Palliative Medicine 2006; **20:** 161–169

Home care of a child dying of a malignancy and parental awareness of a child's impending death

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In this population-based study, we found that parents who are aware that their child will die from a malignancy are more likely to care for their child at home during the child's last month of life compared to parents who are not aware. End-of-life home care was comparable to hospital care for satisfactory pain relief, access to pain relief and access to medications for other physical symptoms. Using an anonymous postal questionnaire, we obtained information from 449 parents in Sweden who had lost a child due to a malignancy between 1992 and 1997, 4 to 9 years before participating in our study. The prevalence of dying at home and being cared for at home during the last month of life was 23.7% when parents realized intellectually more than 1 month in advance that the child would die (versus 12% who did not), 28.7% for parents who sensed that the child was aware of his or her imminent death (versus 7.8% who did not sense this) and 21.9% for those who received information that the child's illness was incurable (versus 9.4% who did not receive the information). Prevalence of children's unrelieved pain was 11.6% for those receiving home care and 15.3% for those receiving care outside the home. *Palliative Medicine* 2006; **20:** 161–169

Key words: awareness; cancer; child; health care facilities; palliative care

Introduction

Family members often want children with cancer to be cared for in the home.[1–5] End-of-life care at home may give comfort for the child; she or he has familiar surroundings and the home environment facilitates visits from friends and extended relatives.[6,7] It may, additionally, provide parents with the opportunity to contribute to the dignity of the death.[2] Nevertheless, in spite of general consensus that end-of-life care at home is desirable to families, only some children are cared for at home when dying of a malignancy. Little is known about why certain parents care for their children at home at the end of life.

Families may be reluctant to care for children at home if they fear that they may not have the skill to take care of pain or other symptoms of their children away from medical facilities.[5,8] Children dying of a malignancy experience substantial pain and suffering.[9] Frequency and intensity of pain may be underestimated,[10] and treated insufficiently.[11] The end of life, when pain can be intense, may be a critical time for children to be close to health-care personnel and to have access to adequate pain relief and hospital facilities. Based on interviews, Papadatou *et al*. suggest that some families choose hospitalization for end-of-life care with the hope that the child's pain can be better controlled in the hospital than in the home.[2] Furthermore, Goldman *et al*. suggest that when the child is cared for at home, the heath care staff may rarely encounter the child, causing the staff to feel inadequately prepared to address the medical and emotional needs of the child and family.[12]

We assessed the relationship between place of the child's end-of-life care in relation to several possible predictors related to parental awareness of the child's impending death. We also examined symptom relief relative to place of end-of-life care.

Methods

Children in Sweden diagnosed with a malignancy before the age of 17, and who died before the age of 25 (between 1992 and 1997), were identified through computerized linkage with the Swedish Cause of Death Register and

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10.1191/0269216306pm1139oa

the Swedish Cancer Register. Linkage was conducted by means of the ten-digit personal identification number assigned to all Swedish citizens. The children's parents were identified from the Swedish Population Register. A parent was defined as being the guardian of the child at the time of the child's diagnosis. Eligible parents were born in one of the Nordic countries, had a listed phone number, and spoke Swedish. In all cases, verification of the diagnosis and permission to contact the family were obtained from the child's former physician. Between August and October 2001, we sent a letter explaining the study aims and an invitation to participate to both mothers and fathers separately. In total there were 561 eligible parents included in the Swedish population registries, of which 112 declined to participate, were not reachable, or agreed to participate but did not return the questionnaire, resulting in a response rate of 80%.

A questionnaire was developed based on seven successive in-depth interviews with bereaved parents. Face-validity was assessed with 15 bereaved parents to ensure the questions were understood correctly. In a pilot study of 22 bereaved parents, the logistics of using a postal questionnaire were tested to determine if there were certain questions or sections of the survey that were unlikely to be answered. The questionnaire was modified based on this pilot test. The final version included 129 questions with a total of 365 items concerning the child's care and the parents' mental health 4 to 9 years after the child's death.

We mailed a questionnaire individually to each of the children's parents. For the purposes of follow-up, this was accompanied by a reply card (not attached and not linkable to the questionnaire) indicating who had returned it. To preserve confidentiality, the questionnaire was returned in one envelope and the card was returned separately. As such, we were unable to identify or compare the responses of parents of the same child. Ten days after mailing the questionnaire, we sent a combined thank-you and reminder card. Parents who did not send in the card indicating that they had returned the survey were contacted by telephone. The Ethics Committee of Karolinska Institutet approved this study.

Four questions were used to assess parental awareness of the child's imminent death. They included: 'When did you realize intellectually that your child was going to die?' ('less than 1 month before his/her death', 'more than 1 month before his/her death'); 'When did you realize emotionally that your child was going to die?' ('less than 1 month before his/her death', 'more than 1 month before his/her death'); 'When do you think that your child realized that he/she was going to die?' ('never realized', 'realized a month or more before she/he died'); 'When did you get the information that your child's illness was incurable' ('never got information or got information less than a month before his/her death', 'got information a month or more before she/he died'). Nine variables were evaluated regarding the care received during the last month before the child's death. These included access to relief of pain, access to relief of pain because of lack of health-care personnel, relief of other symptoms, dietary advice, relief of anxiety, relief of other psychological symptoms, access to play therapy, and receipt of anxiety and depression medication. For these variables, the category 'not relevant' was excluded in the analysis. (See appendix for question wording and response categories.)

Descriptive statistics were performed and odds ratios were calculated to examine the relationship between demographic explanatory variables and our outcome variable of interest. A main variable of interest was whether or not the child was cared for and died at home during the last month of life or in another location. This dichotomous variable, 'Cared for and dying at home', consisted of two categories. One category included only children who were both cared for at home in the last month of life and died at home. The other category included children who either died or were cared for in a location other than home for any period of time during the last month of life. In Tables 2 and 3, items related to demographic characteristics and awareness of the child's death were used as explanatory variables, while the variable regarding place of care and death was the outcome variable. In Tables 4 and 5, place of care and death was used as the explanatory variable, while factors related to children's access to symptom relief and medical care were the outcome variables. We first calculated crude odds ratios and 95% confidence intervals, followed by odds ratios and 95% confidence intervals adjusted for type of malignancy.[13] Because in many cases more than one parent per child completed the survey, odds ratios were also stratified by the gender of the parent responding.

Results

Place of children's death were as follows: 158 (36%) at home, 107 (24%) in the children's oncology ward, 84 (19%) in a general children's ward, 48 (10%) died in the intensive care unit, 19 (5%) in another ward, 14 (3%) in the adult ward, and 10 (2%) in another location.

Demographic characteristics of the sample are displayed in Table 1. Unadjusted odds ratios of dying at home versus at another location are shown in Table 2 in relation to the demographic characteristics of the sample. The results suggest a lower odds of dying and being cared for at home in the last month of life for children with sarcoma or neuroblastoma (OR: 0.6; 95% CI: 0.3, 1.0), and an even lower odds (OR: 0.2; 95% CI: 0.1, 0.4) of dying and being cared for at home for children with

Table 1 Demographic characteristics

Characteristics	No. of parents with loss (%)
No. identified as eligible in registries	561
Reasons for no response	
Refused to participate	30 (5)
Agreed but did not participate	59 (11)
Not reachable	23 (4)
Total non-responders	112 (20)
Providing information	449 (80)
Biological parent of the child	438 (98)
Non-biological parent	9 (2)
Not stated	2 (<1)
Male	191 (43)
Female	251 (56)
Not stated	7 (2)
Age	
<30 years	66 (15)
30–39	232 (52)
40 years or older	146 (32)
Not stated	5 (1)
Marital status at child's diagnosis	
Married or living with the child's other parent	394 (88)
Married or living with another partner	15 (3)
Has a partner but lives alone	10 (2)
Single	25 (6)
Not stated	5 (1)
Marital status at time of survey	
Married or living with the child's other parent	329 (73)
Married or living with another partner	51 (11)
Has a partner but lives alone	17 (4)
Single	45 (10)
Not stated	7 (2)
No. of children at child's diagnosis	
1	82 (18)
2	192 (43)
3	116 (26)
4 or more	54 (12)
Not stated	5 (1)
Parent's level of education	
Elementary school	83 (18)
High school	215 (48)
University	141 (31)
Not stated	10 (2)
Employment status	
Employed	370 (82)
Unemployed	10 (2)
On sick leave/retired	36 (8)
Housewife/husband	5 (1)
Home with children	8 (2)
Student	14 (3)
Not stated	6 (1)
Residential region	
Rural	99 (22)
Village/town	273 (61)
Large city (>500 000 inhabitants)	68 (15)
Not stated	9 (2)
Religiousness	
Not religious at all	185 (41)
Somewhat religious	155 (35)
Quite religious	68 (15)
Very religious	25 (6)
Not stated	16 (4)

leukemia or lymphoma. Regarding other demographic variables, no other clear associations were observed in our sample.

Table 3 shows odds ratios for outcomes related to home care and death at home during the last month (versus being cared for at least part of this period elsewhere or dying elsewhere), in relation to awareness of the child's imminent death as an independent variable. Parents who reported intellectually realizing that their child would die had double the odds that their child die and be cared for at home in the last month of life (OR: 2.2; 95% CI: 1.3, 3.8) compared to parents who reported not intellectually realizing it. Parents reporting that they realized emotionally that their children would die were also associated with a greater odds that their children would die and be cared for at home during the last month (OR: 2.0; 95% CI: 1.2, 3.4) compared to parents not aware emotionally. Finally, parents who sensed that their child was aware of his/her own imminent death had almost five times the odds of caring for the child at home during the last month and for him/her to die at home (OR: 4.7; 95% CI: 2.3, 9.7) compared to those not sensing the child was aware. The odds of children dying and being cared for at home in their last month of life were almost three times higher for parents who reported getting the information that their children's illness was incurable a month or more before the death (OR: 2.7; 95% CI: 1.5, 4.9) compared to those reporting they never got such information. Compared to data of mothers and fathers combined, when the awareness variables were stratified by gender of the respondent in Table 3 some differences were found. Overall, fathers' awareness appeared to be more strongly related to the child dying at home than the mothers' awareness.

Relationships between place of death and the odds ratios of having children's somatic and psychological needs addressed are displayed in Table 4 and Table 5. Although there were fairly high point estimates related to access to relief of pain (OR: 2.1; 95% CI: 0.5, 9.1) and access to relief of other psychological symptoms beside anxiety (OR: 1.7; 95% CI: 0.8, 3.7), these associations were not statistically significant. Regarding the other variables, there were no other notable associations or statistically significant differences between access to relief of symptoms of children who died and were cared for at home during the last month relative to those who were not. Results stratified by gender of the respondent yielded minor differences compared to the unstratified estimates (data not shown). Adjustment for type of malignancy in Tables 3–5, showed only negligible changes in point estimates when compared with unadjusted odds ratios, suggesting that type of malignancy is not a confounder (data not shown).

Table 2 Associations between demographic variables and home as the place where the child was cared for during the last month and died

Demographic variables	No./total[a] (%)	Odds ratios (95% CI)
Age of child at diagnosis		
0–4 (reference)	22/129 (17)	1.0
5–8	17/92 (19)	1.1 (0.6, 2.2)
9–15	12/97 (12)	0.7 (0.3, 1.5)
16–24	19/98 (19)	1.2 (0.6, 2.3)
Type of malignancy in child		
Brain tumor (reference)	38/150 (25)	1.0
Leukemia or lymphoma	7/141 (5)	0.2 (0.1, 0.4)
Sarcoma or neuroblastoma	13/87 (15)	0.6 (0.3, 1.0)
Other malignant disease	12/41 (29)	1.2 (0.6, 2.6)
Age of parent (years)		
20–29 (reference)	15/65 (23)	1.0
30–39	37/222 (17)	0.7 (0.3, 1.3)
40–60	18/131 (14)	0.5 (0.2, 1.1)
Biological parent		
No (reference)	0/9 (0)	1.0
Yes	71/412 (17)	∞ (*P*=0.37)
Gender of parent answering questionnaire		
Male (reference)	26/180 (14)	1.0
Female	44/237 (19)	1.4 (0.8, 2.3)
Marital status at child's diagnosis		
Married or living with the child's other parent (reference)	63/371 (17)	1.0
Married or living with a partner other than the child's other parent	1/13 (8)	0.4 (0.1, 3.1)
Had a partner but lived alone	3/10 (30)	2.1 (0.5, 8.3)
Single	3/24 (13)	0.7 (0.2, 2.4)
Parents level of education		
Elementary school (reference)	11/74 (15)	1.0
Secondary school	38/206 (19)	1.3 (0.6, 2.7)
College	22/138 (16)	1.1 (0.5, 2.4)
No. of children at child's diagnosis		
1 (reference)	15/80 (19)	1.0
2	25/184 (14)	0.7 (0.3, 1.4)
3	17/109 (16)	0.8 (0.4, 1.7)
≥4	13/45 (29)	1.8 (0.7, 4.1)
Parent's residential region		
Rural (reference)	14/95 (15)	1.0
Village or town	53/261 (20)	1.5 (0.8, 2.8)
City (population >500 000)	4/63 (6)	0.4 (0.1, 1.3)
Parent's employed status		
Employed (reference)	56/351 (16)	1.0
Unemployed	2/10 (20)	1.3 (0.3, 6.4)
On sick leave or retired	7/30 (23)	1.6 (0.7, 3.9)
Homemaker or home with children	1/5 (20)	1.3 (0.1, 12.0)
Home with children	2/8 (25)	1.8 (0.3, 8.9)
Student	3/14 (21)	1.4 (0.4, 5.3)
Religiousness		
Not religious (reference)	28/177 (16)	1.0
A little, somewhat or very religious	42/236 (18)	1.2 (0.7, 1.9)
Often had feelings of anxiety the year before the child fell ill		
No (reference)	64/368 (17)	1.0
Yes	6/49 (12)	0.7 (0.3, 1.6)
Often felt depressed the year before the child fell ill		
No (reference)	63/369 (17)	1.0
Yes	7/48 (15)	0.8 (0.4, 1.9)
Have you had contact with other parents who have lost a child to cancer		
No (reference)	32/165 (19)	1.0
Yes	39/253 (15)	0.8 (0.5, 1.3)
Have lost someone close other than child in last 10 years		
No (reference)	18/104 (17)	1.0
Relative or friend	53/306 (17)	1.0 (0.6, 1.8)
Partner	0/5 (0)	0 (P =0.58)
Have someone to share emotional problems with		
Over half to all (reference)	61/351 (17)	1.0
None or almost none	9/60 (15)	0.8 (0.4, 1.8)
Able to absorb information about child's illness		
Moderate/much (reference)	43/246 (18)	1.0
No, or a little	23/115 (20)	1.2 (0.7, 2.1)
Participated in child's care during whole time during last month		
Yes (reference)	67/388 (17)	1.0
No**	4/33 (12)	0.7 (0.2, 1.9)
Felt too heavy a burden for child in last month		
Yes entirely (reference)	10/48 (21)	1.0
No or less than entirely	59/363 (16)	0.7 (0.3, 1.6)

[a] Due to missing data, total respondents to each question do not always sum to 449.

**This category also includes respondents who did not provide information.

Discussion

Across a variety of similar measures of parental awareness, we found strong evidence for an association between a parent's awareness of a child's imminent death and the care of the child during the last month and death at home. A child's care and dying at home did not appear to be associated with adverse symptom control or relief of pain.

Our data support the hypothesis that when families are aware of the child's impending death, they may be more likely to take care of and to have their children die at home. This association appears to be especially strong if parents sense that a child is aware of his or her own imminent death. This finding possibly supports clinical experience suggesting that children prefer to die at home.[12,14] We found an association between the receipt of information that the child's illness was incurable a month before the death and likelihood of end-of-life care at home. This may suggest that parents who are given time to process the information are better able to prepare for the death in ways that they wish, such as by caring for the child at home. Perhaps more counseling or support to prepare parents for a child's death could improve awareness. Alternatively, the association between awareness and place of death may also be due to the fact that parents, who had already decided to have their child die at home, were subsequently more willing to receive or

Table 3 Parents' and child's awareness about death and association with death at home and care at home in the last month

	Overall		Fathers		Mothers	
	No./total (%)	Odds ratio (95% CI)	No./total (%)	Odds ratio (95% CI)	No./total (%)	Odds ratio (95% CI)
Realized intellectually child would die						
No information or became aware <1 month before the death (reference)	28/236 (12)	1.0	10/104 (10)	1.0	17/130 (13)	1.0
Aware >1 month before the death	43/185 (24)	2.2 (1.3, 3.8) P <0.01	16/76 (21)	2.5 (1.1, 5.9) P < 0.05	27/107 (25)	2.2 (1.2, 4.3) P <0.05
Realized emotionally child would die						
No information or became aware <1 month before the death (reference)	46/321 (14)	1.0	14/135 (10)	1.0	31/183 (17)	1.0
Aware >1 month before the death	25/100 (25)	2.0 (1.2, 3.4) P <0.05	12/45 (27)	3.1 (1.3, 7.4) P < 0.01	13/54 (24)	1.6 (0.7, 3.2) P =0.2
Parent's sense that child was aware of his or her imminent death						
Never aware (reference)	14/179 (8)	1.0	5/85 (6)	1.0	9/92 (10)	1.0
Aware >1 month before death	25/87 (29)	4.7 (2.3, 9.7) P <0.01	11/38 (29)	6.5 (2.1, 20.4) P <0.01	14/49 (29)	3.7 (1.5, 9.3) P <0.01
Received information that child's illness was incurable						
No information or became aware <1 month before the death (reference)	16/170 (9)	1.0	6/74 (8)	1.0	10/95 (11)	1.0
Aware >1 month before the death	55/251 (22)	2.7 (1.5, 4.9) P <0.01	20/106 (19)	2.6 (1.0, 6.9) P < 0.05	34/142 (24)	2.7 (1.2, 5.7) P <0.01

P-values correspond to the test of the null hypothesis that the odds ratio is 1.0 versus the two-sided alternative.

request more information than other parents. Another possibility is that this association may be due to the physician's behavior; a physician who believed it was better for the child to die at home may have provided more information about the child's imminent death, thus influencing the parent's decision. Because study information was gathered retrospectively, additional information is needed to conclusively interpret the meaning of these associations.

We can hypothesize several potential reasons why parents may want their child to be cared for and to die at home if they are aware of a child's impending death. Home care may facilitate the family being present at the time of death and promote closure. There is some indication that long-term adjustment may be better for parents whose children have died at home.[15] If dying at home facilitates communication between children and their families, this may be one advantage of home as a place of death for a child with cancer. Lauer *et al*. found an increased likelihood of brothers and sisters having talked about death with their siblings with cancer when they died at home (53%) compared to at the hospital (19%).[14] This may be important because regret about not having talked about death has been associated with a higher risk of experiencing anxiety 4 to 9 years after the loss in bereaved parents.[16] Research by Valdimarsdóttir *et al*. in a study focusing on wives awareness of their husband's impending death from cancer, found that compared to those with short awareness times of 24 hours or less, widows with awareness times of 3 months to 1 year had lower risk of long-term anxiety related symptoms.[17] Further studies are needed to examine the role of awareness of a child's impending death and the mental health of surviving family members.

Overall, we found that dying at home is not negatively related to symptom relief. However, dying at home was strongly related to the type of malignancy. Specifically, patients with leukemia or lymphoma were much less likely to die at home, possibly because they require blood products more frequently than children with other types of malignancies. The fact that symptom relief did not seem to be related to place of death is of interest for parental bereavement, because of parents' concerns about being able to provide adequate relief of symptoms at home,[5,8,18] and parents' experience of mental distress as a result of children's physical pain.[19,20] One previous study has noted some dissatisfaction with pain relief in children cared for at home in 11% of the families, but no comparison is available to know the probability among those at the hospital.[1] The importance of adequate support and contact with the hospital staff for families with children dying at home has been emphasized,[21,22] along with the option of being able to return to the hospital, if necessary.[1]

A major strength of this study is the use of a population-based setting, including nearly 100% of eligible families in Sweden from which we contacted study participants. The use of the national registries enabled us to avoid problems due to selection. Four variables regarding parental awareness of imminent death yielded similar associations, giving us reason to believe that there is, in fact, a strong association between the

Table 4 Associations between child's somatic needs being addressed and care received at home in the last month of life

	Access to relief of pain (moderate or much)		Pain not relieved because of lack of staff (some or many times)		Access to relief of other physical symptoms beside pain (moderate or much)		Access to dietary advice (moderate or much)	
Place of death and place cared for in last month	No./ total (%)	Odds ratio (95% CI)	No./total (%)	Odds ratio (95% CI)	No./total (%)	Odds ratio (95% CI)	No./total (%)	Odds ratio (95% CI)
Home	67/69 (97)	2.1 (0.5, 9.1) P =0.3	8/69 (12)	0.7 (0.3, 1.6) P =0.4	59/68 (87)	1.3 (0.6, 2.7) P =0.5	46/67 (69)	1.0 (0.6, 1.7) P =0.9
Other	321/341 (94)	1.0	52/340 (15)	1.0	275/328 (84)	1.0	226/327 (69)	1.0

CI denotes confidence interval: p-value is for the Pearson chi-square test of independence. Throughout the table the responses that were categorized as not relevant were included in the moderate or much category.

Table 5 Associations between child's psychological needs being addressed and care received at home in the last month of life

	Access to relief of anxiety (moderate or much)		Access to relief of other psychological symptoms beside anxiety (moderate or much)		Access to psychological support (moderate or much)		Child received medication for anxiety or depression in last month (some or many times)		Access to play therapy (moderate or much)	
Place of death and place cared for in last month	No./total (%)	Odds ratio (95% CI)	No./total (%)	Odds ratio (95% CI)	No./total (%)	Odds ratio (95% CI)	No./total (%)	Odds ratio (95% CI)	No./total (%)	Odds ratio (95% CI)
Home	55/70 (79)	1.1 (0.6, 2.1) P =0.8	58/67 (87)	1.7 (0.8, 3,7) P =0.2	46/67 (69)	1.2 (0.7, 2.1) P =0.5	16/70 (23)	1.1 (0.6, 2.1) P =0.7	53/68 (78)	0.9 (0.5, 1.7) P =0.7
Other	250/325 (77)	1.0	250/317 (79)	1.0	215/334 (64)	1.0	70/339 (21)	1.0	268/336 (80)	1.0

CI denotes confidence interval: p-value is for the Pearson chi-square test of independence. Throughout the table the responses that were categorized as not relevant were included in the moderate or much category.

realization that a child will die, and having a child home to die and be cared for in the last month of life. Likewise, concordance between a number of variables related to pain relief and other physical and mental symptoms, none of which showed statistically significant differences according to whether care was received at home compared to other settings, lend credence to our conclusion that these care related factors seem to be unrelated to place of death. The fact that we found almost no differences in demographic factors predicting care and death at home versus elsewhere, indicates that it is unlikely that the associations we did find were confounded by these factors. An advantage of performing this research in a country such as Sweden, which has universal access to health care, is that decisions about end-of-life care are unlikely to be influenced by factors related to insurance or availability of services.

One of the limitations of the study was our inability to classify the outcome variable more specifically because we lacked information on the number of days the child had spent at home during the last month of his/her life. Comparisons would be ideal if children had been either exclusively taken care of at home and died at home, or were exclusively taken care of elsewhere and died elsewhere. Because this was not the case, we chose to include in our outcome of interest only those children who were both cared for at home during the last month and died there. For example, a child who was cared for almost the whole time at home and died at home, but was brought to the hospital for a few days during the last month, would be classified in the 'non-home' group. As a result, it is likely that the associations were attenuated, since some of these children may have resembled the 'home' group more than the group into which they were classified. Meanwhile, because of the strict inclusion criteria for the 'home' group, there was no ambiguity and therefore no misclassification in this direction. We observed some potentially interesting associations that were relatively large in magnitude but not statistically significant due to low power, e.g. with access to relief of pain and access to relief of other phychological symptoms beside anxiety. These associations may be due to chance but further study would be needed to verify this.

Another limitation of our study was that, in some cases, both mothers and fathers of the same child filled in the questionnaire. Unfortunately, because of the anonymity of the questionnaire, we had no way of distinguishing in which families this was the case. Therefore, because of a potential problem of interdependence between responses, we stratified our results by gender. This did not substantially change the associations. Finally, although it diminished our power, since not all of the symptoms and aspects of palliative care were relevant to all families, we excluded those who answered 'not relevant' from the analysis.

Our results suggest that when parents are aware that their child will die, they are more likely to take care of their child at home. When possible, increasing parental awareness of a child's impending death may be desirable. Himelstein *et al*. point out that children are generally aware of their imminent death.[23] Our study underlines the importance of parental recognition of the child's awareness because of its association with care and death of a child at home. Given communication difficulties existing between parents and oncologists,[24] increasing training of healthcare personnel regarding the delivery of this information to parents may be appropriate. Physicians often recognize that there is no chance of a cure substantially earlier than parents (on average 101 days), suggesting it may be possible to inform parents earlier.[9] Also, since the involvement of a psychosocial clinician with the parents during the child's medical care is associated with less of a gap between parents and physician's awareness time,[9] including a psychosocial clinician in palliative care may be one way to increase awareness. Earlier recognition of a child's impending death by parents may lead to more desirable care for children dying of cancer. There is no evidence for differences in the quality of care in terms of relief of children's physical or psychological symptoms between home care and elsewhere, suggesting that this should not be a concern when evaluating parental and child wishes for care and death at home.

Further topics of interest may include studying circumstances in which parents may be more likely to be aware of a child's death and the nature of the health care providers' communication with parents who are aware or unaware of the child's death. Future research is needed to explore other reasons why parents decided to opt for care at home or in the hospital and to understand whether or not they felt afterwards that they had made a good decision.

Acknowledgements

We thank the parents who made this study possible by bravely sharing their experiences with us. We also thank Ulla-Britt Rittvall for telephoning all the parents. This study was supported by the American-Scandinavian Foundation through a grant from the Thord-Gray Memorial Fund, the Swedish Society for Medical Research, and the Capio Research Foundation.

References

1 Sirkia K, Saarinen UM, Ahlgren B, *et al*. Terminal care of the child with cancer at home. *Acta Paediatr* 1997; **86**: 1125–30.

2 Papadatou D, Yfantopoulos J, Kosmidis HV. Death of a child at home or in hospital: experiences of Greek mothers. *Death Stud* 1996; **20**: 215–35.

3 Chambers EJ, Oakhill A. Models of care for children dying of malignant disease. *Palliat Med* 1995; **9**: 181–85.

4 Liben S, Goldman A. Home care for children with life-threatening illness. *J Palliat Care* 1998; **14**: 33–38.

5 Davies B, Deveau E, deVeber B, *et al*. Experiences of mothers in five countries whose child died of cancer. *Cancer Nurs* 1998; **21**: 301–11.

6 Milberg A, Strang P. Met and unmet needs in hospital-based home care: qualitative evaluation through open-ended questions. *Palliat Med* 2000; **14**: 533–34.

7 Whittam EH. Terminal care of the dying child. Psychosocial implications of care. *Cancer* 1993; **71**: 3450–62.

8 Goldman A. Home care of the dying child. *J Palliat Care* 1996; **12**: 16–19.

9 Wolfe J, Grier HE, Klar N, *et al*. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med* 2000; **342**: 326–33.

10 Miser AW, Dothage JA, Wesley RA, *et al*. The prevalence of pain in a pediatric and young adult cancer population. *Pain* 1987; **29**: 73–83.

11 Cummings EA, Reid GJ, Finley GA, *et al*. Prevalence and source of pain in pediatric inpatients. *Pain* 1996; **68**: 25–31.

12 Goldman A, Beardsmore S, Hunt J. Palliative care for children with cancer – home, hospital, or hospice? *Arch Dis Child* 1990; **65**: 641–43.

13 Rothman KJ, Greenland S. *Modern epidemiology*, second edition. Lippencott, Williams and Wilkins, 1998.

14 Lauer ME, Mulhern RK, Bohne JB, *et al*. Children's perceptions of their sibling's death at home or hospital: the precursors of differential adjustment. *Cancer Nurs* 1985; **8**: 21–27.

15 Mulhern RK, Lauer ME, Hoffmann RG. Death of a child at home or in the hospital: subsequent psychological adjustment of the family. *Pediatrics* 1983; **71**: 743–47.

16 Kreicbergs U, Valdimarsdottir U, Onelov E, *et al*. Talking about death with children who have severe malignant disease. *N Engl J Med* 2004; **351**: 1175–86.

17 Valdimarsdottir U, Helgason AR, Furst CJ, *et al*. Awareness of husband's impending death from cancer and long-term anxiety in widowhood: a nationwide follow-up. *Palliat Med* 2004; **18**: 432–43.

18 Stillion JM and Papa datou D. Suffer the children: an examination of psychological issues in children and adolescents with terminal illness. *Am Behav Sci* 2002; **46**: 299–315.

19 Woodgate RL, Degner LF, Yanofsky R. A different perspective to approaching cancer symptoms in children. *J Pain Symptom Manage* 2003; **26**: 800–17.

20 Kreicbergs UVU, Onelov E, Bjork O, *et al*. Care-related distress: a nation wide study of parents who lost a child to cancer. *J Clin Oncol* 2005; **23**: 9162–71.

21 Newman CL, Barton C, Ryder H. Palliative care for children with cancer. *Arch Dis Child* 1990; **65**: 1378.

22 Lansdown R, Goldman A. The psychological care of children with malignant disease. *J Child Psychol Psychiatry* 1988; **29**: 555–67.

23 Himelstein BP, Hilden JM, Boldt AM, *et al*. Pediatric Palliative Care *N Engl J Med* 2004; **350**: 1752–62.

24 Hilden JM, Emanuel EJ, Fairclough DL, *et al*. Attitudes and practices among pediatric oncologists regarding end-of-life care: results of the 1998 American Society of Clinical Oncology survey. *J Clin Oncol* 2001; **19**: 205–12.

Appendix 1

Exact wording of questions from Tables 2–4 with original Swedish

Awareness questions, Table 3	Response categories
When did you realize intellectually that your child was going to die? (*När insåg du förståndsmässigt att ditt barn skulla avlida?*)	– Never realized or awareness less then 1 month before the death – More than one month before he/she died
When did you realize emotionally that your child was going to die? (*När insåg du känslomässigt att ditt barn skulla avlida?*)	– Never realized or awareness less then 1 month before the death – More than one month before he/she died
When do you think that your child realized that he/she was going to die? (*När tror du att ditt barn insåg att han/hon skulle avlida?*)	– Never realized it – Realized more than one month before he/she died
When did you get the information that your child's illness was incurable? (*När fick du bekedet att ditt barns sjukdom inte gick att bota?*)	– Never got information or got information less than a month before his/her death – Got information a month or more before s/he died
Questions on access to pain and symptom relief/access to medical care, Tables 4 and 5	
Indicate the extent to which your child had access to the following from the care service during his/her last month of life: (*Ange i vilken utsträckning ditt barn hade tillgång till följande från sjukvården under hans/hennes sista levnadsmånad:*)	– None – Slight – Moderate or much – Ample (not relevant was excluded)
– relief of pain (–*lindring av smärta*)	
– relief of other physical symptoms beside pain (– *lindring av andra kroppsliga symtom än smärta*)	
– dietary advice (– *kostrådgivning*)	
– relief of anxiety (– *lindring av oro/ångst*)	
– relief of other mental symptoms beside anxiety (– *lindring av andra psykiska symtom än oro/ångst*)	
– psychological support by social worker or psychologist (– *psykologiskt stöd av kurator, eller psykolog*)	
– play therapy (– *lekterapi*)	
Did it ever happen that a lack of care personnel resulted in your child having pain that he/she was not helped with within four hours or so during his/her last month of life? (*Hände det att bristande tillgång till vårdpersonal resulterade i att ditt barn hade smärtor som han/hon inte fick hjälp med inom cirka fyra timmar under sin sista levnadsmånad?*)	– No, never – Yes, on one or more occasions
Did your child receive medication to treat anxiety or depressed mood during his/her last month of life? (*Fick ditt barn mediciner för ångst eller nedstämdhet under hans/hennes sista levnadsmånad?*)	– No, never – Yes, on one or more occasions