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Talking about Death with Children Who Have Severe Malignant Disease

Ulrika Kreicbergs, R.N., Unnur Valdimarsdóttir, Ph.D., Erik Onelöv, M.Sc.,
Jan-Inge Henter, M.D., Ph.D., and Gunnar Steineck, M.D., Ph.D.

ABSTRACT

BACKGROUND

One of the questions faced by the parents of a child who is terminally ill with a malignant disease is whether or not they should talk about death with their child.

METHODS

In 2001, we attempted to contact all parents in Sweden who had lost a child to cancer between 1992 and 1997. Among 561 eligible parents, 449 answered a questionnaire, and 429 stated whether or not they had talked about death with their child.

RESULTS

None of the 147 parents who talked with their child about death regretted it. In contrast, 69 of 258 parents (27 percent) who did not talk with their child about death regretted not having done so. Parents who sensed that their child was aware of his or her imminent death were more likely to regret not having talked about it (47 percent, as compared with 13 percent of parents who did not sense this awareness in their child; relative risk, 3.7; 95 percent confidence interval, 2.3 to 6.0). The same variable was related to having talked about death (50 percent vs. 13 percent; relative risk, 3.8; 95 percent confidence interval, 2.6 to 5.6), as was being religious (42 percent vs. 25 percent; relative risk, 1.7; 95 percent confidence interval, 1.2 to 2.3). The child's age was related to both having talked about death and the parents' regretting not having talked about it.

CONCLUSIONS

Parents who sense that their child is aware of his or her imminent death more often later regret not having talked with their child than do parents who do not sense this awareness in their child; overall, no parent in this cohort later regretted having talked with his or her child about death.

From the Division of Clinical Cancer Epidemiology, Department of Oncology and Pathology (U.K., U.V., E.O., G.S.), and the Childhood Cancer Research Unit (U.K., J.-I.H.), Karolinska Institutet, Stockholm. Address reprint requests to Dr. Steineck at the Division of Clinical Cancer Epidemiology, Karolinska Institutet, Z6:01 Karolinska Hospital, SE-171 76, Stockholm, Sweden, or at gunnar.steineck@onkpat.ki.se.

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ONE OF THE QUESTIONS FACED BY THE parents of a child who is terminally ill with a malignant disease is whether they should talk about death with their child. On the basis of studies of small series of sick children, accounts by children and parents, and professional experience, researchers and professional organizations recommend open and honest communication between parents and the child about the prognosis.¹⁻⁸ Evidence suggests that terminally ill children benefit from talking about their imminent death, but we lack information about how parents perceive such communication.^{9,10}

A terminally ill child may become aware that death is imminent through direct information or by reasoning about his or her health status and health care experiences. The child may express such awareness directly in words or may communicate it indirectly in words, gestures, or drawings.^{3,11,12} Logic suggests that the child's awareness may trigger talks about death or induce in the parents the feeling that they should initiate such a talk.

We asked a cohort of parents who had lost a child to a malignant disease whether they had talked with their child about death and whether, after the child died, they regretted having talked or regretted not having talked about death with the child. We analyzed the prevalence and predictors of these outcomes.

METHODS

STUDY POPULATION

We identified 368 children in Sweden who received a diagnosis of a malignant disease before the age of 17 years and who died, before 25 years of age, between 1992 and 1997. The names were obtained from the Swedish Cause of Death Registry, which was linked to the Swedish Cancer Registry. The children's parents were identified in the Swedish Population Registry. A parent was defined as being the guardian of the child at the time of the child's diagnosis. Parents were eligible for the study if they had been born in one of the Scandinavian countries, had a published telephone number, and understood Swedish. Before the family was contacted, we required the physician who had treated the child to verify the diagnosis and give us permission to contact the family; permission was given for all families. A total of 561 bereaved parents met the criteria for the study.

THE QUESTIONNAIRE

Between August and October 2001, we separately sent mothers and fathers an introductory letter that explained the objectives of the study and invited them to participate. Afterward, we telephoned the parents and asked if they would like to see the questionnaire; 531 said yes. To maintain anonymity, the questionnaires were returned without any name or code in separate envelopes from reply cards on which the parents had written their names, thus notifying us of the return of the questionnaire. The anonymity hindered us from gathering further information, which explains why we lack information on variables such as sex from a few parents. Ten days after the questionnaire had been sent out, a combined thank-you and reminder card was mailed. An interviewer called those parents who had not returned their reply cards. The study was approved by the research ethics committee at Karolinska Institutet in Stockholm. Informed consent was obtained during the telephone contact.

The questionnaire was developed on the basis of seven successive in-depth interviews with bereaved parents. Face validity was assessed with 15 bereaved parents: an investigator accompanied them while they filled out the questionnaire to make sure they understood it correctly. In a pilot study of 22 bereaved parents, methods of data collection were tested, and this led to modifications of the questionnaire. The questionnaire included 129 questions, with a total of 365 items concerning the child's care and the parent's mental health four to nine years after the child's death.

The questionnaire asked about the parent's conversations about death with his or her child as follows: "Did you talk about death with your child at any time?" The response categories were no and yes. If the parent answered no, the follow-up question was "Do you wish that you had?" The responses were yes and no. Parents who answered yes to this question were classified as regretting not having talked about death. If the answer to the first question was yes, we asked, "Do you wish that you had not?" Again, the response alternatives were yes and no. We assessed the parent's assumption about the child's awareness of the inevitability of death as follows: "When do you think your child realized he or she was going to die?" The response alternatives ranged from "Never realized" to "Three years or more before he or she died."

We assessed the parent's current anxiety and de-

pression on a seven-point visual-digital scale, using questions such as: "Have you been anxious during the past month?" (The possible responses ranged from "Never" to "All the time.") This method and the accompanying scales have been used in previous investigations involving more than 3000 persons by the Clinical Cancer Epidemiology group at Karolinska Institutet.¹³⁻¹⁸ The scales correlate with other validated scales such as Spielberger's State-Trait Anxiety Inventory and the depression scale of the Center for Epidemiological Studies.¹⁹

STATISTICAL ANALYSIS

For each outcome (e.g., having talked about death with the child), we calculated the percentage of parents in each category of the independent variable. When comparing the categories, we first calculated the relative risk as the ratio of the percentages, together with the 95 percent confidence interval (using the Mantel-Haenszel formula for the variance).²⁰ Multivariable logistic models were then constructed to determine the relative importance of the independent variables in explaining the variation in the outcome. We used SAS software²¹ (version 8.02), the GENMOD procedure, and forward selection, starting with one bivariable model for each independent variable and outcome. The independent variable with the highest chi-square value was then introduced into trivariable models with the remaining independent variables, and the remaining independent variable with the highest chi-square value was introduced into four-variable models. We continued in this manner as long as all independent variables in the model had a chi-square value that corresponded to a P value below 0.05.

For backward elimination, we started with all independent variables; the variables with the lowest chi-square values were eliminated, one by one, until the P value was below 0.05 for all remaining independent variables in the model. Finally, we used multivariable logistic models to determine adjusted odds ratios — that is, odds ratios for the association between an independent variable and an outcome (e.g., having talked); the model included all independent variables that were found to contribute to the variation in outcome by forward selection.

RESULTS

Among the 561 eligible bereaved parents, 449 (80 percent) answered the questionnaire (Table 1).

Among nonparticipating parents, 54 percent were men, and the age distribution was similar to that of the participants (data not shown). For each of the variables shown in Table 1, some parents did not provide information. This lack of information translates into missing values in Tables 2 and 3.

Of the 449 participating subjects, 438 (98 percent) were biologic parents of the child, 9 (2 percent) were not biologic parents, and 2 (less than 1 percent) did not specify their relationship to the child; 191 (43 percent) were men, 251 (56 percent) were women, and 7 (2 percent) did not specify their sex. Most parents (88 percent) were married to or living with the child's other parent at the time of the child's diagnosis.

Of the 429 parents who provided information, 147 (34 percent) had talked about death with their child, and 282 (66 percent) had not talked about it. None of the 147 parents who had talked about death regretted it. Among 258 parents who responded that they had not talked about death with their child, 69 (27 percent) regretted not having done so, and 189 (73 percent) did not regret not having done so.

Table 2 shows the results of a multivariable analysis of data from the 429 parents who provided information on whether or not they had talked about death with their child. Relative risks (as a ratio of percentages) above 1.0 and 95 percent confidence intervals not including 1.0 were obtained for certain categories of the variables for age of the child at diagnosis (4 to 9 years and 10 to 16 years), age of the child at death (5 to 8 years, 9 to 15 years, and 16 to 24 years), parent's employment status (being on sick leave or retired), parent's religiousness (being somewhat, quite, or very religious), the presence of anxiety in the parent during the year before the child's diagnosis, and the parent's sense that the child was aware of his or her imminent death. The highest relative risk (3.8) and a difference of 37 percentage points (50 percent vs. 13 percent) were obtained for parents who sensed that the child was aware of his or her imminent death, as compared with those who did not sense this awareness.

By forward selection, we obtained a final logistic-regression model with five independent variables. The parent's sense of whether the child was aware of his or her imminent death had the highest chi-square value (28.85, $P < 0.001$), followed by the parent's religiousness (19.04, $P < 0.001$) and the age of the child at diagnosis (10.73, $P = 0.001$); the parent's employment status (chi-square, 5.36; $P = 0.02$) and the parent's age at the child's diagnosis (chi-

Table 1. Characteristics of 561 Parents Who Lost a Child to a Malignant Disease.*

Characteristic	No. of Parents (%)
Nonparticipants	112 (20)
Reason for not participating	
Declined to participate	30 (5)
Agreed to receive questionnaire but did not return it	59 (11)
Not reachable	23 (4)
Participants	449 (80)
Biologic parent of the child	
Yes	438 (98)
No	9 (2)
Not stated	2 (<1)
Sex	
Male	191 (43)
Female	251 (56)
Not stated	7 (2)
Age at child's diagnosis	
<30 yr	66 (15)
30–39 yr	232 (52)
≥40 yr	146 (33)
Not stated	5 (1)
Marital status at child's diagnosis	
Married to or living with the child's other parent	394 (88)
Married to or living with a partner other than the child's other parent	15 (3)
Had a partner but lived alone	10 (2)
Single	25 (6)
Not stated	5 (1)
Current marital status	
Married to or living with the child's other parent	329 (73)
Married to or living with a partner other than the child's other parent	51 (11)
Had a partner but lived alone	17 (4)
Single	45 (10)
Not stated	7 (2)

square, 4.79; $P=0.03$) also contributed to whether the parent talked about death with the child. The same final model was obtained by the procedure of backward elimination. The crude odds ratios shown in Table 2 were adjusted for the five independent variables in the final model; the odds ratios for the five variables in the final model were adjusted for the four other variables. The highest adjusted odds ratio with a confidence interval not including 1.0 was for the parent's sense that the child was aware of his or her imminent death (adjusted odds ratio, 4.5).

Table 3 shows the results of a multivariable

analysis of data from the 258 parents who did not talk about death with their child and whether or not they regretted not having done so. Relative risks above 1.0 and 95 percent confidence intervals not including 1.0 were obtained for certain categories of the following variables: parent's sex (female), age of the child at diagnosis (4 to 9 years and 10 to 16 years), age of the child at death (9 to 15 years and 16 to 24 years), parent's religiousness (being religious), parent's marital status at child's diagnosis (living with a partner other than the child's other parent), and parent's sense that the child was aware of his or her imminent death. The highest relative

Table 1. (Continued.)

Characteristic	No. of Parents (%)
No. of children at child's diagnosis	
1	82 (18)
2	192 (43)
3	116 (26)
≥4	54 (12)
Not stated	5 (1)
Level of education	
Elementary school	83 (18)
Secondary school	215 (48)
College	141 (31)
Not stated	10 (2)
Current employment status†	
Employed	370 (82)
Unemployed	10 (2)
On sick leave or retired	36 (8)
Homemaker	5 (1)
Home with children	8 (2)
Student	14 (3)
Not stated	6 (1)
Residential region	
Rural	99 (22)
Village or town	273 (61)
City (population >500,000)	68 (15)
Not stated	9 (2)
Religiousness	
Not at all religious	185 (41)
Somewhat religious	155 (35)
Quite religious	68 (15)
Very religious	25 (6)
Not stated	16 (4)

* Eligible parents were identified through the Swedish Population Registry. Percentages are calculated separately for the 561 eligible parents and for the 449 who responded to the questionnaire.

† A parent at home with young children is on leave from a job and receives a government benefit, whereas a homemaker does not.

risk (3.7) and a difference of 34 percentage points (47 percent vs. 13 percent) were obtained for parents who sensed that the child was aware of his or her imminent death, as compared with those who did not sense this awareness.

By forward selection, we obtained a final logistic-regression model with three independent variables: parent's sense that the child was aware of his or her imminent death had the highest chi-square value (18.63, $P < 0.001$), followed by age of the child

at death (13.38, $P < 0.001$) and parent's sex (8.05, $P = 0.005$). The final model obtained by backward elimination included the parent's sense that the child was aware of his or her imminent death (chi-square, 20.96; $P < 0.001$), the age of the child at diagnosis (chi-square, 12.71; $P < 0.001$), and the parent's sex (chi-square, 8.68; $P = 0.003$). The crude odds ratios shown in Table 3 were adjusted for the three independent variables in the final model obtained by forward selection (the odds ratio for each

Table 2. Relative Risks, Odds Ratios, and Adjusted Odds Ratios for Having Talked about Death with the Child, According to Categories of Variables.*

Variable	Talked about Death no./total no. (%)	Relative Risk (95% CI)	Odds Ratio	
			Unadjusted	Adjusted (95% CI)
Parent				
Biologic	142/419 (34)	1.0	1.0	1.0
Nonbiologic	5/9 (56)	1.6 (0.9–3.0)	2.4	1.9 (0.4–9.7)
Parent's sex				
Male	54/182 (30)	1.0	1.0	1.0
Female	92/242 (38)	1.3 (1.0–1.7)	1.5	1.2 (0.7–1.9)
Parent's age at child's diagnosis				
<30 yr	19/65 (29)	1.0	1.0	1.0
30–39 yr	73/219 (33)	1.1 (0.7–1.7)	1.2	0.6 (0.2–1.5)
≥40 yr	53/141 (38)	1.3 (0.8–2.0)	1.5	0.8 (0.4–1.8)
Child's age at diagnosis				
0–3 yr	32/157 (20)	1.0	1.0	1.0
4–9 yr	49/120 (41)	2.0 (1.4–2.9)	2.1	1.8 (0.9–3.5)
10–16 yr	63/146 (43)	2.1 (1.5–3.0)	2.3	2.2 (1.0–4.7)
Child's age at death				
0–4 yr	20/128 (16)	1.0	1.0	1.0
5–8 yr	33/91 (36)	2.3 (1.4–3.8)	2.8	2.5 (1.1–5.5)
9–15 yr	48/96 (50)	3.2 (2.0–5.0)	4.9	2.7 (0.9–7.8)
16–24 yr	43/104 (41)	2.6 (1.7–4.2)	3.5	1.8 (0.5–6.9)
Type of cancer in child				
Brain tumor	53/149 (36)	1.0	1.0	1.0
Leukemia or lymphoma	46/143 (32)	0.9 (0.7–1.2)	0.8	1.0 (0.6–1.8)
Sarcoma or neuroblastoma	34/91 (37)	1.1 (0.7–1.5)	1.1	1.1 (0.6–2.2)
Other malignant disease	13/43 (30)	0.8 (0.5–1.4)	0.8	0.6 (0.2–1.6)
Parent's level of education				
Elementary school	28/76 (37)	1.0	1.0	1.0
Secondary school	61/209 (29)	0.8 (0.6–1.1)	0.7	0.5 (0.2–0.9)
College	56/139 (40)	1.1 (0.8–1.6)	1.2	0.9 (0.5–1.8)
Parent's current employment status†				
Employed	115/357 (32)	1.0	1.0	1.0
Unemployed	5/10 (50)	1.6 (0.8–2.9)	2.1	2.5 (0.6–10.5)
On sick leave or retired	16/32 (50)	1.6 (1.1–2.3)	2.1	1.8 (0.7–4.4)
Homemaker	2/5 (40)	1.2 (0.4–3.7)	1.4	2.2 (0.3–16.8)
Home with children	4/8 (50)	1.5 (0.8–3.2)	2.1	4.4 (1.0–20.1)
Student	5/13 (38)	1.2 (0.6–2.4)	1.3	1.8 (0.4–7.3)
Parent's residential region				
Rural	32/94 (34)	1.0	1.0	1.0
Village or town	95/264 (36)	1.1 (0.8–1.5)	1.1	1.1 (0.6–2.1)
City (population >500,000)	19/67 (28)	0.8 (0.5–1.3)	0.8	1.2 (0.6–2.8)
Parent's religiousness				
Not at all religious	44/177 (25)	1.0	1.0	1.0
Somewhat, quite, or very religious	101/242 (42)	1.7 (1.2–2.3)	2.2	1.8 (1.1–3.0)

Table 2. (Continued.)

Variable	Talked about Death no./total no. (%)	Relative Risk (95% CI)	Odds Ratio	
			Unadjusted	Adjusted (95% CI)
Parent's marital status at child's diagnosis				
Married to or living with the child's other parent	127/377 (34)	1.0	1.0	1.0
Married to or living with a partner other than the child's other parent	6/15 (40)	1.2 (0.6–2.2)	1.3	0.8 (0.2–2.7)
Had a partner but lived alone	3/9 (33)	1.0 (0.4–2.5)	1.0	1.0 (0.2–5.3)
Single	10/24 (42)	1.2 (0.8–2.0)	1.4	1.4 (0.5–4.0)
No. of children at child's diagnosis				
1	21/78 (27)	1.0	1.0	1.0
2	60/187 (32)	1.2 (0.8–1.8)	1.3	0.8 (0.4–1.7)
3	43/112 (38)	1.4 (0.9–2.2)	1.7	1.0 (0.5–2.2)
≥4	21/48 (44)	1.6 (1.0–2.6)	2.1	1.9 (0.7–4.9)
Anxiety in parent during the year before child's diagnosis				
No	121/375 (32)	1.0	1.0	1.0
Yes	25/48 (52)	1.6 (1.2–2.2)	2.3	1.5 (0.7–3.1)
Depression in parent during the year before child's diagnosis				
No	123/374 (33)	1.0	1.0	1.0
Yes	23/49 (47)	1.4 (1.0–2.0)	1.8	1.3 (0.6–2.7)
Loss of another child				
No	137/406 (34)	1.0	1.0	1.0
Yes	6/15 (40)	1.2 (0.6–2.2)	1.3	0.7 (0.2–2.7)
Loss of another relative or friend during previous 10 yr				
No	28/105 (27)	1.0	1.0	1.0
Yes; other parent or partner	3/5 (60)	2.3 (1.0–4.9)	4.1	8.1 (0.9–70.3)
Yes; relative or friend	112/311 (36)	1.4 (1.0–1.9)	1.5	1.5 (0.8–2.6)
Parent's sharing of worries				
Very little or not at all	19/61 (31)	1.0	1.0	1.0
Less than half or half of worries	45/132 (34)	1.1 (0.7–1.7)	1.1	1.1 (0.5–2.4)
Most or all of worries	79/222 (36)	1.1 (0.8–1.7)	1.2	1.3 (0.7–2.8)
Contact with other parents who had lost a child to a malignant disease				
No	50/175 (29)	1.0	1.0	1.0
Yes	97/251 (39)	1.4 (1.0–1.8)	1.6	1.0 (0.6–1.7)
Parent's sense that the child was aware of his or her imminent death				
Not aware	24/183 (13)	1.0	1.0	1.0
Aware	112/225 (50)	3.8 (2.6–5.6)	6.6	4.5 (2.6–7.7)

* Data are based on the 429 parents who provided information on having talked about death. Because some parents did not provide information on specific variables, the denominators do not always add up to 429. When appropriate, odds ratios were adjusted for parent's age at the child's diagnosis, child's age at diagnosis, parent's employment status, parent's religiousness, and parent's sense that the child was aware of his or her imminent death.

† A parent at home with young children is on leave from a job and receives a government benefit, whereas a homemaker does not.

Table 3. Relative Risks, Odds Ratios, and Adjusted Odds Ratios for Regretting Not Having Talked about Death with the Child, According to Categories of Variables. *

Variable	Regretted Not Having Talked about Death no./total no. (%)	Relative Risk (95% CI)	Odds Ratio	
			Unadjusted	Adjusted (95% CI)
Parent				
Biologic	68/253 (27)	1.0	1.0	1.0
Nonbiologic	1/4 (25)	0.9 (0.2–5.1)	0.9	1.2 (0.1–15.8)
Parent's sex				
Male	24/120 (20)	1.0	1.0	1.0
Female	44/134 (33)	1.6 (1.1–2.5)	2.0	2.6 (1.3–5.1)
Parent's age at child's diagnosis				
<30 yr	9/41 (22)	1.0	1.0	1.0
30–39 yr	31/134 (23)	1.1 (0.5–2.0)	1.1	0.7 (0.2–1.8)
≥40 yr	29/81 (36)	1.6 (0.9–3.1)	2.0	0.8 (0.2–2.7)
Child's age at diagnosis				
0–3 yr	13/106 (12)	1.0	1.0	1.0
4–9 yr	22/69 (32)	2.6 (1.4–4.8)	2.4	1.0 (0.4–2.9)
10–16 yr	34/80 (43)	3.5 (2.0–6.1)	3.4	0.8 (0.2–3.2)
Child's age at death				
0–4 yr	11/92 (12)	1.0	1.0	1.0
5–8 yr	12/55 (22)	1.8 (0.9–3.9)	1.8	1.7 (0.6–4.6)
9–15 yr	19/45 (42)	3.5 (1.8–6.8)	4.8	2.8 (1.0–7.7)
16–24 yr	26/60 (43)	3.6 (1.9–6.8)	5.0	4.9 (2.0–12.1)
Type of cancer in child				
Brain tumor	30/89 (34)	1.0	1.0	1.0
Leukemia or lymphoma	18/87 (21)	0.6 (0.4–1.0)	0.5	0.5 (0.2–1.1)
Sarcoma or neuroblastoma	15/54 (28)	0.8 (0.5–1.4)	0.8	1.1 (0.5–2.5)
Other malignant disease	6/26 (23)	0.7 (0.3–1.5)	0.6	0.5 (0.1–1.5)
Parent's level of education				
Elementary school	13/45 (29)	1.0	1.0	1.0
Secondary school	35/138 (25)	0.9 (0.5–1.5)	0.8	0.8 (0.3–2.0)
College	21/73 (29)	1.0 (0.6–1.8)	1.0	1.0 (0.4–2.6)
Parent's current employment status†				
Employed	57/221 (26)	1.0	1.0	1.0
Unemployed	2/4 (50)	1.9 (0.7–5.3)	2.9	4.0 (0.4–39.1)
On sick leave or retired	6/16 (38)	1.5 (0.7–2.8)	1.7	1.4 (0.4–4.4)
Homemaker	1/3 (33)	1.3 (0.3–6.5)	1.4	1.7 (0.1–22.1)
Home with children	1/3 (33)	1.3 (0.3–6.5)	1.4	5.2 (0.4–64.6)
Student	1/8 (13)	0.5 (0.1–3.1)	0.4	1.4 (0.2–13.1)
Parent's residential region				
Rural	15/57 (26)	1.0	1.0	1.0
Village or town	40/154 (26)	1.0 (0.6–1.6)	1.0	1.2 (0.5–2.7)
City (population >500,000)	14/45 (31)	1.2 (0.6–2.2)	1.3	1.9 (0.7–5.3)

Table 3. (Continued.)

Variable	Regretted Not Having Talked about Death	Relative Risk (95% CI)	Odds Ratio	
			Unadjusted	Adjusted (95% CI)
	<i>no./total no. (%)</i>			
Parent's religiousness				
Not at all religious	24/128 (19)	1.0	1.0	1.0
Somewhat, quite, or very religious	43/123 (35)	1.9 (1.2–2.9)	2.3	1.9 (1.0–3.6)
Parent's marital status at child's diagnosis				
Married to or living with the child's other parent	57/230 (25)	1.0	1.0	1.0
Married to or living with a partner other than the child's other parent	7/8 (88)	3.5 (2.5–5.0)	21.2	22.4 (2.2–227.4)
Had a partner but lived alone	2/5 (40)	1.6 (0.5–4.8)	2.0	2.1 (0.3–15.2)
Single	3/12 (25)	1.0 (0.4–2.8)	1.0	1.4 (0.3–6.5)
No. of children at child's diagnosis				
1	9/47 (19)	1.0	1.0	1.0
2	32/118 (27)	1.4 (0.7–2.7)	1.6	1.0 (0.4–2.9)
3	24/66 (36)	1.9 (1.0–3.7)	2.4	1.9 (0.6–5.4)
≥4	4/25 (16)	0.8 (0.3–2.4)	0.8	1.0 (0.2–4.4)
Anxiety in parent during the year before child's diagnosis				
No	61/234 (26)	1.0	1.0	1.0
Yes	6/21 (29)	1.1 (0.5–2.2)	1.1	0.8 (0.3–2.6)
Depression in parent during the year before child's diagnosis				
No	60/233 (26)	1.0	1.0	1.0
Yes	7/22 (32)	1.2 (0.6–2.4)	1.3	1.4 (0.5–4.2)
Loss of another child				
No	67/247 (27)	1.0	1.0	1.0
Yes	2/8 (25)	0.9 (0.3–3.1)	0.9	0.5 (0.1–3.2)
Loss of another relative or friend during previous 10 yr				
No	13/72 (18)	1.0	1.0	1.0
Yes; other parent or partner	1/2 (50)	2.8 (0.6–12.1)	4.5	5.1 (0.3–91.5)
Yes; relative or friend	55/181 (30)	1.7 (1.0–2.9)	2.0	1.8 (0.8–3.9)
Parent's sharing of worries				
Very little or not at all	10/38 (26)	1.0	1.0	1.0
Less than half or half of worries	25/79 (32)	1.2 (0.6–2.2)	1.3	1.1 (0.4–2.9)
Most or all of worries	32/133 (24)	0.9 (0.5–1.7)	0.9	0.8 (0.3–2.0)
Contact with other parents who had lost a child to a malignant disease				
No	25/113 (22)	1.0	1.0	1.0
Yes	44/145 (30)	1.4 (0.9–2.1)	1.5	1.1 (0.6–2.1)
Parent's sense that the child was aware of his or her imminent death				
Not aware	18/144 (13)	1.0	1.0	1.0
Aware	49/105 (47)	3.7 (2.3–6.0)	6.1	4.7 (2.4–9.1)

* Data are based on the 258 parents who provided information on not having talked about death and whether or not they regretted it. Because some parents did not provide information on specific variables, the denominators do not always add up to 258. When appropriate, odds ratios were adjusted for parent's sex, child's age at death, and parent's sense that the child was aware of his or her imminent death.

† A parent at home with young children is on leave from a job and receives a government benefit, whereas a homemaker does not.

of the three variables in the final model was adjusted for the two other variables). The highest adjusted odds ratio with a confidence interval not including 1.0 was for the category of being married to or living with a partner other than the child's other parent under the variable of parent's marital status at child's diagnosis (adjusted odds ratio, 22.4).

Among parents who regretted that they had not talked about death with their child, 33 percent (23 of 69) reported their current anxiety level as moderate or high (defined as a score of 3 to 7 on a visual-analogue scale of 1 to 7), as compared with 21 percent (39 of 184) among those who did not regret that they had not talked about death (relative risk, 1.6; 95 percent confidence interval, 1.0 to 2.4). We lacked information from five parents. Among parents who regretted not having talked about death with their child, 17 of 44 women (39 percent) experienced anxiety, as compared with 6 of 24 men (25 percent; relative risk, 1.5; 95 percent confidence interval, 0.7 to 3.4). There was no significant difference in reported anxiety between women and men who did not regret not having talked about death with their child (relative risk, 1.0; 95 percent confidence interval, 0.6 to 1.8). Thirty-three of 69 parents (48 percent) who regretted not having talked about death reported a moderate or high level of depression (defined as a score of 3 to 7 on a visual-analogue scale of 1 to 7), as compared with 39 of 184 (21 percent) of those who did not regret not having talked about death (relative risk, 2.3; 95 percent confidence interval, 1.6 to 3.3). We lacked information from five parents.

Most children (63 percent) were not informed that their illness was incurable, as reported by the parents. In 17 percent of the cases in which parents responded to this question, the information was delivered by the physician together with both parents. Data from the parents who had talked about death with their child and from those who regretted not having done so were analyzed in relation to the length of time since the child's death (four to nine years), and the results were similar according to the length of follow-up (data not shown).

Most parents — 326 of 430 (76 percent) — talked with each other at some time about their child's forthcoming death, and 116 of 432 (27 percent) talked with their child about death during the child's last month of life. When talking about death with the child, 110 of 432 parents (25 percent) used the word "death." (There were a few more responses to these questions than to the one

in which parents stated whether or not they had talked about death, which explains why the denominators are greater than 429.)

Many parents (191 of 419, or 46 percent) reported that they never sensed that their child was aware of his or her imminent death. A total of 91 parents (22 percent) reported that they first sensed this awareness during the child's last week of life, 48 parents (11 percent) sensed it no sooner than two to four weeks before death, 50 parents (12 percent) sensed it one to three months before death, and 39 parents (9 percent) sensed it four months or more before death.

DISCUSSION

In this cohort, which comprised almost all parents who had lost a child to a malignant disease in Sweden from 1992 to 1997, no parent who provided information regretted having talked with his or her child about death. In contrast, nearly a third of the parents who had not talked about death with their child regretted that they had not done so. Parents who had sensed that their child was aware of his or her imminent death were more likely to regret not having talked about it than were those who had not sensed this awareness on the part of the child; mothers were also more likely than fathers to regret not having talked about death, as were parents of older children, as compared with parents of younger children. Parents who had talked about death were more likely to have sensed that their child was aware of his or her imminent death, and they were likely to be religious and on sick leave or retired; they were also older than parents who had not talked about death and had an older child.

Our finding that no parent who had talked about death with his or her child regretted it supports the recommendation by the International Society of Paediatric Oncology that parents communicate honestly with a sick child about the prognosis. Evidence suggests that accurate information about the expected course of the disease is beneficial for most children,⁹ perhaps because it allows their inner lives (i.e., the awareness of their imminent death) and the outer world (i.e., the information they receive from health care workers and parents) to become congruent, thereby preventing frustration.

Parents who sensed that their child was aware of his or her imminent death were much more likely to talk about death with their child than were oth-

er parents. We have no data on the basis of which to conclude whether parents understood and met an unformulated need on the part of the child to talk about death, or whether the child clearly expressed a desire to talk. Moreover, we can only speculate about explanations for our finding that parents who sensed that their child was aware of his or her imminent death were particularly prone to regret not having talked about death. Parents who regretted that they had not talked about death had a higher level of anxiety at follow-up than did others. Perhaps these parents felt that the child was left with his or her thoughts, alone and without comfort. It is possible that the parents who did not respond to the sense that the child was aware of his or her imminent death by talking to the child about it experienced an inner conflict, a conflict that continued after the child's death, when it no longer could be resolved.

It is conceivable that children are aware of their impending death even if parents or health care workers do not always notice this awareness.^{2,11,12} Thus, a higher percentage of children than that reflected by the parents' reports in this study may have been aware of their imminent death. We do not know how our findings would change if some of the parents were told after the death that their child, contrary to what they had sensed, had been fully aware of his or her imminent death.

Parents of older children were more likely to have talked with them about death than were parents of younger children. If they had not done so, these parents more often regretted it. A child's age at the diagnosis and at death are strongly correlated, and we cannot disentangle the relative importance of these factors. Thoughts about death may be triggered both when the diagnosis of a malignant disease is made and when the information about incurability is received, if at all. Our results indicate that the child's age affects the extent to which these thoughts about death result in verbal communication between the child and the parent.

We found that religious parents were more likely to talk about death with their child than were nonreligious parents. It is conceivable that existential issues, including the concept of life after death,

are discussed more often in religious families than in nonreligious ones. A separate analysis from this collection of data indicated that mothers spent more time with their sick children than fathers did, which might explain why a higher percentage of the mothers regretted not having talked about death.²² Parents who are on sick leave or retired may spend more time with their children and have more time to talk about death than employed parents do, which possibly explains why these parents were more likely to have talked about death with their child than were employed parents.

Our population-based setting and high participation rate suggest only minor selection problems; still, we cannot exclude the possibility that some nonparticipating parents had talked about death and regretted it. Extensive multivariable modeling with the use of various approaches raised no concern that parents' sense of their child's awareness of his or her imminent death explained a major portion of the variation of both outcomes we studied. Our use of anonymous, self-administered questionnaires mimicked the technique of blinding and prevented interviewer-related bias.²³ The time that had elapsed since the child's death did not appear to influence the outcomes we studied, which indicates that memory fallacy had only a minor influence. Generalizability to other populations may be compromised by culture-specific needs for parents who have a child who is terminally ill with cancer.

Parents who seek advice — "Should I, or should I not, talk with my child about death?" — might benefit from knowing that no parent in this study regretted having talked about it. In addition, the fact that many parents who had sensed that their child was aware of his or her imminent death later regretted not having talked about death emphasizes the clear responsibility of health care workers to help parents respond to the wants and needs of a terminally ill child.

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