Symptoms and suffering at the end of life in children with cancer: an Australian perspective

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ABSTRACT

Objective: To examine the symptoms, level of suffering, and care of Australian children with cancer at the end of life.

Design, setting and participants: In a study conducted at the Royal Children's Hospital, Melbourne, parents of children who had died of cancer over the period 1996–2004 were interviewed between February 2004 and August 2006. Parents also completed and returned self-report questionnaires.

Main outcome measures: Proportions of children suffering from and treated for various symptoms; proportion of children receiving cancer-directed therapy at the end of life; proportion of children whose treatment of symptoms was successful; location of death.

Results: Of 193 eligible families, 96 (50%) were interviewed. All interviews were conducted in person, and occurred a mean of 4.5 years (SD, 2.1 years) after the child's death. Eighty-four per cent of parents reported that their child had suffered "a lot" or "a great deal" from at least one symptom in their last month of life — most commonly pain (46%), fatigue (43%) and poor appetite (30%). Children who received cancer-directed therapy during the end-of-life period (47%) suffered from a greater number of symptoms than those who did not receive treatment ($P = 0.03$), but the severity of symptoms did not differ between these groups. Of the children treated for specific symptoms, treatment was successful in 47% of those with pain, 18% of those with fatigue and 17% of those with poor appetite. Of the 61 families who felt they had time to plan where their child would die, 89% preferred to have their child die at home. The majority of children (61%) died at home. Of those who died in hospital, less than a quarter died in the intensive care unit.

Conclusions: Relatively high rates of death at home and low rates of unsuccessful medical interventions suggest a realistic approach at the end of life for Australian children dying of cancer. However, many suffer from unresolved symptoms, and greater attention should be paid to palliative care for these children.

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In Australia, cancer is the leading cause of non-accidental death in childhood, and children with cancer make up the majority of those receiving end-of-life care.[1] Over the past three decades, there has been increasing interest internationally in the medical aspects of palliation in childhood cancer, with data suggesting that current approaches are failing to meet the needs of patients and their families.[2-4] Commonly reported symptoms, including pain, fatigue, poor appetite and dyspnoea, are typically suffered by over 75% of patients,[5-9] and psychological problems, such as sadness and uncontrolled anxiety, have been documented in a high proportion of children dying of cancer.[8,9] Medical reports also suggest that, despite no realistic chance of cure, many children continue to receive cancer-directed therapy during the end-of-life period[8,9] and die unnecessarily in hospital.[9,10]

However, the results of international studies may not be directly applicable to children dying of cancer in Australia. Firstly, there are major differences in health care systems between Australia and other countries. Secondly, compared with countries such as Canada, the United States and the United Kingdom, Australia has more limited access to and use of experimental (Phase I and Phase II) anticancer agents and fewer oncologists providing care to children with cancer at the end of life. Thirdly, Australia's great geographical distances often necessitate increased provision of local and regional services. While symptoms of children dying in an Australian hospital have been well documented[11] and remain a concern for families, who usually prefer to care for their children at home,[12] there is sparse information on families' experiences of caring for children dying of cancer in Australia.

METHODS

Participants

Our study was conducted at the Royal Children's Hospital, Melbourne. Parents of children who had died of cancer over the period 1996–2004 were interviewed between February 2004 and August 2006. Parents were eligible for our study if they were English-speaking, had no known major psychiatric illness, and had had a child who died at least 1 year before study enrolment. Permission to contact the parents was also required from the child's primary oncologist and the social worker responsible for the family's care.

Parents who met eligibility criteria received a letter inviting them to participate in our study, along with a reply-paid "opt-in" or "opt-out" postcard. If parents returned an opt-in postcard, they were further contacted by telephone to arrange an interview.

Measures and procedure

Once parents had provided written informed consent, trained clinical psychologists conducted structured, in-person interviews and provided self-report questionnaires. The content of the interview and questionnaires was developed by one of us (JW) and has previously been reported.[9] Some measures and language were adjusted for use in the Australian population. A summary of items in the structured interview and self-report questionnaire is given in Box 1. In most cases, one parent was interviewed, but occasionally, both parents asked to be present during the interview. The self-report questionnaire was completed once for each participating family.

Statistical analyses

In cases in which questions were left unanswered or information was unavailable, the elements in question were excluded from our analysis. Variables were graded with the use of five-point Likert scales. Statistical analysis was performed using Fisher's exact probability test, the χ^2 test for independence and the Mann–Whitney U test for independent observation.

1 Items in the structured interview and self-report questionnaire

Structured interview

- Section A: Prior experience with end-of-life care
- Section B: Definition of the end-of-life care period
- Section C: Quality of life
- Section D: Caregiver–family relationship
- Section E: Decision making

Self-report questionnaire

- Section F: Death of the child
- Section G: Role of cancer therapy in end-of-life care
- Section H: Medical problems
- Section I: Parental variables

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Ethics approval

Our study was approved by the Human Research Ethics Committee of the Royal Children's Hospital, Melbourne.

RESULTS

Of 193 families who were identified as eligible for our study, 144 could be located and 100 agreed to participate. Parents from 96 families (response rate, 50%) were ultimately interviewed. Compared with all patients treated at the Royal Children's Hospital between 1996 and 2004, members of our patient cohort did not differ significantly in age at diagnosis and type of diagnosis (data not shown). Interviews took place a mean of 4.5 years (SD, 2.1 years) after the child's death, and lasted for an average of 144 minutes (range, 45–420 minutes). Of the 96 parents who were interviewed, 89 subsequently returned self-report questionnaires.

Parent and child characteristics

At the time of interview, the mean age of parents was 43.6 years (SD, 8.1 years). Most participating parents were women (82%) and most were white (95%). Forty-nine per cent of the parents had some level of tertiary education, and 60% identified with a Christian faith.

Fifty-seven per cent of the children were boys, with a mean age of 6.7 years (SD, 5.2 years) at diagnosis. The average duration of disease was 2.7 years (SD, 2.4 years; range, 1 month to 12.5 years), and the mean age at death was 9.4 years (SD, 5.8 years). Thirty-six per cent of the children had leukaemia, 32% had a brain tumour, and the remaining 32% had other solid tumours (most commonly neuroblastoma, Ewing's sarcoma or rhabdomyosarcoma). There were no significant differences, for any of these variables, between children from participating families and those from eligible families who did not participate in our study (Box 2). The mean duration of palliative care (defined from the point when the parent accepted there was no realistic chance of cure) was 4.3 months (SD, 8.3 months; range, 1 day to 6 years).

Supportive care services

Most parents (82%) recalled a meeting in which they discussed the involvement of out-of-hospital palliative care services in their child's end-of-life care. Overall, 75% of parents decided that they would like to involve out-of-hospital palliative care, and all but one of these families did so.

Quality of care

Most parents were satisfied with the overall quality of care provided by the oncologist, with 67% rating it as very good or excellent. The quality of care provided by out-of-hospital palliative care services was rated as very good or excellent by 74% of parents whose children received care from such services.

Therapy

Almost half of the children (47%) received cancer-directed therapy during their end-of-life period (ie, when it was felt that there was no realistic chance of cure). Of these, 33% were reported to have experienced significant side effects from the treatment.

A third of parents whose children received cancer-directed treatment during the end-of-life period felt that the primary goal of therapy was to lessen the child's suffering as much as possible, but many commented that the treatment had not been effective. Other commonly reported primary goals included to extend life for as long as possible (12%) and to ensure that everything possible had been done (12%). In addition, 30% of children received alternative or complementary therapy (including homoeopathy, naturopathy and Chinese medicine) during their end-of-life period.

Symptoms and suffering

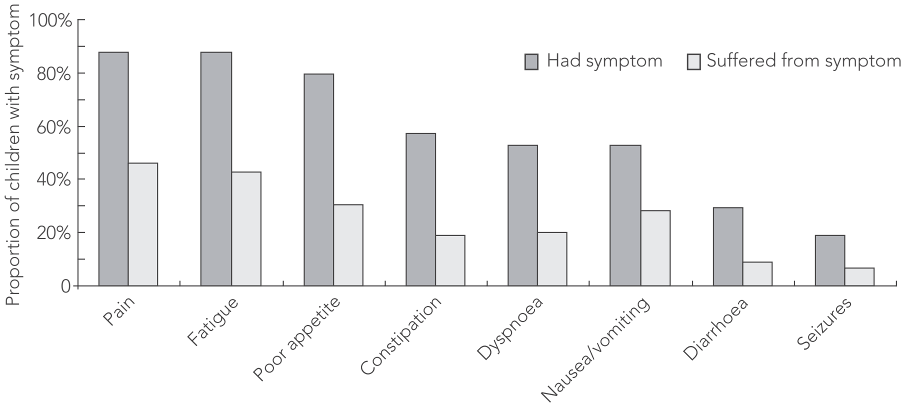
The proportion of children who, according to parental reports, suffered from specific symptoms during the last month of life, and the proportion who suffered "a lot" or "a great deal" as a result, are summarised in Box 3. Children who received cancer-directed therapy during the end-of-life period suffered from a greater number of symptoms than those who did not receive treatment (*P* = 0.03); however, the severity of symptoms did not differ between these groups. The most frequently reported symptoms were pain, fatigue and poor appetite. The proportion of children who were reported to experience significant suffering from these symptoms varied from 46% (in the case of pain) to 7% (in the case of seizures). Overall, 84% of children were reported to have experienced "a lot" or "a great deal" of suffering from at least one symptom, and 43% from three or more symptoms.

The proportions of children treated for various symptoms in the last month of life and the reported success rates of treatment are shown in Box 4. The most commonly treated symptoms were pain (in 95%), constipation (in 74%) and nausea/vomiting (in 70%), and the least commonly treated symptom was fatigue (in 14%). Symptoms were more likely to be treated in children who experienced a high level of suffering than in other children: fatigue (24% v 5%),

2 Clinical and demographic characteristics of participating and non-participating eligible children

	Eligible, participating	Eligible, non-participating	*P*
Number of patients	96	97	
Male sex (%)	57	57	0.93
Mean age (years)			
At diagnosis	6.7	6.4	0.67
At death	9.4	8.7	0.43
Diagnoses (%)			0.18
Leukaemia	36	48	
Brain tumour	32	27	
Other solid tumour	32	24	

3 Proportion of children who experienced specific symptoms compared with the proportion who, according to parental reports, suffered "a lot" or "a great deal" as a result of these symptoms in the last month of life



dyspnoea (82% v 47%), constipation (94% v 65%), and poor appetite (52% v 36%).

The most successful treatments (expressed as the proportion of treated children whose treatment was successful) were those for pain (47%), dyspnoea (47%) and seizures (36%). The least successful treatments were for diarrhoea (9%), fatigue (18%) and poor appetite (17%) (Box 4). The implementation and success of treatments were not affected by whether the child died in hospital or at home, with one exception: dyspnoea was significantly more likely to be treated in children who died in hospital than in those who died at home ($P = 0.02$).

Psychological symptoms

During the last month of life, 42% of children were reported to have been more than a little sad, 38% to have had little or no fun, and 21% to have often been afraid. In the end, regardless of whether death occurred in hospital or at home, 83% of parents reported that their child's death was somewhat or very peaceful.

Location of death

Sixty-one parents (63%) felt that they had time in advance to plan the location of their child's death and, of these, 89% preferred to have their child die at home. Overall, 61% of children died at home. Of those who died in hospital, almost a quarter died in the intensive care unit and the rest died on the oncology ward or at a local hospital. Life-sustaining treatments (eg, cardiopulmonary resuscitation, life support) were pursued in only eight children. Of the children whose parents had time to plan the location of death, all except two died in the planned location.

Bereavement

Eighty families (83%) recalled having been offered bereavement follow-up by the hospital. Follow-up after death was provided by the primary oncologist ($n = 54$), another doctor ($n = 22$), nursing staff ($n = 48$) and/or a social worker ($n = 36$).

DISCUSSION

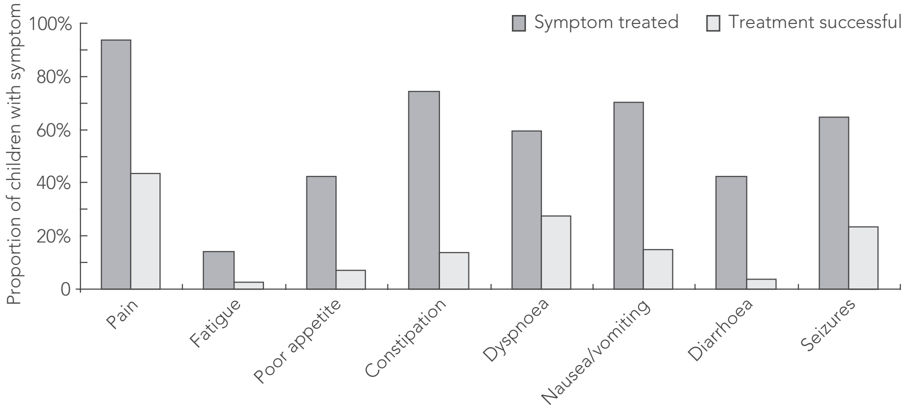
Recent guidelines for paediatric palliative care in Australia emphasise that high-quality medical care should be readily available and should focus on meeting the needs of not only patients but also their families and communities.[13] To date, it has not been established whether the care of children dying of cancer in Australia achieves these goals. Our study cohort, recruited from the largest of the eight specialist paediatric oncology units in Australia, appears to be representative in age and tumour types of the childhood cancer population. Although data on parental factors such as age, ethnicity, educational level and religion were not available for all families whose children were cared for between 1996 and 2004, we believe that, allowing for the exclusion of non-English-speaking parents, the sample was representative.

It was pleasing to find that most families were offered out-of-hospital palliative care services. Because of the relative rarity of death from medical causes in childhood and the large geographical areas covered, this step often necessitates collaboration with adult-based palliative care services and local and regional health services. Without this cooperation, adequate services could not be provided. Overall, families appeared to be satisfied with this component of their child's palliative care.

A key finding of our study was the lower level of aggressive, cancer-directed treatment during the end-of-life period compared with the level in a similar cohort in the US (Box 5). Whether this reflects a more enlightened approach to palliative care or a reduced capacity to offer novel and experimental treatments is unclear. Certainly, with regard to children in our study who received cancer-directed therapy in the end-of-life period, the primary reasons for most of the treatment were to relieve suffering and extend life. It is noteworthy that these treatments appeared to be ineffective, even for symptom control. It was not possible in our study to determine whether patients who received cancer-directed treatments had medical problems directly related to their tumour burden.

As in other international studies, pain, fatigue and poor appetite were the three most commonly reported symptoms during

4 Proportion of children treated for various symptoms and reported success rates of treatment in the last month of life



5 Comparison of characteristics of end-of-life care in our study with those of previous international studies

Study	Wolfe et al[9]	Theunissen et al[8]	Jalmsell et al[6]	Hongo et al,[5] Fujii et al[10]	Heath et al
Country	United States	Netherlands	Sweden	Japan	Australia
Years	1990–1997	1999–2002	1992–1997	1994–2000	1996–2004
Number of patients	103	32	368	28	96
Palliative care discussion	66%	nr	nr	71%	82%
Cancer-directed treatment	56%	28%	nr	nr	47%
Complementary treatment	28%	nr	nr	nr	30%
Symptoms					
Suffering from one or more symptoms	89%	100%	nr	nr	84%
Suffering from three or more symptoms	51%	> 50%	nr	nr	43%
Pain	81%	75%	73%	75%	87%
Fatigue	98%	72%	86%	71%	87%
Poor appetite	81%	75%	71%	100%	80%
Dyspnoea	81%	41%	38%	82%	53%
Died in hospital	51%	12%	nr	71%	39%
Died in ICU	23%	nr	nr	nr	9%

ICU = intensive care unit. nr = not reported.

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the end-of-life period. The rates of these symptoms in our Australian population appeared to be very similar to those reported previously in US, European and Japanese populations (Box 5). It was pleasing that, in our study, a substantial proportion of children who experienced significant suffering from symptoms received treatment. However, it was disappointing that current treatments appear inadequate, with success rates of under 50% for all symptoms and under 20% for symptoms such as fatigue, poor appetite, constipation and diarrhoea. Given the positive impact that specialist paediatric palliative care services have had overseas,[14] it is hoped that their recent introduction in the state of Victoria will improve symptom control and lessen suffering for children dying of cancer.

A striking difference between our study and previously published international studies was the low proportion of patients who died in hospital and, more specifically, in intensive care units (Box 5). The one study that reported a higher proportion of children dying at home[8] was skewed by the elimination of children who died from treatment-related complications and those who were treated for less than 6 months. As in other international studies, nearly all parents in our study indicated a preference for their child to die at home, so the high rate of deaths at home was a positive finding. Furthermore, our finding that most symptoms were just as likely to be treated at home as in hospital, and that treatment was no less likely to be successful, supports the feasibility of providing adequate care at home.[15,16] In addition, in view of previously reported evidence of better psychological outcomes in parents whose child dies at home,[15,17,18] these findings are reassuring. The universal provision of bereavement services may also be a vital component of recovery from such a traumatic event.

There are a number of shortcomings of our study that restrict interpretation of the results. Our findings, based on a single hospital, may not accurately reflect the experiences in other areas of Australia, particularly the more remote areas of central, northern and western Australia. In addition, the possibility of selection bias cannot be discounted. In particular, the exclusion of non-English-speaking parents and those with psychiatric conditions (which constituted about 10% of parents) may have underestimated important problems relating to communication and access to services, as well as issues of cultural diversity. Recall bias is another factor that cannot be excluded. The information collected was retrospective, relying on accurate recollection by parents some years after the death of their child. Although the significance of events surrounding the death of a child means that parents are not likely to forget them easily, it is possible that their interpretation may have been affected by their own subsequent bereavement experiences. Furthermore, parental impressions of their child's symptoms and suffering may not accurately reflect the child's actual experience. Data from adult studies suggest that proxies' perceptions of patients' pain alters (downwards) with time[19] and is influenced by the caregiver burden[20] — factors that were not accounted for in our study.

CONCLUSION

Relatively high rates of death at home and low rates of heroic medical interventions suggest a realistic approach to care of children with cancer at the end of life. However, many Australian children who die of cancer suffer from unresolved symptoms. Greater attention should be paid to palliative care for these children.

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COMPETING INTERESTS

None identified.

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