Cancer-Related Symptoms Most Concerning to Parents During the Last Week and Last Day of Their Child's Life
Michele Pritchard, Elizabeth Burghen, Deo Kumar Srivastava, James Okuma, Lisa Anderson, Brent Powell, Wayne L. Furman and Pamela S. Hinds

*Pediatrics* 2008;121:e1301
DOI: 10.1542/peds.2007-2681

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://pediatrics.aappublications.org/content/121/5/e1301.full.html
Cancer-Related Symptoms Most Concerning to Parents During the Last Week and Last Day of Their Child’s Life

Michele Pritchard, PhD, RN, CPNPa, Elizabeth Burghen, MSN, MBAa, Deo Kumar Srivastava, PhDb, James Okuma, MSa, Lisa Anderson, MDiva, Brent Powell, MDivb, Wayne L. Furman, MDb, Pamela S. Hinds, PhD, RN, FAANb

aDepartment of Oncology, bDivision of Nursing Research, cDepartment of Biostatistics, and dPatient Care Services, St Jude Children’s Research Hospital, Memphis, Tennessee

The authors have indicated they have no financial relationships relevant to this article to disclose.

What’s Known on This Subject
Children dying of cancer experience multiple (<8) symptoms at end of life. Parents who witness a child’s symptom-ridden death may suffer additionally during their bereavement. Having more research-based information about symptoms could benefit clinicians’ efforts to diminish the child’s suffering and the parent’s immediate and future suffering.

What This Study Adds
Unlike the majority of previously published pediatric articles, this study did not rely on a symptom checklist to solicit parents’ responses about the presence of a specific symptom at their child’s end of life. Open-ended queries allowed parents to identify the symptoms of most concern for them during the last week and last day of their child’s life.

ABSTRACT

OBJECTIVE. Studies of symptoms in children dying a cancer-related death typically rely on medical chart reviews or parental responses to symptom checklists. However, the mere presence of a symptom does not necessarily correspond with the distress it can cause the child’s parents. The purpose of this study was to identify the cancer-related symptoms that most concerned parents during the last days of their child’s life and the strategies parents identified as helpful with their child’s care.

METHODS. Sixty-five parents of 52 children who had died a cancer-related death within the previous 6 to 10 months participated in telephone interviews. Eligibility criteria included being the parent or guardian of a child aged 0 to 21 years who had died within the previous 6 to 10 months after being treated at a pediatric cancer center, having been with their child during the last week of the child’s life, speaking English, being willing to participate, and having access to a telephone.

RESULTS. Eighteen symptoms of concern were identified as occurring during their child’s final week and final day of life. The most frequently reported symptoms at both times included changes in behavior, changes in appearance, pain, weakness and fatigue, and breathing changes. The proportion of reported symptoms did not differ according to patient gender, disease, or location of death (intensive care, elsewhere in the hospital, or home). The most helpful strategies used by health care professionals to assist the child or parents included giving pain and anxiety medications, spending time with the child or family, providing competent care, and giving advice.

CONCLUSIONS. This knowledge can guide professionals in preparing parents for the symptoms that a child imminently dying of cancer is likely to experience and in providing care that will be helpful to parents.
the child’s parents.7,8 Parents presented with an open-ended question, as was used in this study, may identify symptoms or signs of illness that may not be included on a prepared checklist.

We conducted a series of interviews with recently bereaved parents, inquiring about the most concerning symptoms experienced by their child during the last week and final day of life. The conceptual model guiding this research was the “transition to end-of-life care” model. In this model, patients’ symptoms are central to parents’ understanding and believing that their child will not be cured and, thus, facilitate the family transition from curative to end-of-life care.9 Symptoms were defined as any perceptible changes in the child’s body or functioning, emotions, or behavior.

METHODS

Setting
This single-site study took place at the largest freestanding pediatric cancer center in the United States. The center has 62 inpatient beds and an average of 380 new patients with cancer treated annually. During the past several years, 102 to 142 patients treated at the center have died each year.

Instruments
The demographic study form contained 14 items related to the patients’ personal, disease, and treatment characteristics, including the care given during the final week and last 24 hours of life. This form was completed by the study team using the combined sources of the child’s medical chart and parent interview responses. The telephone interview included 3 primary symptom questions and 3 concluding queries related to parent perceptions of the emotional burden of study participation (Table 1).

Design and Study Procedures
A descriptive, exploratory design was used and was approved by the center’s institutional review board. Two study team members received automated computer-generated notification of each child’s death. A study team member identified the cause of death and confirmed all of the eligibility criteria, including whether parents would be emotionally burdened by being contacted about the study, with the deceased child’s attending physician or fellow before contacting the eligible parents. Eligibility criteria included being the parent or guardian of a child aged 0 to 21 years who had died within the previous 6 to 10 months after being treated at the center, having been with their child during the last week of the child’s life, speaking English, being willing to participate, and having access to a telephone. Eligible parents were first contacted through a letter that contained a detailed description of the study purpose and procedures. The interview questions and a copy of the consent documents were also included. Approximately 10 days after the mailing of the letter, and, as described in the letter, a member of the study team who was not familiar to the family attempted to contact them by telephone. Consent forms mailed to the parents needed to be completed and returned to the study team before the actual study interview could be scheduled.

Interviewers completed initial and quarterly training sessions throughout the study. Telephone interviews lasted an average of 35 minutes (range: 11–120 minutes). Telephone interviews were the method of choice, because most eligible parents did not live close to the hospital. Consent was reviewed at the beginning of each telephone interview and was tape recorded, as was the entire interview, with the parents’ permission.

Within 1 to 3 weeks after the telephone interview, a chaplain who was a member of the study team contacted each participating parent to ask 3 questions related to the risk/benefit ratio of participating in the study (see insert). Two study team members independently reviewed all of the information extracted from medical charts for accuracy, and 3 team members verified the accuracy of all of the entered data.

Sample
A total of 170 potentially eligible families were identified during the study period. Of these families, 5 were considered not to be eligible because of concerns about emotional burden and 4 because they were not English speaking. From the 161 eligible families, 65 parents of 52 deceased children (participation rate: 32.3%) participated in telephone interviews. Of these parents, 48 mothers and 4 fathers identified themselves as the primary caregiver. In 13 instances, both parents of the same child participated in the study, and in all but 2 exceptions, the parents in those couples were interviewed during separate telephone contacts.

Patient Characteristics
Most of the 52 patients were male (61.5%) and white (86.5%) with a solid tumor (42.3%) or a brain tumor (34.6%). Most died at home (57.7%) and had a “do not resuscitate” status (57.7%). Their median survival from diagnosis was 1.5 years, and most had experienced either a disease recurrence (48.1%) or progression (50.0%). Only 4 died of treatment-related causes. The
great majority (82.7%) had received radiation as part of their treatment. During the last week of life, 17 patients had received ≥1 blood transfusion, and 14 had ≥1 medical procedure (Table 2).

Of the 161 eligible families, 7 (4.3%) were lost to follow-up, and 31 (19.3%) declined to participate. The most frequently offered reason for declining to participate was “too hard/too soon to talk” (n = 15 [48.4%]). Of the 71 families (44.1%) who did not respond to the letter of invitation and could not be reached by telephone, 7 (9.9%) had disconnected telephone lines, and 50 (70.4%) did not answer their telephones, although the study team attempted to make such contacts for an average of 7 times per family. Of those who could be reached by telephone and did not decline, 8 (11.3%) said they wanted to participate but did not return their signed consent forms during the eligibility period, and 6 (8.4%) asked to be immediately interviewed at the time of the telephone contact rather than return of the signed consents before the interview, as mandated by the institutional review board.

**Planned Analysis**

Three members of the study team used content analysis techniques and consensus coding to identify, categorize, and define the reported symptoms of concern. Descriptive statistics were used to describe demographic data, missing data, symptom frequencies and patterns, and strategies implemented to help or relieve symptoms. Differences by diagnosis and locale of death (ICU, elsewhere in the hospital, or at home) were assessed using the exact χ² test. Parent reports were analyzed in terms of primary care parents (n = 52), all of the mothers (n = 48) and all of the fathers (n = 17), and both mothers and fathers from the 13 participating couples. Because findings did not differ among these 3 sets of parent reports, only the findings from the largest group (primary care parents) are reported here. All of the analyses were completed for the last week and the last 24 hours of the child’s life.

**RESULTS**

**Child’s Final Week**

Eighteen unique symptoms of concern were identified by the 52 primary care parents a total of 193 times. The symptoms most frequently cited included pain, change in behavior, not eating, change in appearance, breathing changes (dyspnea), weakness and fatigue, and change in sleep patterns (Table 3). Although the study included more parents of patients with solid tumors than with brain tumors or leukemia or lymphoma, most symptoms (n = 78 [40.4%]) were reported by parents of brain tumor patients (Table 4).

Symptoms of concern by each of the 3 parent comparisons did not differ by the child’s diagnosis, gender, or location of death (Tables 5 and 6). Even so, certain differences were noted, including change in behavior reported by 72.2% of parents of patients with a brain tumor but only by 36.4% of patients with a solid tumor

<table>
<thead>
<tr>
<th>TABLE 2</th>
<th>Patient and Treatment Data (n = 52)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Characteristic</td>
<td>Data</td>
</tr>
<tr>
<td>Age at diagnosis, y</td>
<td>6.0</td>
</tr>
<tr>
<td>Median</td>
<td>0.02–19.6</td>
</tr>
<tr>
<td>Gender, n (%)</td>
<td>Female 20 (38.5)</td>
</tr>
<tr>
<td>Male 32 (61.5)</td>
<td></td>
</tr>
<tr>
<td>Race, n (%)</td>
<td>White 45 (86.5)</td>
</tr>
<tr>
<td>Black 7 (13.5)</td>
<td></td>
</tr>
<tr>
<td>DNR orders, n (%)</td>
<td>Yes 30 (57.7)</td>
</tr>
<tr>
<td>No 4 (7.7)</td>
<td></td>
</tr>
<tr>
<td>Unknown 18 (34.6)</td>
<td></td>
</tr>
<tr>
<td>Relapse/progression, n (%)</td>
<td>1 10 (40.0)*</td>
</tr>
<tr>
<td>2 12 (48.0)*</td>
<td></td>
</tr>
<tr>
<td>3 3 (12.0)*</td>
<td></td>
</tr>
<tr>
<td>Patients with relapses</td>
<td>25 (48.1)</td>
</tr>
<tr>
<td>Patients with progression</td>
<td>26 (50.0)</td>
</tr>
<tr>
<td>Ventilator, n (%)</td>
<td>On 2 (3.8)</td>
</tr>
<tr>
<td>Off 50 (96.2)</td>
<td></td>
</tr>
<tr>
<td>Radiation, n (%)</td>
<td>Yes 43 (82.7)</td>
</tr>
<tr>
<td>No 8 (15.4)</td>
<td></td>
</tr>
<tr>
<td>Unknown 1 (1.9)</td>
<td></td>
</tr>
<tr>
<td>Disease type, n (%)</td>
<td>Brain tumor 18 (34.6)</td>
</tr>
<tr>
<td>Leukemia/lymphoma 12 (23.1)</td>
<td></td>
</tr>
<tr>
<td>Solid tumor 22 (42.3)</td>
<td></td>
</tr>
<tr>
<td>Survival time, y</td>
<td>1.5</td>
</tr>
<tr>
<td>Median</td>
<td>0.2–14.9</td>
</tr>
<tr>
<td>No. of protocols, n (%)</td>
<td>Unknown 1 (1.9)</td>
</tr>
<tr>
<td>1 6 (11.5)</td>
<td></td>
</tr>
<tr>
<td>2 11 (21.2)</td>
<td></td>
</tr>
<tr>
<td>3 8 (15.4)</td>
<td></td>
</tr>
<tr>
<td>4 9 (17.3)</td>
<td></td>
</tr>
<tr>
<td>&gt;4 17 (32.6)</td>
<td></td>
</tr>
<tr>
<td>No. of chemotherapy drugs</td>
<td>Median 7</td>
</tr>
<tr>
<td>Range 0–18</td>
<td></td>
</tr>
<tr>
<td>IV treatment during last week, n (%)</td>
<td>Yes 23 (44.2)</td>
</tr>
<tr>
<td>No 12 (23.1)</td>
<td></td>
</tr>
<tr>
<td>Unknown 17 (32.7)</td>
<td></td>
</tr>
<tr>
<td>Location of death, n (%)</td>
<td>Home 30 (57.7)</td>
</tr>
<tr>
<td>Hospital (not ICU) 10 (19.2)</td>
<td></td>
</tr>
<tr>
<td>St Jude domiciliary 4 (7.7)</td>
<td></td>
</tr>
<tr>
<td>St Jude ICU 7 (13.5)</td>
<td></td>
</tr>
<tr>
<td>Unknown 1 (1.9)</td>
<td></td>
</tr>
<tr>
<td>Family counseling, n (%)</td>
<td>Yes 12 (23.1)</td>
</tr>
<tr>
<td>No 34 (65.4)</td>
<td></td>
</tr>
<tr>
<td>Unknown 6 (11.5)</td>
<td></td>
</tr>
</tbody>
</table>
and change in sleep pattern reported by 42.9% of parents whose child died in intensive care but only by 17.6% of parents whose child died at home.

Child’s Final Day

Eighteen unique symptoms were identified by parents (12 by fathers and 18 by mothers) as most concerning to them on the last day of their child’s life a total of 162 times. The symptoms most frequently cited included change in behavior, breathing changes, pain, change in appearance, weakness and fatigue, and change in heart rate (Table 3). Slightly more symptoms were reported by parents of brain tumor patients (38.9%) and the fewest by parents of children with leukemia or lymphoma (26.5%; Table 4). The proportions of symptoms reported by disease group did not differ significantly, but certain symptoms did have sizable differences worth noting, including heart rate change reported more frequently \( (P = .09) \) for children with leukemia (33.3%) than for those with brain tumors (5.6%), breathing changes more frequently for children with leukemia (66.7%) than for those with solid tumors (45.5%), and change in appearance more frequently for brain tumor patients (44.4%) than for those with solid tumors (13.6%). Proportions of symptoms did not differ by gender or by location of death (Table 4), but change in appearance was reported twice as often for parents who died at home (29.4%) as for those in intensive care (14.3%). Similarly, change in heart rate was reported twice as often in parents who died in intensive care (28.6%) as in those who died at home (11.8%). Of the 162 symptoms reported by parents, 70 (43.2%) were described as getting worse, 40 (24.7%) were described as staying the same, 14 (8.6%) were described as varying during the day, and 15 (9.3%) were described as getting better. Parents did not rate the remaining 23 symptoms.

Most of the concerning symptoms decreased between the 2 time points with 1 exception, breathing changes, which increased from the week before death (28.8%) to the day of death (55.8%), nearly doubling by parent report. The largest decreases in symptom frequency were reported for pain (from 67.8% to 55.8%) and not eating (from 30.8% to 9.6%). The symptom proportions reported by parents for disease type and location of death were quite similar for both report times.

Strategies That Helped

The most frequently reported actions of health care professionals identified by the primary care parents included giving pain or anxiety medications \( (n = 25 \ [31.3\%]) \), providing competent care \( (n = 10 \ [12.5\%]) \), helping to keep the child comfortable \( (n = 8 \ [10.0\%]) \), spending time with the child or family \( (n = 8 \ [10.0\%]) \), bringing supplies \( (n = 6 \ [7.5\%]) \), and giving advice \( (n = 5 \ [6.3\%]) \). In response to the question about what other did that helped the parents the most, the most frequent responses included spending time with them \( (n = 35 \ [21.6\%]) \), nothing (they perceived that they met their child’s care needs themselves; \( n = 31 \ [19.1\%]) \), giving them advice \( (n = 15 \ [9.2\%]) \), providing competent care to the child \( (n = 14 \ [8.6\%]) \), and being there at the time of death \( (n = 8 \ [4.9\%]) \).

Feedback About the Interview Questions

Of the 52 primary care parents who responded to the closing interview questions, 50 indicated that the questions were effective in allowing them to say all that they wanted to say. Frequent comments included “the questions were clear,” “they were fine,” “they helped,” and “they were good.” Forty-one parents (78.8%) indicated that the study interview questions did not cause them distress, but 11 (21.2%) indicated that the questions did upset them. Each of those 11 parents indicated that they had anticipated that responding to the questions would cause them distress and that the distress was no worse than they had expected. Thirty nine (75.0%) of the parents declined, and 13 (25.0%) accepted our offer to find community-based support resources for them. Those who declined indicated that they already had resources they were using with satisfaction or had chosen not to use such resources.

Follow-up Responses

Forty four (84.6%) of 52 primary care parents participated in the follow-up telephone contact. In response to the question about what was good about participating in the study, 23 (52.3%) indicated being able to help other parents or the hospital “that helped us,” 13 (29.5%) reported talking to an interviewer who “wanted to listen and conveyed caring,” 5 (11.4%) reported interpreting the study contact as a sign that the hospital cared about them, and 4 (9.1%) reported having an opportunity to revisit the decisions they made and the actions they took to take care of their dying child and realizing that they had done all that they could during that time. Three (6.8%) reported “nothing in particular.” In response to the question about what was bad about participating, 30 parents (68.2%) responded “nothing,” and 15 (34.1%) indicated that difficult memories were stirred, but 5 of those parents added that this was not bad and was what
<table>
<thead>
<tr>
<th>Symptom</th>
<th>Definition</th>
<th>Frequency Total/Parents (%)</th>
<th>Example Quotes</th>
</tr>
</thead>
</table>
| Pain                          | Physical suffering that ranged in degrees                                    | 21/21 (40.4) / 39/35 (67)   | "He was in a lot of pain."  
"She hurt a lot – the mind was willing, the body just wasn’t able."  
"It looked like he didn’t really realize we were there . . . about the only person he ever really responded to, really, was his sister."  
"He continued to stare at the ceiling. His speech was slurred. He wasn’t talking anymore. I think everything was just shutting down." |
| Change in behavior            | Notable differences in the usual activities of the child and in the child’s interactions with others or change in the senses (especially not hearing or seeing) | 45/31 (59.6) / 35/28 (53.8) | "It looked like he didn’t really realize we were there . . . about the only person he ever really responded to, really, was his sister."  
"He continued to stare at the ceiling. His speech was slurred. He wasn’t talking anymore. I think everything was just shutting down." |
| Not eating                    | Child not able to swallow food and/or drink and may or may not have had a desire for food/drink | 8/8 (15.4) / 20/20 (38.5)   | "Physically he was hungry, but he could not eat, could not swallow."  
"The one symptom that we noticed that concerned us the most and that we knew, without a doubt, that we only had a few hours left with him was his coloring drastically changed."  
"The one thing, I think, that was the hardest was that he didn’t look like himself. He’d lost a lot of weight and they had taken him off fluids . . . That was really hard to see him like that." |
| Change in appearance          | Notable differences in how the child looked                                  | 15/14 (26.9) / 21/15 (28.8) | "He had his oxygen mask on, and this thick stuff started running out of his nose, and so I got the suctioning, and I suctioned it. And when I took his oxygen mask off his face, his fingers and lips were like turning purple."  
"His breathing. It was a very shocking symptom. It was a scary symptom for us to see, and it hurt us as parents to watch because we knew how hard it was . . . he could hardly breathe. And every breath, we thought, that might be it. We kept holding our breath and thinking, ‘That’s it. He’s not coming back,’ and it was hard to see that, because it was so painful. It looked so painful to us. We’re not sure if he was conscious enough for it to be painful for him. But as parents, it was very hard for us to watch that.”  
"The one thing, I think, that was the hardest was that he didn’t look like himself. He’d lost a lot of weight and they had taken him off fluids . . . That was really hard to see him like that.” |
| Breathing changes             | Any notable differences in the child’s respiratory effort and/or pattern     | 30/29 (55.8) / 15/15 (28.8) | "He had his oxygen mask on, and this thick stuff started running out of his nose, and so I got the suctioning, and I suctioned it. And when I took his oxygen mask off his face, his fingers and lips were like turning purple."  
"His breathing. It was a very shocking symptom. It was a scary symptom for us to see, and it hurt us as parents to watch because we knew how hard it was . . . he could hardly breathe. And every breath, we thought, that might be it. We kept holding our breath and thinking, ‘That’s it. He’s not coming back,’ and it was hard to see that, because it was so painful. It looked so painful to us. We’re not sure if he was conscious enough for it to be painful for him. But as parents, it was very hard for us to watch that.” |
| Weakness and fatigue          | Patient unable to participate in usual activities and needing assistance with certain functions | 7/7 (13.5) / 11/11 (21.2)   | "Basically, he was just so fatigued and so exhausted."  
"He was so tired he could not get up on his own."  
"He would sleep a lot."  
"She did a lot of sleeping; she would wake up and then sleep for a long period of time.”  
"He would sleep a lot."  
"He was so tired he could not get up on his own." |
| Change in sleep pattern       | Patient asleep for longer or shorter periods than usual                     | 6/6 (11.5) / 12/11 (21.2)   | "He would sleep a lot."  
"She did a lot of sleeping; she would wake up and then sleep for a long period of time.”  
"He would sleep a lot."  
"She did a lot of sleeping; she would wake up and then sleep for a long period of time.”  
"It was a very shocking symptom. It was a scary symptom for us to see, and it hurt us as parents to watch because we knew how hard it was . . . he could hardly breathe. And every breath, we thought, that might be it. We kept holding our breath and thinking, ‘That’s it. He’s not coming back,’ and it was hard to see that, because it was so painful. It looked so painful to us. We’re not sure if he was conscious enough for it to be painful for him. But as parents, it was very hard for us to watch that.”  
"The one thing, I think, that was the hardest was that he didn’t look like himself. He’d lost a lot of weight and they had taken him off fluids . . . That was really hard to see him like that.” |
| Change in bowel and bladder   | Patient incontinent or constipated                                          | 5/5 (9.6) / 9/7 (13.5)      | "The shutting down of her body – the not urinating or no bowel movements.”  
"He had diarrhea.”  
"She couldn’t keep anything down.”  
"He, just out of the blue, got very sick – throwing up.”  
"He had diarrhea.”  
"She couldn’t keep anything down.”  
"He, just out of the blue, got very sick – throwing up.” |
| Nauseous or vomiting          | Patient feeling like he/she was going to vomit or actually ejecting stomach contents | 5/5 (9.6) / 7/7 (13.5)      | "The shutting down of her body – the not urinating or no bowel movements.”  
"He had diarrhea.”  
"She couldn’t keep anything down.”  
"He, just out of the blue, got very sick – throwing up.”  
"He had diarrhea.”  
"She couldn’t keep anything down.”  
"He, just out of the blue, got very sick – throwing up.” |
| Talking to God or angels       | Patient having conversations with individuals that others in the room are not able to see and patient described seeing heavenly beings | 1/1 (1.9) / 6/6 (11.5)      | "Told his mom that he had seen a person floating in his room and had asked his mom to please look at this person also and his mom was unable to see anyone in the room.”  
"Told his mom that he had seen a person floating in his room and had asked his mom to please look at this person also and his mom was unable to see anyone in the room.”  
"Told his mom that he had seen a person floating in his room and had asked his mom to please look at this person also and his mom was unable to see anyone in the room.”   
"He had diarrhea.”  
"She couldn’t keep anything down.”  
"He, just out of the blue, got very sick – throwing up.”  
"He had diarrhea.”  
"She couldn’t keep anything down.”  
"He, just out of the blue, got very sick – throwing up.” |
they had expected. One (2.3%) described the questions as somewhat redundant. In response to the question soliciting any additional comments, 35 (79.5%) responded “nothing”; 5 (11.4%) encouraged the continuation of such “important,” “caring” research; 2 (4.5%) spoke of the kindness of the interviewers; and 2 (4.5%)...
asked to be contacted in the future if they could help by sharing their stories and experiences.

**DISCUSSION**

Health care professionals have an opportunity to make a difference in the actual experience and the perceptions of the parents of dying children. Giving careful attention to the symptoms of most concern to parents during the last week and last day of their child’s life may alter their perceptions of their child’s suffering and of their ability as parents to protect their child even while he or she is dying. Reducing child and parent suffering during the child’s final days may be one of the most significant ways that health care providers can contribute to the parents’ future well-being. Attention to the symptoms of most concern to parents may also contribute to the development of interventions for those symptoms.

This study is the first to our knowledge to document the parental perspective regarding the symptoms that were most concerning to them during their child’s final week and final day of life. This was accomplished through an interview 6 to 10 months after the child’s cancer-related death, in contrast to previous studies that have relied on parent responses to structured questionnaires, medical chart review, or clinician reports 1 to 8 years after the child’s death. Certain of the symptoms reported by parents in our study, such as pain, breathing changes, loss of appetite, vomiting, and fatigue, have been identified previously as symptoms that children with cancer suffer at the end of life in studies that relied on medical chart review, symptom checklists, or clinician experiences.²,⁶,⁸,¹¹–¹⁵

Two symptoms of concern most frequently identified by parents in our study were changes in their child’s behavior and appearance; these are rarely mentioned in previously published pediatric end-of-life symptom studies. Health care professionals preparing families for their child’s last week and last day may inadvertently not address 2 of the most concerning symptoms for parents if they do not mention the likelihood of changes in behavior or appearance.

Psychological symptoms (ie, anger, fear, sadness, loss of perspective, and loss of independence) did not emerge in our interviews to the same extent as were reported retrospectively by parents in the Netherlands whose reports were specifically solicited using a checklist.¹⁴ Although the psychological symptoms may not be the most concerning symptoms to parents during the last week and day of their child’s life, we cannot know from our current methods. Modifying our interview question into 3 questions that address each component (behavioral, emotional, and physical) might facilitate parental responses to each component in future studies and allow us to know with more certainty whether emotional symptoms are or are not most concerning to parents. Conversely, asking the more global approach first may be a way to identify the symptoms that are of upmost concern for parents. The 3 more specific questions (about behavioral, emotional, and physical symptoms) could then be asked individually and responses compared between the global and the more specific questions.

Eighteen concerning symptoms were identified by participating parents for the last week and last day of their child’s life. The types of most concerning symptoms of the last day were nearly identical to those of the last week, implying that concerning symptoms are unlikely to change in type during the final week. Although similar in type of symptom, the frequency of the identified symptoms differed somewhat, with the 18 symptoms being reported a total of 193 times for the last week and a total of 162 times for the last day. The number of times that certain concerning symptoms were reported differed between the last week and last day. Pain was the most frequently reported symptom of the last week but third most concerning for the last day. Change in behavior was the second most frequently mentioned symptom of the last week but first for the last day. Breathing changes were the fifth most frequently mentioned symptom of concern for the last week but second for the last day. Not eating was third on the list for the final week and not listed at all among the top 5 symptoms for the final day.

The concerning symptoms did not differ by gender, disease, or location of death. Children with a solid tumor have been identified previously as more likely to die at home than children with leukemia.¹⁶ Others have reported that the presence of severe symptoms dictates the location of death, because parents who had wanted their child to die at home will admit their child to the hospital to have better symptom control strategies available.⁵,¹⁷,¹⁸

Our lack of finding such differences in concerning symptoms by diagnosis or location of death may be a factor of our sample size. Analysis of location of death, diagnosis, and most concerning symptoms does merit additional study with a larger group of patients.

Of particular importance is that the strategies of health care professionals and others such as friends and lay persons reported by parents as most helpful to them

---

**TABLE 6** Differences According to Patient Gender as Reported by Primary Care Parents

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Girls (N = 20)</th>
<th>Boys (N = 32)</th>
<th>P*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>14</td>
<td>21</td>
<td>66</td>
</tr>
<tr>
<td>Change in behavior</td>
<td>10</td>
<td>18</td>
<td>56</td>
</tr>
<tr>
<td>Not eating</td>
<td>7</td>
<td>9</td>
<td>28</td>
</tr>
<tr>
<td>Change in appearance</td>
<td>6</td>
<td>9</td>
<td>28</td>
</tr>
<tr>
<td>Breathing changes</td>
<td>6</td>
<td>9</td>
<td>28</td>
</tr>
<tr>
<td>Change in sleep pattern</td>
<td>5</td>
<td>6</td>
<td>19</td>
</tr>
<tr>
<td>Weakness and fatigue</td>
<td>5</td>
<td>6</td>
<td>19</td>
</tr>
<tr>
<td>Needing blood product</td>
<td>3</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Change in bowel/bladder</td>
<td>2</td>
<td>5</td>
<td>16</td>
</tr>
<tr>
<td>Change in temperature</td>
<td>1</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Coma</td>
<td>1</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Difficulty swallowing</td>
<td>1</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Increased secretions</td>
<td>1</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Seizing</td>
<td>1</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Talking to God/angels</td>
<td>1</td>
<td>3</td>
<td>16</td>
</tr>
<tr>
<td>Vomiting</td>
<td>1</td>
<td>6</td>
<td>19</td>
</tr>
</tbody>
</table>

* Data are from Fisher’s exact test.
were not symptom specific, as we had anticipated. Instead, most helpful strategies tended to be generic and included giving the child pain and anxiety medications, spending time with the child or family, providing competent care, and giving advice. These actions are non-symptom-related actions, for the most part, and instead are actions of human compassion and emotional support. Open communication between parents and their dying child’s health care providers has been identified as a parent preference in multiple studies; 1 outcome of open communication and parent access to their child’s providers is parental satisfaction with their dying child’s symptom experience and improved family well-being.2,4,19,20 It is possible that the parents did not recognize or focus on symptom-specific interventions at that critical time, but these parents were experienced in the care of a seriously ill child, and, thus, the more likely explanation is that the more generic strategies were of special comfort to them.

There are important limitations to our study. Most concerning to us is the low participation rate. Parent participation rates in our previous end-of-life studies have ranged from 48% to 76%.21 We attribute the low participation rate in this study first to our study procedures, primarily the multiple steps required in our consent procedure, which 14 parents described as burdensome and interfering with their ability to participate. The second potential contributing factor is the study time period, 6 to 10 months after the child’s death, which may not be the optimal time to approach parents (15 parents indicated this timing was too soon). Theunissen et al14 used a mailed questionnaire for their end-of-life symptom study and reported an impressive parent participation rate of 80%. The questionnaire was mailed only to parents whose child had been treated for ≥6 months at the hospital originating the study, who had received palliative care, and who had died 1 to 3 years previously. Narrowly defined eligibility criteria may contribute to a lower refusal rate. The nonresponse rate in our study is difficult to explain, but the size of that rate certainly indicates that our findings cannot be considered as representing all bereaved parents whose child has died a cancer-related death. A final limitation of our work is that it is a single-institution study with findings that primarily represent children who died of cancer at home and not of treatment toxicity in the hospital. Our participating parents, thus, best represent bereaved parents who had helped to make end-of-life decisions on behalf of their ill child and not parents who were pursuing curative options at the time of their child’s death. We were relieved and encouraged by the positive parent responses to study participation; parent comments support our impression that parents who self-select to participate in end-of-life studies do so in a well-informed manner based on self-awareness of what is or is not burdensome for them.

CONCLUSIONS
Attention to the symptoms of most concern to parents during the last week and last day of their child’s life is most warranted. Certainly there will be clinical situations in which the symptoms of most concern cannot be sufficiently reduced or prevented, and the best that the clinician can do is to be present with the parents in their suffering. Future research needs to study the relationship between the child’s symptom experience at the end of life with the subsequent well-being of the child’s family members and health care providers. Developing interventions for the symptoms of greatest concern may ultimately contribute to more desirable longer-term outcomes for these survivors.

ACKNOWLEDGMENTS
This research was supported in part by grants from the Oncology Nursing Foundation, the National Cancer Institute Center support grant P30 CA 21765, and the American Lebanese Syrian Associated Charities.

We sincerely appreciate the thoughtful editing of this article by David Galloway, ELS, senior scientific editor at St Jude Children’s Research Hospital and the insights of several colleagues who reviewed the article, including Drs Sheri Spunt, Javier Kane, Justin Baker, and Jamis Gattuso, as well as Nancy K. West.

REFERENCES


Cancer-Related Symptoms Most Concerning to Parents During the Last Week and Last Day of Their Child's Life

Michele Pritchard, Elizabeth Burghen, Deo Kumar Srivastava, James Okuma, Lisa Anderson, Brent Powell, Wayne L. Furman and Pamela S. Hinds

_Pediatrics_ 2008;121;e1301

DOI: 10.1542/peds.2007-2681

Updated Information & Services

including high resolution figures, can be found at:

http://pediatrics.aappublications.org/content/121/5/e1301.full.html

References

This article cites 16 articles, 4 of which can be accessed free at:

http://pediatrics.aappublications.org/content/121/5/e1301.full.html#ref-list-1

Citations

This article has been cited by 4 HighWire-hosted articles:

http://pediatrics.aappublications.org/content/121/5/e1301.full.html#related-urls

Subspecialty Collections

This article, along with others on similar topics, appears in the following collection(s):

Tumors

http://pediatrics.aappublications.org/cgi/collection/tumors

Permissions & Licensing

Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at:

http://pediatrics.aappublications.org/site/misc/Permissions.xhtml

Reprints

Information about ordering reprints can be found online:

http://pediatrics.aappublications.org/site/misc/reprints.xhtml

PEDIATRICS is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. PEDIATRICS is owned, published, and trademarked by the American Academy of Pediatrics, 141 Northwest Point Boulevard, Elk Grove Village, Illinois, 60007. Copyright © 2008 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 0031-4005. Online ISSN: 1098-4275.