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Bereaved Parents' Perceptions About When Their Child's Cancer-Related Death Would Occur

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Abstract

Parents of terminally ill children with cancer frequently ask clinicians when their child will die. Such information helps parents prepare for the child's death. To identify how parents perceived when their child's cancer-related death would occur, we conducted a secondary analysis of telephone interviews with 49 bereaved parents six to ten months after their child's death to extract their descriptions of this occurrence. The parents knew in advance that their child was going to die, but they described when their child's death would occur in three different ways: anticipated (parents observed changes that alerted them that death was imminent; *n*=22, 52.4%), surprising (parents were surprised that their child died on that particular day; *n*=13, 31.0%), and overdue (parents had been waiting for the end of their child's apparent suffering; *n*=7, 16.7%). These categories did not differ by patients' diagnosis, sex, or location of death, but differed slightly by symptom patterns. Parents who reported the occurrence of their child's death as surprising reported fewer symptom changes on the last day of their child's life, as compared to the last week of life, than did the parents in the other two categories. These findings indicate that parents of children with terminal cancer can perceive when their child's death would occur very differently: Some are surprised, while others feel they have waited too long for their child's release from suffering. Clinicians can use these descriptions and the associated symptom patterns to help families prepare for their child's last week and last day.

Keywords

Parental perceptions; end of life; timing of cancer-related death; symptoms; pediatric oncology

Introduction

When parents of children with terminal cancer realize that their child will not survive, they work to prevent or reduce their child's suffering (1) and to prepare themselves for the manner

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and time of death. Parents report that they are helped to prepare by information they receive from clinicians about the symptoms that their child may experience near the end of life (2). They also describe this kind of information as contributing to their subsequent well-being as bereaved parents (3). Parents in one study identified the lack of such information from clinicians as “an important problem” (4). Parents also want to know when a child may die. Although clinicians may not be able to predict when the death will occur, information about other parents’ experiences may help to prepare them.

In a previous study of symptoms that most concerned parents during the last day and last week of their child’s life (2), we conducted telephone interviews with 65 bereaved parents six to ten months after their child’s death. Here, we report a secondary analysis aimed at identifying how these parents perceived when their child’s death would occur. We also examined whether the symptom patterns reported by parents differed according to their perceptions of the occurrence of death.

Methods

In the primary study, which was prospectively approved by the St. Jude Children’s Research Hospital Institutional Review Boards, 65 parents of 52 children ages two months to 19.6 years who had died a cancer-related death six to ten months earlier participated in telephone interviews about the symptoms that most concerned them during their child’s final week and final day of life. All participants were guardians of their child, were present during the last week of the child’s life, were able to speak English, gave written consent to participate, and had access to a telephone. Eligible parents were identified each month from patient records and were first contacted through a letter from the research team describing the study purpose and procedures in detail. Interview questions and consent documents were included. Approximately 10 days after the mailing and as described in the letter, a member of the study team who was not familiar with the family contacted the parents by telephone. Study interviews were scheduled only after consent forms had been completed and returned to the study team. The study team members assigned to conduct the telephone interviews were not familiar with the participating parents.

Setting

St. Jude Children’s Research Hospital is the only free-standing pediatric cancer center in the United States. The center has 60 inpatient beds, and an average of 380 new cancer patients have been treated annually over the past five years. During the past seven years, 102 to 142 patients treated at St. Jude have died each year. All but two parents were in their homes when interviewed by telephone; of the remaining two, one asked to be called at his place of work and one asked to be called at a hotel while on a business trip.

Sample

Of the 65 parents who participated in the larger study, 60 described their child’s death. In 11 interviews, information about when their child’s death would occur was unclear (n=1), or uninterpretable because of poor audio quality (*n*=10). The remaining 49 parent interviews included those from seven couples. To avoid confounding data, our secondary analysis included only the child’s primary caregiver in each of the seven couples, leaving 42 participants (39 mothers and 3 fathers). However, a comparison of responses within each couple is provided.

Most of the 42 patients were male (24, 57.1%) and white (42, 85.7%), and had solid tumors (19, 45.2%) or brain tumors (14, 33.3%). Most died at home (25, 59.5%) and had a “do not resuscitate” order (22, 53.4%). Table 1 describes the patients’ characteristics as extracted from the child's medical record. All of the parents acknowledged having been told by their child's attending physician that their child would not survive.

Secondary Analysis

This descriptive, exploratory study was approved by the St. Jude Children's Research Hospital Institutional Review Board. Because it was a secondary analysis, separate informed consent was waived. Two members of the study team reviewed all transcribed parent interviews for accuracy and completeness. One member of the team, using the qualitative method of semantic content analysis (5), reviewed all transcribed interviews and identified the segments in which parents described their perceptions about when their child's death would occur. A second team member separately reviewed the same transcribed interviews to confirm the identified segments. Subsequently, one member of the team analyzed the identified segments using phrases as the unit of analysis and identified three categories of parental description of their perceptions about when their child's death would occur. Two additional raters independently identified the same categories. The three categories were those in which parents described the occurrence of their child's death as: 1) anticipated (a change in one or more symptoms alerted parents to the child's imminent death), 2) surprising (parents knew that their child would die but were surprised that the child died on that day), and 3) overdue (parents had waited for days to weeks for their child's release from apparent suffering, believing that their child could die at any moment). The 42 parents' reports (in the primary study) of symptoms of concern observed during their child's last day and last week of life were qualitatively compared across the three categories.

Three additional study team members then reviewed each transcribed interview, confirmed that the three categories represented all interview segments that addressed parental perceptions about when the child's death would occur, and independently categorized each parent's description by using a semantic content analysis based on phrases being the unit of analysis (5). Inter-rater reliability was calculated for the independent categorizations and was calculated again after the raters met to review and discuss phrases for which initial category assignment was inconsistent. The initial rater agreement was 74.6%; after consensus discussion, rater agreement was 100%. The categories of parent descriptions of when their child's death would occur were compared to patient diagnosis, sex, and location by death by using the χ^2 test.

Results

Parental perceptions about when their child's death would occur was categorized as having been anticipated by 22 (52.4%), as having been surprising by 13 (31.0%), and as having been overdue by 7 (16.7%). Example parent quotes from each category are listed in Table 2. Parent quotes in the anticipated death category indicated symptom changes; physical weakening was most commonly cited (n=20 of 42 parents). Parent quotes in the "surprising" category indicated that the child's final day had been typical or positive while those in the "overdue" category indicated surprise that their child could have lived so long in his or her existing clinical condition that included apparent suffering (n=7). Parents' characterization of when their child's death would occur was not statistically associated with patient diagnosis, sex or location of death (Table 3). Both parents in three of the seven couples described when their child's death occurred as "surprising." In each of the other four couples, the categories differed ("overdue" vs. "anticipated" in three couples.

The 42 parents who described when their child's d eath would occur also reported 17 different symptoms that were of most concern to them on the day of their child's death. Parents in the "anticipated" category reported 16 of these symptoms, those in the "overdue" category reported 10, and those in the "surprising" category reported 13. Four symptoms were reported in all three categories: change in breathing, change in appearance, change in behavior, and pain.

Parents in the “anticipated” category reported two additional categories of symptoms on the last day of their child’s life, as compared to the child’s last week of life, whereas parents in the other two categories reported fewer categories of symptoms on the day of death, as compared to the final week. Four symptoms (needing blood products, not eating, talking to God or angels or about dying, and weakness and fatigue) were reported appreciably less frequently during the last day of life than during the last week of life in all three categories. Parents in the “anticipated” category reported only one symptom category that was unchanged between the child’s last day and last week, whereas parents in the “surprised” category reported four and parents in the “overdue” category reported three categories that were unchanged between the last week and last day of their child’s life.

Discussion

Our findings indicate that parents may perceive that the cancer-related death of their child occurred without warning, occurred when expected (after definite clues), or occurred when long overdue. Further, couples can experience the occurrence of their child’s death differently. Three couples who participated in our study experienced the occurrence of their child’s death (“surprising”) similarly, but four couples experienced it differently (“anticipated” vs. “overdue”). Another study showed poor agreement between spouses about the primary goal of end-of-life care for children dying of cancer, suggesting that spouses may bring different perspectives to the end-of-life period (6). The differences may reflect different amounts of time spent with the dying child, although the retrospective design of our study does not allow us to confirm this. However, spouses may find it useful to know that they may perceive when their child’s death will occur differently and thus may have different initial reactions at the time of death.

The anticipated deaths were characterized by symptoms that parents reported were new or of new intensity and that were perceived as cues signaling their child’s imminent death. These symptoms tended to be observable physical changes such as a decrease in the child’s interactions or movements, or a change in the way the child looked at the parent. These observations, interpreted by parents as signaling the child’s imminent death, are similar to those reported by Jakobsson and colleagues (7), who examined the medical records of 229 patients at the end of life and identified a “turning point” (the identification of active dying and the reorientation of care) in 160 of these patients’ records. They documented 30% of the turning points to have occurred during the last day, 33% during the last two to seven days, and 19.5% during the last 30 days of life. The remaining turning points occurred as much as 210 days before death.

In a retrospective study of parents whose child had died of cancer one to eight years previously, 30% reported perceiving changes in their child’s appearance or behavior that indicated to them that their child would not survive (1). In our study, 52.4% of the parents reported observing clues that alerted them that their child would die that day. This percentage is higher than that extracted from clinicians’ documentation (7) and higher than that in the retrospective study that used a longer recall period than that used in our study (1). The parent reports, although collected retrospectively, indicate that their intimate knowledge of their child’s behavior and appearance, even at the end of life, provided a unique insight into when their child’s death would occur.

The deaths categorized as surprising followed what parents described as a typical or even a good day, often including some improvement. The child had reportedly gone to school or clinic, had participated in activities, or had been more engaged in activities or social interactions than in recent days. The parents also reported more symptom categories that were unchanged as compared to the other two groups of parents. Therefore, parents in the “surprised” category had fewer clues that this day would be the child's final day. Alternatively, it is possible that these parents were unconsciously less willing to acknowledge unwelcome or ominous changes, although our interview data do not support this interpretation.

Parents who felt that their child's final day was overdue often referred to their child's extreme, overt suffering and their child's survival for longer than the parent thought was humanly possible. Parents described waiting at the bedside for days to weeks, not wanting to be absent when their child died and believing that death might come at any moment.

Adult patients and their family caregivers attribute their interest in projected time of death to a desire to prepare themselves or their family members (8–12). The difficulty of predicting when a child with progressive cancer will die is well described. Our findings do not help to resolve that problem, but they do help to explain the challenges of such predictions, and they add to the information that clinicians can offer parents about their child's last day. Parents are likely to find comfort in knowing what the experience was like for other parents, including changes in their child's appearance, behavior, or emotions that alerted them to approaching death. It may be of special comfort to some parents to know that they are not the only parents who have waited apprehensively as their child clings to life that has little remaining quality. As well, parents may be comforted by the willingness of their child's clinicians to discuss how and when their child's death might occur.

Our results were derived from a secondary analysis of retrospectively reported parent perceptions and are therefore subject to inherent limitations. The original study was not designed to assess parents' perceptions of when their child's death would occur, and this question was not directly asked. However, all but five of the interviewed parents described the circumstances of their child's death. An additional limitation was that because many patients did not die at the study site, we were unable to link the parents' description of the occurrence of their child's death to the proximate cause of death. This kind of detail would help clinicians to prepare the parents for likely end-of-life experiences specific to the individual child's condition.

Conclusion

Parents who must face their child's death benefit from learning that they may have different experiences regarding when their child's death will occur. Parents may also benefit from knowing what symptoms have alerted other parents to the fact that death is imminent. Clinicians may use our findings to help parents, surprised by when their child's death occurred, to understand that often there are few signs that death is imminent. Future studies should prospectively examine these categories of parental perception and their association with patient symptoms and parents' bereavement experiences.

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Table 1

Patient Characteristics (*n* = 42)

Characteristic	***n* (%)**[a]
Age at diagnosis (yrs)	
Mean (SD)	6.72 (6.0)
Median (range)	4.18 (0.02–19.6)
Sex	
Female	18 (42.9)
Male	24 (57.1)
Race	
White	42 (85.7)
Black	7 (14.3)
DNR Orders	
Yes	22 (53.4)
No	3 (7.1)
Unknown/missing	10 (40.5)
Disease type[b]	
Brain tumor	14 (33.3)
Leukemia/lymphoma	9 (21.4)
Solid tumor	19 (45.2)
Survival time since diagnosis (yrs)	
Median	1.2
Range	0.2–14.9
Location of death	
Home	25 (59.5)
Hospital (not ICU)	6 (14.3)
Hospital ICU	6 (14.3)
Hospital campus housing	4 (9.5)
Unknown	1 (2.4)

DNR = do not resuscitate; ICU = intensive care unit.

[a] Unless otherwise specified.

[b] Two patients had 2 diagnoses; the later diagnosis was used for this analysis.

[c] Percentages reported are of the patients with relapse or progression.

Table 2

Categories of Parental Descriptions of their Perceptions about When Their Child's Death Occurred

Category (n, %)	**Examples of Descriptions**
Anticipated (22, 52.4)	"You could tell. I guess you could say he was starting to shut down. He didn't really want anything to do with really anybody. He just wanted to lay there." "His breathing. It was really mostly his breathing. Because at night, it was kind of, I kind of woke up really early in the morning and he was sleeping next to me and I just could sense that his, you know that this was…the end of his life and it was his breathing…" "We knew Thursday night that she wasn't going to live and I sensed, when I called everybody, 'they said it could be a week but I am telling you it's within a few days.'" "The day that she died - that morning we knew she was going to die because she wouldn't open her eyes. She wouldn't talk to us, she wouldn't move. She was kind of limp. So we knew that day, that was going to be her last day."
Surprising (13, 31.0)	"And I said (to his brothers), 'He's not doing good. Brother may go at any time. But we never once dreamed it would be the very next day after telling them this." "It was a normal day. He was happy, playful. He didn't have any symptoms. …We knew he was going to die but we didn't know it was that day." "Well, the day he died he was his normal self. He seemed like he was doing okay…until the night before he died because he was just like his old self again…Me personally, I thought he was getting better…we got up and we did a lot of stuff together before he passed away." "Because she went to school that day. Then we also went to the clinic afterward to get some blood. And she was doing fine, you know." "We were all taken by surprise." "Because we didn't expect it. I don't know if you could ever expect it to be a particular day but I didn't expect it to be that day."
Overdue (7, 16.7)	"I didn't think he would last that long. He was on the ventilator and when we took him off the ventilator he lived for four more days." "The emotional part is you just don't know when it's going to happen and you're sitting there waiting for it and it's almost anticipating it because you don't want to miss it and just…just keep on going. The stress that it puts on you, of waiting for that to happen. You know it's going to happen and to have to wait for it, it kind of takes a toll on you after a while." "So, you know, his passing was kind of a relief in that perspective. I was…you know, you're sad to see him go but you're relieved that he's in a better place." "And we had been surprised that she had lasted as long as she had. We had been on constant vigil the last week thinking any moment could be the moment that she would leave."

Table 3

Category of When Death Occurred According to Patient and Clinical Characteristics

	n	Category of Occurrence			***P*-value** (χ^2 **test)**
		Anticipated	**Surprising**	**Overdue**	
Diagnosis					0.63
Brain tumor	14	5 (35.7%)	6 (42.9%)	3 (21.4%)	
Leukemia/lymphoma	9	6 (66.7%)	2 (22.2%)	1 (11.1%)	
Solid tumor	19	11 (57.9%)	5 (26.3%)	3 (15.8%)	
Sex					0.70
Female	18	9 (50.0%)	5 (27.8%)	4 (22.2%)	
Male	24	13 (54.2%)	8 (33.3%)	3 (12.5%)	
Location of death					0.14
Home/ St. Jude domicile	28	17 (60.7%)	6 (21.4%)	5 (17.9%)	
St. Jude (not ICU)	8	3 (37.5%)	5 (62.5%)	0 (0.0%)	
St. Jude ICU	6	2 (33.3%)	2 (33.3%)	2 (33.3%)	

ICU = intensive care unit.