

Special Article

SYMPTOMS AND SUFFERING AT THE END OF LIFE IN CHILDREN WITH CANCER

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**ABSTRACT**

**Background** Cancer is the second leading cause of death in children, after accidents. Little is known, however, about the symptoms and suffering at the end of life in children with cancer.

**Methods** In 1997 and 1998, we interviewed the parents of children who had died of cancer between 1990 and 1997 and who were cared for at Children's Hospital in Boston, the Dana-Farber Cancer Institute, or both. Additional data were obtained by reviewing medical records.

**Results** Of 165 eligible parents, we interviewed 103 (62 percent), 98 by telephone and 5 in person. The interviews were conducted a mean ( $\pm$ SD) of  $3.1 \pm 1.6$  years after the death of the child. Almost 80 percent died of progressive disease, and the rest died of treatment-related complications. Forty-nine percent of the children died in the hospital; nearly half of these deaths occurred in the intensive care unit. According to the parents, 89 percent of the children suffered "a lot" or "a great deal" from at least one symptom in their last month of life, most commonly pain, fatigue, or dyspnea. Of the children who were treated for specific symptoms, treatment was successful in 27 percent of those with pain and 16 percent of those with dyspnea. On the basis of a review of the medical records, parents were significantly more likely than physicians to report that their child had fatigue, poor appetite, constipation, and diarrhea. Suffering from pain was more likely in children whose parents reported that the physician was not actively involved in providing end-of-life care (odds ratio, 2.6; 95 percent confidence interval, 1.0 to 6.7).

**Conclusions** Children who die of cancer receive aggressive treatment at the end of life. Many have substantial suffering in the last month of life, and attempts to control their symptoms are often unsuccessful. Greater attention must be paid to palliative care for children who are dying of cancer. (N Engl J Med 2000;342:326-33.)

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CANCER is the leading cause of nonaccidental death in childhood.<sup>1</sup> There has, however, been little evaluation of the overall experience at the end of life of children who are dying of cancer or of their symptoms other than pain.<sup>2,3</sup> A number of studies have demonstrated that among adults, the quality of care at the end of life is suboptimal.<sup>4-8</sup> For example, one study of elderly patients found that there was considerable suffering at the end of life, with up to 25 percent of patients experiencing moderate-to-severe pain in the last three days of life.<sup>7</sup> It is not known whether the experiences of dying children are similar.

The care of children at the end of life may be particularly complex. For most children with cancer, the primary goal of treatment is to achieve a cure.<sup>9</sup> Considerations of the toxicity of therapy, the quality of life, and growth and development are usually secondary to this goal. As a result, it may be difficult for physicians to change their focus even when there is little hope of a cure. Unfortunately, about 25 percent of children with cancer eventually die of their disease.

High-quality palliative care is now an expected standard at the end of life.<sup>10-14</sup> Yet it is not known whether the care of children with cancer meets this standard.<sup>15,16</sup> We interviewed the parents of children who had died of cancer and abstracted data from the children's charts to determine the patterns of care among children who die of cancer, the symptoms experienced in the last month of life and the effectiveness of their treatment, and the factors related to suffering from pain at the end of life.

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## METHODS

### Design of the Study

The study was conducted at Children's Hospital and the Dana-Farber Cancer Institute in Boston. We interviewed the parents of children who had died of cancer between 1990 and 1997. Parents were considered eligible if they were English-speaking, they lived in North America, their child had died of cancer more than one year before the study began, and their child's former physician permitted us to contact them (such permission was denied in the case of 15 families [8 percent]). Eligible parents were sent a letter containing a postage-paid postcard that they could return if they did not wish to participate. Of 165 eligible parents, 143 were located, 107 of whom agreed to participate. We interviewed one parent per family; the parent who participated was designated by the family. We completed 103 interviews between September 1997 and August 1998, for an overall rate of response of 62 percent (103 of 165 eligible parents). The interview lasted an average of 113 minutes and was conducted a mean ( $\pm$ SD) of  $3.1 \pm 1.6$  years after the death of the child.

The institutional review boards of Children's Hospital and the Dana-Farber Cancer Institute approved the study. All parents gave oral informed consent.

### Data Collection

The questionnaire was developed on the basis of a review of the literature and the opinions of focus groups of parents and medical care givers. Whenever possible, the questions were drawn from previously validated surveys.<sup>17</sup> However, the majority were formulated according to guidelines suggested by Streiner and Norman.<sup>18</sup> A test of the instrument conducted before the study assessed content, wording, burden on respondents, cognitive validity, and willingness to participate and found that the questionnaire was satisfactory.

A trained interviewer and one of the investigators conducted the interviews. The majority of interviews were conducted over the telephone; five were conducted in person at the request of the parent. Parents were asked whether their child had had the following symptoms during the last month of life: pain, poor appetite, nausea and vomiting, constipation, diarrhea, dyspnea, or fatigue. They were also asked to rate the degree to which the child appeared to suffer as a result of each symptom (on a five-point Likert scale), whether the child received treatment for the symptom, and if so, how successful the treatment was. Parents were asked to assess the child's level of anxiety and fear, the child's mood, and the degree to which he or she had fun in the last month of life, as a means of determining the quality of life. Additional data were collected on the parents' perception of the degree of involvement of the physician in care at the end of life, the quality of care provided by the primary medical team, the quality of communication, the involvement of home care staff (from a hospice or the visiting nurse association), decisions to issue or to refrain from issuing a do-not-resuscitate order, and the peacefulness of the child's death. The parents were also asked to provide their age, sex, race, level of education, annual household income, and religion.

The number of years of experience of each physician was determined by subtracting the date on which internship was begun from the patient's date of death. The physician's sex was also recorded.

Trained personnel abstracted data from the children's charts. Data from every 10th chart were also abstracted by one of the study investigators. When discrepancies were found, the chart was reviewed again by both abstractors, and the appropriate response was determined by consensus. The following data were collected: the child's sex; diagnosis; dates of birth, diagnosis, and death; number, types, and timing of cancer-directed treatment regimens and enrollment in clinical trials; symptoms in the last month of life; discussion of the use of hospice or home care to provide care at the end of life; cause of death (classified as progressive disease or a treatment-related complication); and place of death. For in-hospital deaths, information was abstracted on whether the patient was intubated in the last 24 hours of life, whether cardiopulmonary

resuscitation was performed at the time of death, and whether ventilatory or other types of support were withdrawn.

### Statistical Analysis

Analyses were conducted with the SAS statistical software package. In cases in which a question was left unanswered or data were not available from the child's chart, we excluded these elements from the analyses. Variables graded with the use of Likert scales were dichotomized as specified in the text and tables. We used a two-tailed Fisher's exact test<sup>19</sup> to compare dichotomized responses and Student's *t*-test<sup>19</sup> to examine continuous independent variables. We used the kappa statistic<sup>19</sup> to compare physicians' documentation of symptoms and parents' perceptions of symptoms. We used McNemar's test<sup>19</sup> to determine whether a symptom was more likely to be reported by the parents or to be noted in the child's chart.

We used logistic-regression analyses to assess factors associated with suffering from pain. We adjusted for the possibility that the parents of patients who had the same physician may have had similar responses ("physician clustering").<sup>20</sup> All models were fitted with use of the SAS Genmod procedure. Associations between clinical, sociodemographic, and attitudinal variables were examined in univariate analyses. Factors that were found to be associated ( $P < 0.10$ ) were entered into a multivariate logistic-regression model that was adjusted for the interval between the child's death and the parental interview, cause of death, age at death, and place of death as potential confounders.

## RESULTS

### Parents

The parents were on average  $43 \pm 7.7$  years old at the time of the interview. Most were white (91 percent) and female (86 percent). The range of reported median household income was \$25,000 to \$49,999 per year. Seventy-six percent of the parents had more than a high-school education, and 50 percent were Catholic.

### Children

The clinical characteristics of the children are summarized in Table 1. As compared with the children of parents who were interviewed, the children of nonrespondents did not differ significantly with respect to sex, diagnosis, age at death, duration of disease, enrollment in clinical trials, receipt of a bone marrow transplant, or place of death. The children of nonrespondents were more likely than the children of parents who participated to have had cardiopulmonary resuscitation (26 percent vs. 6 percent,  $P = 0.03$ ).

The death of one child was not classified because his records were not available for review. In the case of the other 102 children, 21 percent died of a treatment-related complication and 79 percent died of progressive disease. The children who died of a treatment-related complication were more likely to have had a hematologic cancer, to have received fewer cancer-directed regimens, and to have undergone bone marrow transplantation as the last cancer-directed regimen. Seventy-six percent of the children who died of a treatment-related complication underwent bone marrow transplantation as the last cancer-directed therapy. These children received an average of 2.5 different cancer-directed regimens, suggesting that they

**TABLE 1. CHARACTERISTICS OF 103 CHILDREN ACCORDING TO THE CAUSE OF DEATH.\***

CHARACTERISTIC	ALL CHILDREN (N=103)	CAUSE OF DEATH†		P VALUE‡
		PROGRESSIVE DISEASE (N=81)	TREATMENT- RELATED COMPLICATION (N=21)	
Female sex — no. of patients (%)	46 (45)	32 (40)	14 (67)	0.03
Age at diagnosis — yr	8.1±6.1	8.3±6.1	7.2±6.4	0.43
Duration of disease — yr	2.7±3.3	2.6±2.8	3.3±4.9	0.49
Age at death — yr	10.8±6.7	10.9±6.7	10.5±7.0	0.8
Type of cancer — no. of patients (%)				
Leukemia or lymphoma	50 (49)§	30 (37)	20 (95)	<0.001
Brain tumor	23 (22)	22 (27)	0	
Other solid tumors	30 (29)	29 (36)	1 (5)	
No. of cancer-directed regimens	3.7±2.1	4.0±2.2	2.5±1.4	<0.001
Enrollment in clinical studies — no. of patients (%)				
Any type of study	76 (74)	60 (75)	15 (71)	0.78
Phase 3 study	38 (37)	28 (35)	10 (48)	0.32
Phase 2 study	38 (37)	31 (38)	6 (29)	0.46
Phase 1 study	24 (23)	24 (30)	0	0.003
Bone marrow transplantation — no. of patients (%)				
One	37 (36)	23 (28)	13 (62)	<0.001
Two	5 (5)	2 (2)	3 (14)	
As last cancer-directed regimen	22 (21)	6 (7)	16 (76)	<0.001
Cancer-directed treatment in last month of life — no. of patients (%)¶	50 (56)	32 (48)	18 (86)	0.002
Use of complementary therapy — no. of patients (%)	25 (28)	22 (31)	3 (19)	0.54

\*Plus-minus values are means ±SD.

†The records of one child were not available for review, precluding classification of the cause of death.

‡Fisher's exact test was used for categorical variables, and a two-sample Student's t-test was used for continuous variables.

§Data were missing for one patient.

¶Data were available for a total of 89 children: 67 who died of progressive disease and 21 who died of treatment-related complications. The records of one child were not available for review.

||Data were available for a total of 88 children: 71 who died of progressive disease and 16 who died of treatment-related complications. The records of one child were not available for review.

had relapsed or refractory disease, and 95 percent had a hematologic cancer.

### Physicians

Of the 42 physicians who cared for the children, 31 percent were women. They had an average of 7.1 years of experience.

### Patterns of Care at the End of Life

A discussion of hospice care was documented in the charts of about two thirds of the children who died of progressive disease and had occurred an average of 58.1 days before death (Table 2). Sixty-six percent of the entire cohort had a do-not-resuscitate order documented in the chart, with the order established an average of 33.6 days before death in the case of children who died of progressive disease and 1.7 days before death in the case of those who died

of a treatment-related complication. Forty-nine percent of the children died in the hospital.

Among the children who died in the study hospital (Table 3), 45 percent died in the intensive care unit. Forty-one percent had support withdrawn; in most cases this involved the withdrawal of a ventilator. Cardiopulmonary resuscitation was attempted in only 7 percent of the children. The children who died of a treatment-related complication were more likely to have received ventilatory support in the last 24 hours of life and to have had cardiopulmonary resuscitation attempted than those who died of progressive disease.

### Symptoms and Suffering

The proportion of children who, according to their parents, had a specific symptom during the last month of life and the proportion who had "a great deal" or

**TABLE 2. PATTERNS OF CARE AT THE END OF LIFE ACCORDING TO THE CAUSE OF DEATH.\***

CHARACTERISTIC	ALL CHILDREN (N=103)	CAUSE OF DEATH†		P VALUE‡
		PROGRESSIVE DISEASE (N=81)	TREATMENT- RELATED COMPLICATION (N=21)	
Home care				
Parental report of home care — no. (%)§	66 (67)	65 (84)	1 (5)	<0.001
Discussion of hospice documented in chart — no. (%)	52 (51)†	52 (64)	0	
Time from discussion of hospice to death — days	58.1±76.0	58.1±76.0	0	
Do-not-resuscitate order				
Parental report of order — no. (%)¶	82 (82)	70 (88)	11 (58)	0.006
Order documented in chart — no. (%)	67 (66)†	57 (70)	9 (43)	
Time from documentation of order to death — days	29.5±54.5	33.6±57.8	1.7±3.2	<0.001
Death at home — no. (%)	50 (49)	48 (59)	1 (5)	<0.001

\*Plus-minus values are means ±SD.

†The records of one child were not available for review.

‡Fisher's exact test was used for categorical variables, and a two-sample Student's t-test was used for continuous variables.

§Data were available for a total of 98 children: 77 who died of progressive disease and 21 who died of treatment-related complications.

¶Data were available for a total of 100 children: 80 who died of progressive disease and 19 who died of treatment-related complications. The records of one child were not available for review.

**TABLE 3. PATTERNS OF CARE AMONG 44 CHILDREN WHO DIED IN THE STUDY HOSPITAL, ACCORDING TO THE CAUSE OF DEATH.\***

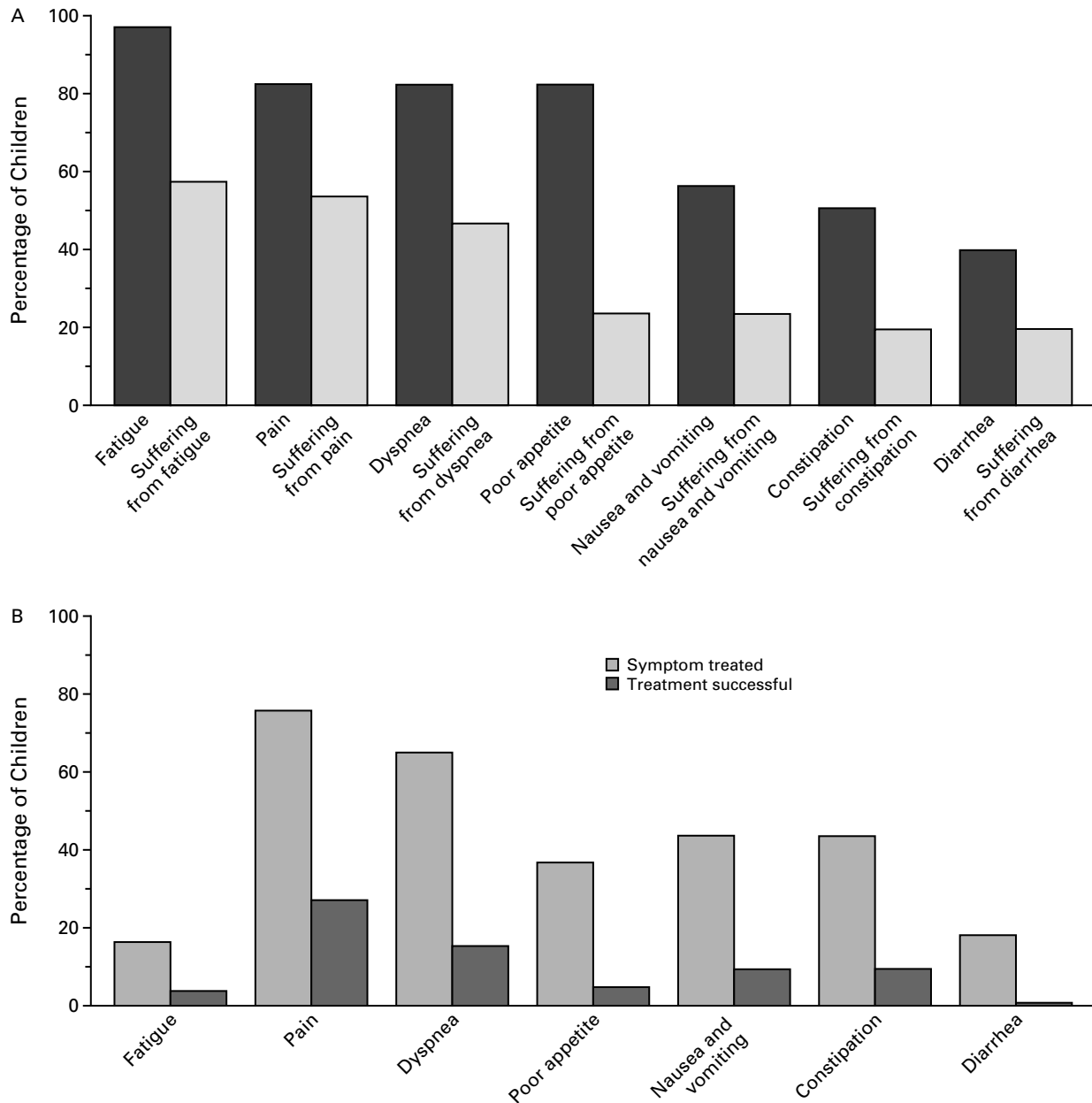
CHARACTERISTIC	ALL CHILDREN (N=44)	CAUSE OF DEATH†		P VALUE‡
		PROGRESSIVE DISEASE (N=26)	TREATMENT- RELATED COMPLICATION (N=17)	
number (percent)				
Location in hospital				
Intensive care unit	20 (45)	4 (15)	15 (88)	<0.001
Bone marrow transplantation unit	7 (16)	6 (23)	1 (6)	
Oncology ward or other	17 (39)	16 (62)	0	
Dependence on ventilator in last 24 hours of life	20 (45)	4 (15)	16 (94)	<0.001
Withdrawal of support				
Ventilatory support withdrawn	18 (41)	5 (19)	12 (71)	0.001
Other type of support withdrawn§	2 (4)	2 (8)	0	
Cardiopulmonary resuscitation attempted	3 (7)	0	3 (18)	0.04

\*Of the 53 children who did not die at home, 44 died in the study hospital, 6 died in other hospitals, and 3 died in other locations.

†The records of one child were not available for review, precluding classification of the cause of death.

‡Fisher's exact test was used.

§Antibiotics were withdrawn in the case of one patient, and biphasic positive airway pressure was withdrawn in the case of another.



**Figure 1.** The Degree of Suffering from and the Success of Treatment of Specific Symptoms in the Last Month of Life. Panel A shows the percentages of children who, according to parental report, had a specific symptom in the last month of life and who had “a great deal” or “a lot” of suffering as a result. Panel B shows the percentages of children who, according to parental report, were treated for a specific symptom in the last month of life, and in whom treatment was successful (rather than “somewhat successful” or “not successful”).

“a lot” of suffering as a result are shown in Figure 1A. Fatigue, pain, dyspnea, and poor appetite were the most commonly reported problems. The percentage of children who suffered from these symptoms ranged from 19 percent (in the case of constipation and diarrhea) to 57 percent (in the case of fatigue). Overall, 89 percent of the children experienced a lot

or a great deal of suffering from at least one symptom, and 51 percent from three or more symptoms. On average, the children who died of a treatment-related complication suffered from more symptoms than those who died of progressive disease (3.4 vs. 2.5,  $P=0.03$ ).

The percentage of children who were treated for

**TABLE 4.** DISCORDANCE BETWEEN THE REPORTS OF PARENTS AND PHYSICIANS REGARDING THE CHILDREN'S SYMPTOMS IN THE LAST MONTH OF LIFE.\*

SYMPTOM	REPORTED BY PARENT BUT NOT BY PHYSICIAN (N=92)	REPORTED BY PHYSICIAN BUT NOT BY PARENT (N=92)	KAPPA STATISTIC (95% CI)	P VALUE†
	number (percent)			
Fatigue	44 (48)	1 (1)	-0.02 (-0.07 to 0.02)	<0.001
Pain	15 (16)	11 (12)	0.10 (-0.12 to 0.32)	0.56
Dyspnea	19 (21)	10 (11)	0.10 (-0.11 to 0.31)	0.14
Poor appetite	33 (36)	1 (1)	0.29 (0.15 to 0.43)	<0.001
Constipation	31 (34)	7 (8)	0.16 (-0.02 to 0.33)	<0.001
Nausea and vomiting	25 (27)	18 (20)	0.06 (-0.14 to 0.26)	0.36
Diarrhea	20 (22)	8 (9)	0.31 (0.12 to 0.51)	0.04

\*Data were missing for 10 children for whom there was no documentation of clinic or hospital visits in the last month of life and for 1 child whose records were not available for review. CI denotes confidence interval.

†McNemar's test was used.

each symptom, according to their parents, and the success of treatment are shown in Figure 1B. Among the children with symptoms, the most commonly treated symptoms were pain (in 76 percent) and dyspnea (in 65 percent); however, treatment of these symptoms was successful in less than 30 percent of children (27 percent and 16 percent, respectively). Treatment of pain and dyspnea was more likely to be successful in patients who died of progressive disease than in those who died of a treatment-related complication ( $P=0.04$  and  $P=0.05$ , respectively).

As would be expected, during the last month of life the majority of children had little or no fun (53 percent), were more than a little sad (61 percent), and were not calm and peaceful most of the time (63 percent), according to their parents. Twenty-one percent were described as often being afraid. The children who died of a treatment-related complication had a poorer quality of life than those who died of progressive disease, in terms of the degree of fun ( $P=0.03$ ), level of sadness ( $P=0.03$ ), and mood ( $P=0.002$ ). The interval between the discussion of hospice care, as documented in the chart, and death was longer for children who were described by their parents as being calm and peaceful most of the time during the last month of life ( $P=0.01$ ). Overall, 70 percent of the parents described their child's death as very peaceful, regardless of the cause.

#### Parental Assessment of the Quality of Care

Most parents were satisfied with the overall quality of care provided by the oncologist, with 81 percent rating it as very good or excellent. The quality of care provided by the primary nurse and psychosocial clinician was rated as very good or excellent by 90 percent and 77 percent of the parents, respec-

tively. These ratings did not differ significantly according to the cause of death. The quality of care provided by home care nurses was rated as very good or excellent by 71 percent of the parents.

#### Factors Associated with Pain-Related Suffering

In univariate analyses, factors reported by the parents that were associated with a child's suffering from pain were lack of active involvement by the oncologist in care at the end of life and the perception of receiving conflicting information from care givers. Lack of involvement of the oncologist was also associated with significantly more suffering from pain in a multivariate logistic-regression model, after adjustment for physician clustering, the interval between the child's death and the parental interview, the cause of death, the child's age at death, and the place of death (odds ratio, 2.6; 95 percent confidence interval, 1.0 to 6.7).

#### Discordance between Parental Reports and Documentation of Symptoms by Physicians

There was considerable discordance between the parents' reports of their child's symptoms and the documentation of symptoms by physicians (Table 4). Parents were significantly more likely than physicians to report that their child had fatigue ( $P<0.001$ ), poor appetite ( $P<0.001$ ), constipation ( $P<0.001$ ), and diarrhea ( $P=0.04$ ).

## DISCUSSION

We sought to evaluate the care and suffering at the end of life of children who died of cancer. We found that these children received aggressive care. Nearly half the children died in the hospital, and almost half these deaths occurred in the intensive care unit. Al-

most half the children who died in the hospital received ventilatory support in the last 24 hours of life. Other investigators have reported a similarly high proportion of inpatient deaths among children with cystic fibrosis.<sup>21</sup> In comparison, only 25 percent of adults in one study were hospitalized at the time of death.<sup>22</sup> In that study, older age was associated with higher rates of decisions to withhold aggressive care.<sup>23</sup> Our findings suggest that at the other end of the age spectrum, children may receive particularly aggressive care at the end of life.

We found that children who died of cancer experienced substantial suffering in the last month of life. According to parental reports, 89 percent of the children experienced substantial suffering from at least one symptom, most commonly fatigue, pain, or dyspnea. We also found that treatment was seldom successful, even in the case of symptoms that are typically considered to be amenable to treatment. Fewer than 30 percent of parents reported that the treatment of pain was successful, and only 10 percent reported that nausea and vomiting or constipation was controlled.

Fatigue was the most frequently reported symptom, and most of the children with fatigue suffered a great deal from it, according to their parents. Furthermore, there was little attempt on the part of clinicians to treat this problem. These results are consistent with those of previous studies of adults at the end of life.<sup>7</sup> The causes of fatigue in children with cancer are multifactorial and include the natural progression of the disease, poor nutritional status, depression, and anemia. Although there may be no effective therapy for some of these factors, there is growing evidence that the treatment of some of the causes of fatigue can relieve suffering.<sup>24-26</sup> Our data suggest that there may be a lack of awareness among physicians that the suffering caused by certain symptoms typically experienced at the end of life may be amenable to palliation.

Our results suggest several modifiable factors that may be contributing to suffering among children at the end of life. We found significant discordance between the reports of parents and physicians regarding the children's symptoms. Thus, suffering may result in part from a lack of recognition of the problem by the medical team. This hypothesis is supported by the finding that parents who reported that the physician was not actively involved in care at the end of life were more likely to report that their child suffered a great deal from pain. We also found that earlier discussion of hospice care was associated with a greater likelihood that parents would describe their child as calm and peaceful during the last month of life. Both observations are consistent with the hypothesis that active involvement by care givers committed to palliation can help alleviate the suffering of dying children.

We found that most of the children who died of a treatment-related complication had refractory or re-

lapsed hematologic cancer, a condition associated with a low likelihood of long-term survival.<sup>27,28</sup> Bone marrow transplantation was the last cancer-directed therapy in the majority of these children. Almost all the children who died in the hospital of treatment-related complications died in the intensive care unit, after ventilatory support was withdrawn. These children had more symptoms, less successful control of pain and dyspnea, and a poorer quality of life than those who died of progressive disease. Therefore, when aggressive cancer-directed therapy is undertaken in children whose likelihood of long-term survival is low, concurrent attention to palliation may be appropriate.

Our study has a number of limitations. Our findings are based primarily on parents' perceptions, which were obtained an average of 3.1 years after the death of their child. Parents' perceptions may not accurately reflect the actual experience of their child. It is also possible that their perceptions changed over time. However, our reliance on parental reports does not differ from the norm in pediatrics. Furthermore, the interval between the child's death and the parental interview was not associated with the parental report of the degree of the child's suffering from pain.

Selection bias may also have influenced our findings. Physicians denied us permission to contact 8 percent of families, and 22 percent of parents declined to participate. It is reassuring that the only significant difference between the children of parents who responded and the children of those who did not respond was the proportion who underwent cardiopulmonary resuscitation.

Finally, we studied the patterns of care at a single institution. However, the care of children with cancer is often regionalized in the United States because of the need for personnel trained in subspecialties.<sup>29</sup> Thus, our findings may reflect the experiences of many children with cancer.

Our results suggest that greater attention to symptom control and the overall well-being of children with advanced disease might ease their suffering. Recognition of this problem by the medical community should prompt efforts to improve both communication between parents and care givers and the quality of life for children who are dying of cancer. The potential benefit of such efforts could be substantial.

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