With Leukemia**

	Leukemia/Lymphoma, *n/N* (%)	Brain Tumor, *n/N* (%)	RR (95% CI)	Sarcoma/Neuroblastoma, *n/N* (%)	RR (95% CI)
Physical fatigue	120/140 (86)	122/147 (83)	1.0 (0.9–1.1)	81/87 (93)	1.1 (1.0–1.2)
Reduced mobility	94/143 (66)	119/146 (82)	1.2 (1.1–1.4)[a]	72/88 (82)	1.2 (1.1–1.5)[a]
Pain	106/142 (75)	93/146 (64)	0.9 (0.7–1.0)[a]	73/87 (84)	1.1 (1.0–1.3)
Poor appetite	114/141 (81)	76/144 (53)	0.7 (0.5–0.8)[a]	69/87 (79)	1.0 (0.9–1.1)
Nausea	90/143 (63)	91/146 (62)	1.0 (0.8–1.2)	55/85 (65)	1.0 (0.8–1.3)
Weight loss	88/141 (62)	67/146 (46)	0.7 (0.6–0.9)[a]	64/86 (74)	1.2 (1.0–1.4)
Sleepiness (daytime)	84/139 (60)	87/141 (62)	1.0 (0.8–1.2)	49/84 (58)	1.0 (0.8–1.2)
Vomiting	70/142 (49)	76/147 (52)	1.0 (0.8–1.3)	41/86 (48)	1.0 (0.7–1.3)
Depression	69/141 (49)	64/138 (46)	0.9 (0.7–1.2)	37/85 (44)	0.9 (0.7–1.2)
Disturbed sleep due to pain	63/137 (46)	56/143 (39)	0.9 (0.6–1.1)	47/83 (57)	1.2 (0.9–1.6)
Troublesome swellings/edema	73/136 (54)	48/142 (34)	0.6 (0.5–0.8)[a]	43/82 (52)	1.0 (0.8–1.3)
Difficulties in swallowing	57/142 (40)	85/145 (59)	1.5 (1.1–1.9)[a]	30/83 (36)	0.9 (0.6–1.3)
Constipation	36/142 (25)	65/145 (45)	1.8 (1.3–2.5)[a]	38/84 (45)	1.8 (1.2–2.6)[a]
Shortness of breath	57/142 (40)	41/140 (29)	0.7 (0.5–1.0)	40/84 (48)	1.2 (0.9–1.6)
Anxiety	49/138 (36)	51/139 (37)	1.0 (0.8–1.4)	28/85 (33)	0.9 (0.6–1.4)
Impaired speech	28/140 (20)	87/145 (60)	3.0 (2.1–4.3)[a]	15/86 (17)	0.9 (0.5–1.5)
Urinary problems	43/142 (30)	44/144 (31)	1.0 (0.7–1.4)	30/85 (35)	1.2 (0.8–1.7)
Paralysis	15/141 (11)	79/144 (55)	5.2 (3.1–8.5)[a]	18/86 (21)	2.0 (1.0–3.7)[a]
Disturbed sleep due to anxiety	27/136 (20)	38/138 (28)	1.4 (0.9–2.1)	26/82 (32)	1.6 (1.0–2.5)[a]

[a] Significance at 95% confidence interval.

age of their child at death. Children over 9 years were reported to be more troubled by anxiety than the younger children, with a risk ratio of 1.8 (1.2–2.6) for children 9–15 years and 2.0 (1.3–2.9) for children over 16 years at death (Table 3). Compared with parents of children dying before the age of 4, the parents that lost a child at the age of 9–15 expressed that their child's sense of well-being was affected moderately or severely by difficulties in swallowing, anxiety, depression, reduced mobility, impaired speech, disturbed sleep due to anxiety, troublesome swellings/edema, and urinary problems significantly more often (Fig 3; Table 3).

DISCUSSION

Our study shows that physical fatigue, reduced mobility, pain, and poor appetite are the symptoms that most frequently moderately or severely affect the child with a malignancy during the last month of life as reported by his or her parents (Fig 1). These findings were consistent irrespective of the type of malignancy and the age of the

TABLE 3 **RRs and CIs for Being Moderately or Severely Affected by a Specific Symptom During the Last Month of Life in Children Aged 5 to 8, 9 to 15, and >16 Years Compared With Children Aged ≤4 Years**

	0–4 y, *n/N* (%)	5–8 y, *n/N* (%)	RR (95% CI)	9–15 y, *n/N* (%)	RR (95% CI)	≥16 y, *n/N* (%)	RR (95% CI)
Physical fatigue	104/123 (85)	76/89 (85)	1.0 (0.9–1.1)	89/97 (92)	1.1 (1.0–1.2)	84/100 (84)	1.0 (0.9–1.1)
Reduced mobility	90/125 (72)	77/92 (84)	1.2 (1.0–1.3)[a]	83/98 (85)	1.2 (1.0–1.4)[a]	64/96 (67)	0.9 (0.8–1.1)
Pain	92/125 (74)	68/90 (76)	1.0 (0.9–1.2)	72/97 (74)	1.0 (0.9–1.2)	67/97 (69)	0.9 (0.8–1.1)
Poor appetite	96/126 (76)	57/89 (64)	0.8 (0.7–1.0)	70/94 (75)	1.0 (0.8–1.1)	68/98 (69)	0.9 (0.8–1.1)
Nausea	81/125 (65)	52/91 (57)	0.9 (0.7–1.1)	69/97 (71)	1.1 (0.9–1.3)	57/97 (59)	0.9 (0.7–1.1)
Weight loss	80/125 (64)	47/92 (51)	0.8 (0.6–1.0)	61/94 (65)	1.0 (0.8–1.2)	62/98 (63)	1.0 (0.8–1.2)
Sleepiness (daytime)	75/121 (62)	53/88 (60)	1.0 (0.8–1.2)	58/93 (62)	1.0 (0.8–1.2)	52/95 (55)	0.9 (0.7–1.1)
Vomiting	66/126 (52)	44/91 (48)	0.9 (0.7–1.2)	56/97 (58)	1.1 (0.9–1.4)	40/97 (41)	0.8 (0.6–1.1)
Depression	46/124 (37)	45/89 (51)	1.4 (1.0–1.9)[a]	55/95 (58)	1.6 (1.2–2.1)[a]	44/90 (49)	1.3 (1.0–1.8)
Disturbed sleep due to pain	63/123 (51)	34/89 (38)	0.7 (0.5–1.0)	47/94 (50)	1.0 (0.7–1.3)	45/95 (47)	0.9 (0.7–1.2)
Troublesome swellings/edema	49/119 (41)	41/90 (46)	1.1 (0.8–1.5)	57/95 (60)	1.5 (1.1–1.9)[a]	36/92 (39)	1.0 (0.7–1.3)
Difficulties in swallowing	51/123 (42)	36/91 (40)	1.0 (0.7–1.3)	52/94 (55)	1.3 (1.0–1.8)[a]	49/96 (51)	1.2 (0.9–1.6)
Constipation	41/123 (33)	45/92 (49)	1.5 (1.1–2.0)	43/97 (44)	1.3 (1.0–1.9)	29/94 (31)	0.9 (0.6–1.4)
Shortness of breath	46/124 (37)	33/89 (37)	1.0 (0.7–1.4)	38/95 (40)	1.1 (0.8–1.5)	35/94 (37)	1.0 (0.7–1.4)
Anxiety	29/122 (24)	29/87 (33)	1.4 (0.9–2.2)	40/95 (42)	1.8 (1.2–2.6)[a]	43/92 (47)	2.0 (1.3–2.9)[a]
Impaired speech	36/121 (30)	32/92 (35)	1.2 (0.8–1.7)	43/96 (45)	1.5 (1.1–2.1)[a]	24/96 (25)	0.8 (0.5–1.3)
Urinary problems	32/123 (26)	32/92 (35)	1.3 (0.9–2.0)	42/96 (44)	1.7 (1.2–2.4)[a]	29/95 (31)	1.2 (0.8–1.8)
Paralysis	32/123 (26)	32/92 (35)	1.3 (0.9–2.0)	35/92 (38)	1.5 (1.0–2.2)	21/97 (22)	0.8 (0.5–1.3)
Disturbed sleep due to anxiety	25/121 (21)	18/86 (21)	1.0 (0.6–1.7)	32/93 (34)	1.7 (1.1–2.6)[a]	25/91 (28)	1.3 (0.8–2.2)

[a] Significant at 95% confidence interval.

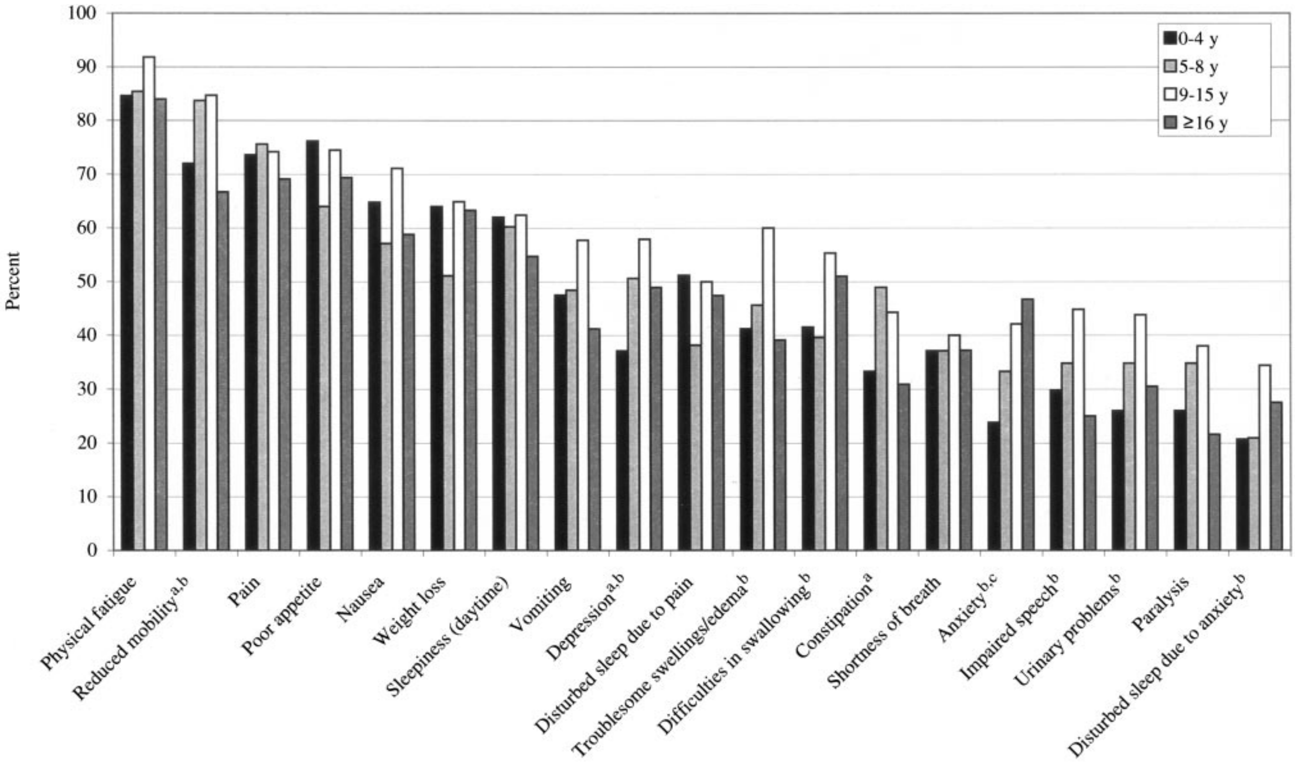

FIGURE 3
Overview of the frequency that various symptoms moderately or severely affect the well-being of children with cancer during their last month of life with respect to the age of the child. [a] Statistically significant difference between the age groups 0 to 4 and 5 to 8 years; [b] statistically significant difference between the age groups 0 to 4 and 9 to 15 years; [c] statistically significant difference between the age groups 0 to 4 and ≥16 years.

child (Figs 2 and 3). In addition, the parents also reported a variety of other symptoms that, despite our continuous improvements in palliative care for children, may severely affect the terminally ill child. Notably, we found no significant differences in how any of the 19 symptoms studied were reported with regard to the gender of the parents.

The parents of children dying between the ages 9 to 15 years reported a higher number of symptoms than other parents (Table 3). This could be the result of the fact that these children were older and thus mature enough to describe and distinguish between the different symptoms. These children were also still firmly connected to their parents and had not yet reached the age at which most children create a life that is separated from their parents.

As expected, there were differences in how the symptoms were rated depending on the diagnosis of the child (Table 2). Parents who had a child with a brain tumor more frequently reported a moderate or high effect on the child's well-being from difficulties in swallowing, paralysis, reduced mobility, impaired speech, and constipation than the parents of a child with leukemia/lymphoma. Our results indicate that we need to be observant of these symptoms because they represent significant suffering for children with brain tumors. Children with sarcoma/neuroblastoma suffered more frequently from paralysis and constipation than children with leukemia/lymphoma, and parents of children with leukemia/lymphoma reported that their children suffered more from pain, poor appetite, and troublesome swellings/edema than parents of children with brain tumors.

There are currently few studies on the frequency of various symptoms in terminally ill children and, to our knowledge, our study is the first that is nationwide and population based. Previous studies have shown that a majority of children having a malignancy suffer severely from at least 1 symptom during their last month of life.[8,10,13] Symptoms that are reported most commonly are pain,[8–10,13,17] fatigue,[8] lack of energy[13] or weakness,[9] poor appetite,[8,10,13] and weight loss.[9] One study found dyspnea, fatigue, and anxiety to be more common in children with leukemia/lymphoma than in children with brain tumors.[10] The symptom burden of dying children has also been reported to be reduced at an intensive care unit compared with a hospital ward.[13]

Our study confirms that physical fatigue, pain, and poor appetite are common symptoms in terminally ill children with malignancies; in addition, reduced mobility, nausea, weight loss, and sleepiness are also frequently reported. Differences in symptom prevalence between studies might be explained by differences in diagnosis as well as by differences in methods, ie, which symptoms were asked for, how the symptoms could be rated, and how the children were selected (our population-based study had a higher proportion of children with brain tumors than previous studies).

We report a nationwide study of symptoms in children with malignancies during their last month of life as reported by the parents 4 to 9 years after the death of their child. Our study has the strength of being population based and covering answers from both mothers and fathers with an answer rate of 80%. The 112 parents that were not reachable, declined to participate, or failed to return the questionnaire represent a limitation to our study. Recall bias is another limitation to be considered. In pediatrics, we are often dependent on answers provided by the parents and because losing one's child is one of the most stressful life events possible,[18,19] we assume that these parents are able to recall and rate specific symptoms in their children years after their loss. However, the long delay between the death of the child and reporting of symptoms must be considered. One way to limit problems with recall might be through a mechanism of patients self-reporting their symptoms.[20]

Our results show that there are many symptoms, eg, physical fatigue, decreased mobility, pain, and poor appetite, to be aware of during the palliative care of children with malignancies. Improved knowledge of the symptoms that affect children with malignancies in the palliative phase will help to improve the care to further minimize suffering toward the end of the child's life.

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