

Absorbing Information about a Child's Incurable Cancer

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Key Words

Prognostic information · Childhood cancer · Communication

Abstract

Purpose: To assess parents' ability to absorb information that their child's cancer was incurable and to identify factors associated with parents' ability to absorb this information. **Patients and Methods:** An anonymous mail-in questionnaire study was performed as a population-based investigation in Sweden between August and October of 2001. 449 parents who lost a child to cancer 4–9 years earlier (response rate 80%) completed the survey. 191 (43%) of the bereaved parents were fathers and 251 (56%) were mothers. **Results:** Sixty percent of parents (n = 258) reported that they were able to absorb the information that their child's illness was incurable. Parents were better able to absorb this information when the information was given in an appropriate manner (RR 1.6; CI 1.3–2.0), when they shared their problems with others during the child's illness course (RR 1.4; CI 1.1–1.8) and when they had no history of depression (RR 1.3; CI 1.0–1.8). Parents who reported that they were able to absorb the information were more likely to have expressed their farewells to the child in their desired manner (RR 1.3; CI 1.0–1.5). **Conclusions:** Parents who received information that their child's

illness was incurable in an appropriate manner are more likely to absorb that information. Whether or not parents are able to absorb the information that their child's cancer is incurable has implications in terms of preparation for the child's impending death.

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Introduction

When a child reaches the point that his or her cancer is incurable, parents have most likely gone through a number of challenging conversations with the medical team. Such conversations likely occurred at diagnosis of their child's cancer, at recurrences, and when the goal of care shifts from curative to palliative care.

Interestingly, there is substantial variability in how well parents are informed throughout the different stages of their child's illness. Patients and families feel better

Studies originating from the same data set have been published in *The Lancet* (2004), *Psychological Medicine* (2004), *The New England Journal of Medicine* (2004), *Pediatrics* (2006), *Palliative Medicine* (2006), *Journal of Palliative Medicine* (2006), *Journal of Clinical Oncology* (2005, 2007, 2008), *Acta Oncologica* and *Lancet Oncology* (2007).

informed at the beginning of the illness, and they experience more uncertainty as the illness progresses [1–5]. In fact, Wolfe et al. [4] found fairly high concordance between parents' and physicians' beliefs about the likelihood of cure at diagnosis. As the child's condition deteriorated, however, parents' understanding and/or acceptance that their child did not have a realistic chance of cure was substantially delayed.

Parents' perception of insufficient and uncaring delivery of information by health care professionals was associated with lingering regret [6] and emotional distress [7, 8]. Several studies have revealed the importance parents place on clear, understandable and complete information about their child's condition [3, 5, 9–12]. For example, parents rate the quality of care higher when they feel that clear information was given about what to expect during end-of-life care [13].

The importance of clear information about the child's condition is further highlighted by findings suggesting that parental understanding of the child's condition and prognosis may also play an important role in their end-of-life decision-making process [4]. For example, Wolfe et al. [4] found that elements of palliative care were more likely to be integrated into the child's care when both the physicians and parents recognized earlier on that the child had no realistic chance of cure and that both parents and physicians shared the common goal of lessening the suffering of the child.

Even if parents *are* given information about the condition and prognosis of their child, it is unclear whether and under what circumstances they are able to actually absorb the information provided.

In this study we examined how, when, and from whom mothers and fathers of a child with cancer reported having received information about their child's terminal condition. Furthermore, we identified factors associated with parental ability to absorb this information. Finally, we explored outcomes associated with mothers and fathers being able to absorb the information that their child's cancer was incurable.

Methods

Study Design

368 children diagnosed with cancer prior to the age of 17 and deceased before the age of 25 between 1992 and 1997 in Sweden were identified by means of the Swedish Cause of Death Registry and the Swedish Cancer Registry and their parents through the Swedish Population Registry. To be eligible, parents needed to be the guardian of the child at the time of diagnosis, have a listed

phone number, be born in any of the Nordic countries, and speak Swedish. 561 parents were determined eligible. The diagnosis of the child was verified, and the child's former physician was asked for permission to contact each parent. Permission to contact all parents was given.

Data Collection

In order to recruit the parents, a letter of introduction inviting them to participate and explaining the purpose of the study was sent to each parent between August and October of 2001. Ten days later, the parents received a phone call and were asked whether they would like to participate. If they agreed, an anonymous, mail-in questionnaire, as well as a response card, were sent to them. The parents were asked to return the response card separately from the questionnaire as a way of maintaining anonymity and keeping track of who had returned the questionnaire. Ten days after the questionnaire was sent out, a card was sent to each parent thanking them for participating and at the same time reminding those parents who had not yet returned the questionnaire to do so. The parents who still had not returned the questionnaire another 10 days later were called by an interviewer and offered assistance in filling out the questionnaire if necessary.

Instrument Development

In order to develop the questionnaire, interviews with parents who had lost a child to cancer as well as discussions with health care professionals were performed to elicit relevant themes. Questions were constructed related to the different themes. The final version of the questionnaire included 129 questions with a total of 365 items.

The questionnaire was tested face-to-face in order to assure correct understanding of all questions. As a last preparatory step, a pilot study was performed to evaluate participation rate, internal loss to follow-up, and study logistics.

The questions covered aspects of information from the time of diagnosis, at possible recurrence, and when the child's illness had reached incurability.

Parents were asked whether they had been able to absorb the information that their child's illness was incurable. Response options included: (1) not relevant, I never received such information; (2) no, not at all; (3) to a certain extent; (4) yes, for the most part; (5) yes, completely. All variables associated with 'absorption of information' were also asked as single-item questions.

In addition, parents were asked about their marital status, age, sex, number of children, education, employment status, and region of residence.

Analysis

Statistics were produced using SPSS version 15. We reported information variables as proportions for mothers and fathers separately, as well as in combination; p values for the differences between mothers and fathers were computed using the χ^2 statistic. We dichotomized the question 'absorption of information', collapsing 'no, not at all' and 'to a certain extent' and collapsing 'yes, for the most part' and 'yes, completely' and calculated proportions of each independent variable for the bivariable categories. To compare categories we calculated the relative risk as the ratio of proportions, together with the 95% confidence interval. The p values for univariate associations were calculated using the Fisher

Exact (two-sided) statistic for bivariate analyses and χ^2 when there were more than two response categories.

Multivariable binary logistic models were then constructed to determine the relative importance of the independent variables in order to explain the variation in the outcome. Those parents who stated that they did not receive such information were excluded. For selection of variables we used both forward selection and backward elimination.

The entire study was approved by the Regional Ethics Committee of the Karolinska Institutet.

Results

Characteristics of participating parents are shown in table 1.

Receipt of Information

Table 2 summarizes from whom and when parents received information about diagnosis, recurrence, and incurability of their child's illness, as well as whether they thought the information was given in an appropriate manner. About half of the parents received the information regarding the child's diagnosis when the child was present, and around 30% of the parents reported that the child was present when they received the information that his or her illness was incurable. Furthermore, around 60% of parents reported that they were informed about the incurability of their child's illness in an appropriate manner (either yes, entirely; or yes, for the most part).

201 (86%) mothers and 163 (88%) fathers reported that they wanted the information on incurability from the physician immediately once their child's illness was regarded as incurable.

Absorption of Information about Incurability

Thirty-seven (9%) parents reported that they were 'not at all' able to absorb the information that their child's cancer was incurable, 83 (20%) were able to absorb it 'to a certain extent', 141 (33%) 'for the most part' and 117 (27%) 'completely'. Fifty-one (12%) parents stated that they never received such information.

Table 3 displays variables associated with parents' ability to absorb information regarding their child's illness being incurable. Parents with no history of depression, those who reported that they shared their problems with others during the child's illness, and those who thought that the information was given in an appropriate manner were more likely to have absorbed the information given.

Table 1. Characteristics of the parents studied who had lost a child to cancer 4–9 years earlier

Characteristics	Bereaved parents, n
Identified as eligible in registries	561
Reasons for not responding	
Refused to participate	30 (5%)
Agreed but did not participate	59 (11%)
Could not be contacted	23 (4%)
Total nonresponders	112 (20%)
Participating parents	449 (80%)
Biological parent	438 (98%)
Non-biological parent	9 (2%)
Not stated	2 (<1%)
Gender	
Male	191 (43%)
Female	251 (56%)
Not stated	7 (2%)
Age	
<30 years	66 (15%)
30–39 years	232 (52%)
40 years or older	146 (32%)
Not stated	5 (1%)
Marital status today	
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%)
Number of children at child's diagnosis	
1	82 (18%)
2	192 (43%)
3	116 (26%)
4 or more	54 (12%)
Not stated	5 (1%)
Level of education	
Elementary school	83 (18%)
Secondary 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%)
Region of residence	
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%)

Table 2. Characteristics of how parents received information about their child's illness¹

	Fathers (n = 191)	Mothers (n = 251)	Total (n = 442)
<i>How did you get the information that your child had cancer?</i>			
N/A; I never got such information	1 (0.5)	3 (1.2)	4 (0.99)
With physician, child and other parent present	78 (40.85)	82 (32.7)	160 (36.2)
With physician and other parent present	53 (27.8)	63 (25.1)	116 (26.2)
With physician and child present	12 (6.3)	36 (14.3)	48 (10.9)
With physician	5 (2.6)	36 (14.3)	41 (9.3)
From other parent	23 (12.0)	9 (3.6)	32 (7.2)
From child	1 (0.5)	0 (0)	1 (0.2)
Via telephone	12 (6.3)	14 (5.6)	26 (5.9)
Other	3 (1.6)	6 (2.4)	9 (2.0)
Missing	3 (1.6)	2 (0.8)	5 (1.1)
<i>How did you get the information that your child's illness had recurred the first time?</i>			
N/A; the illness never recurred	20 (10.5)	40 (15.9)	60 (13.6)
With physician, child and other parent present	47 (24.6)	50 (19.9)	97 (21.9)
With physician and other parent present	24 (12.6)	28 (11.1)	52 (11.8)
With physician and child present	11 (5.8)	28 (11.2)	39 (8.8)
With physician	4 (2.1)	15 (6.0)	19 (4.3)
From other parent	15 (7.8)	8 (3.2)	23 (5.2)
From child	1 (0.5)	0 (0)	1 (0.2)
Via telephone	13 (6.8)	16 (6.4)	29 (6.6)
Other	9 (4.7)	17 (6.8)	26 (7.5)
Missing	47 (24.6)	49 (19.5)	96 (21.7)
<i>Was the information that your child's illness had recurred given in what you consider to be an appropriate manner?</i>			
N/A; the illness never recurred	21 (10.9)	42 (16.7)	63 (14.2)
No, not at all	10 (5.2)	18 (7.2)	28 (6.3)
To a certain extent	21 (11)	18 (7.2)	39 (8.8)
Yes, for the most part	49 (25.6)	62 (24.7)	111 (25.1)
Yes, entirely	37 (19.4)	54 (21.5)	91 (20.6)
Missing	53 (11.8)	57 (12.9)	110 (24.9)
<i>How did you get the information that your child's illness was incurable?</i>			
N/A; I never got such information	27 (14.1)	35 (13.9)	62 (13.8)
With physician, child and other parent present	52 (27.2)	55 (21.9)	107 (24.2)
With physician and other parent present	75 (39.3)	97 (38.6)	172 (38.9)
With physician and child present	7 (3.7)	15 (6.0)	22 (4.8)
With physician	8 (4.2)	28 (11.2)	36 (8.1)
From other parent	4 (2.1)	5 (2.0)	9 (2.0)
Via telephone	6 (3.1)	6 (2.4)	12 (2.7)
By letter	1 (0.5)	1 (0.4)	2 (0.5)
Other	4 (2.1)	4 (1.6)	8 (1.8)
Missing	7 (3.7)	5 (2.0)	12 (2.7)
<i>When did you get the information that your child's illness was incurable?</i>			
N/A; I never got such information	23 (12.0)	28 (11.1)	51 (11.5)
Within 24 h before he/she died	12 (6.3)	19 (7.6)	31 (7.0)
A few days before he/she died	6 (3.1)	13 (5.2)	19 (4.3)
A week before he/she died	8 (4.2)	12 (4.8)	20 (4.5)
2-4 weeks before he/she died	25 (13.1)	25 (10.0)	50 (11.3)
1-3 months before he/she died	55 (28.8)	69 (27.5)	124 (28.1)
4-6 months before he/she died	33 (17.3)	41 (16.3)	74 (16.7)
7-11 months before he/she died	13 (6.8)	17 (6.8)	30 (6.8)
1 year before he/she died	3 (1.6)	11 (4.4)	14 (3.2)
2 years or longer before he/she died	6 (3.1)	10 (4.0)	16 (3.6)
Missing	7 (3.7)	6 (2.4)	13 (2.9)

Table 2 (continued)

	Fathers (n = 191)	Mothers (n = 251)	Total (n = 442)
<i>Was the information that your child's illness was incurable given in what you consider to be an appropriate manner?</i>			
N/A; I never got such information	25 (13.1)	27 (10.8)	52 (11.8)
No, not at all	21 (11.0)	31 (12.4)	52 (11.8)
To a certain extent	28 (14.7)	32 (12.8)	60 (13.6)
Yes, for the most part	54 (29.3)	66 (26.3)	120 (27.1)
Yes, entirely	53 (27.8)	87 (34.7)	140 (31.7)
Missing	10 (5.2)	8 (3.2)	18 (4.1)

¹ Seven parents did not state their gender, therefore we can only present data on 442 parents by gender. Figures in parentheses are percentages.

In multivariate modeling of factors associated with parents' ability to absorb information about the child's incurable cancer most of the variance was explained by whether the information was given in an appropriate manner ($p < 0.001$), when the curative treatment ended ($p = 0.045$), and whether the parents had someone to share their problems with during the child's illness ($p = 0.051$, table 4).

Outcomes Associated with Absorbing Information about Incurability

Parents who reported having absorbed the information that their child's cancer was incurable were more likely to have expressed their farewells to the child in the way that they wanted to (RR 1.3; CI 1.0–1.5). No significant results were found when looking at where the child died and its association with whether or not parents had absorbed the information about their child's incurability.

Discussion

Communication and specifically the provision of information is one of the most important aspects of professional care-taking. The manner in which information about incurability is delivered in end-of-life communication has great implications on how patients and family caregivers experience quality of care [14–16]. To our knowledge, no previous studies have addressed parents' ability to absorb information about the child's cancer being incurable. In our study, over 50% of parents were unable to fully absorb information regarding their child's incurability. However, absorption of this information was more likely if parents perceived that it was

given in an appropriate manner. Thus, the quality of physician communication may substantially impact parents' ability to 'hear' news that understandably is so difficult to bear.

About half of the parents reported that information about recurrence as well as incurability of the child's illness was given in an appropriate manner. Our data does not allow us to determine which factors hinder communicating appropriately, however, other studies suggest possible explanations. An important contributing factor may be related to the limited training of physicians in the area of communication [17]. Physicians may also wonder whether discussing prognostic information is the right thing to do [18–20] and assume that discussing difficult aspects of the illness may not meet the parents' needs [4, 21]. They may also worry that it may upset patients [19, 22–25], or take away hope [24–31]. However, in a study by Mack et al. [11], it was shown that parents of pediatric cancer patients do want detailed prognostic information about their child's illness, even if the information is emotionally upsetting. Furthermore, they found that discussing prognostic information does not take away hope [11]. All in all, these results emphasize the critical importance of physician education about communication in order to enable parents to absorb distressing information. It also highlights the significance of implementing communication guidelines [11, 32, 33] in clinical practice.

Being informed without delay about the child's terminal condition may provide an opportunity for the parents to make end-of-life decisions according to their traditions and values and prepare for the child's impending death, preparations which have been shown to be beneficial to bereaved parents in the long term [34, 35].

Table 3. Variables associated with parents' ability to absorb information regarding their child's disease being incurable

	Parent able to absorb information	RR	CI	p value (χ^2 /Fisher)
How did you receive the information that your child's illness was incurable?				
Physician	227/332 (68)	1.3	1.0–1.6	0.828
Info from other	17/26 (65)	1.0	ref.	
Anxiety the year before your child's diagnosis				
No	226/323 (70)	1.2	0.9–1.6	0.120
Yes	25/43 (58)	1.0	ref.	
Depression the year before your child's diagnosis				
No	227/323 (70)	1.3	1.0–1.8	0.035
Yes	23/43 (53)	1.0	ref.	
Marital status at child's diagnosis				
Married/cohabited with other parent	225/329 (68)	1.0	ref.	0.583
Married/cohabited with other	6/11 (55)	0.8	0.5–1.4	
In a relationship	5/9 (56)	0.8	0.5–1.5	
Single	17/23 (74)	1.1	0.8–1.4	
Duration of illness				
<1 year	90/127 (71)	1.1	0.9–1.3	0.295
>1 year	156/239 (67)	1.0	ref.	
Type of cancer				
Brain tumor	95/143 (66)	1.0	ref.	0.730
Leukemia	77/109 (71)	1.1	0.9–1.3	
Sarcoma	61/87 (70)	1.1	0.9–1.3	
Other	21/34 (62)	0.9	0.7–1.2	
Was the information that your child's illness was incurable given in what you consider to be an appropriate manner?				
Yes	201/258 (78)	1.6	1.3–2.0	<0.001
No	53/110 (48)	1.0	ref.	
When did your child's curative treatment cease?				
Last days	80/109 (73)	1.3	1.0–1.5*	0.090
Week–3 months	120/174 (69)	1.2	1.0–1.4	
4 months–more than 3 years	50/85 (59)	1.0	ref.	
Parent had someone to share their own problems with during the child's illness				
Most to all	138/190 (73)	1.4	1.1–1.8	0.013
Less or more than half	83/122 (68)	1.3	1.0–1.7	
None or almost none	29/56 (52)	1.0	ref.	
When did you receive information that your child's illness was incurable?				
Last week	45/69 (65)	1.0	0.8–1.2	0.398
2 weeks–3 months	122/170 (72)	1.1	0.9–1.3	
4 months–more than 2 years	86/132 (65)	1.0	ref.	

Table 4. Multivariable logistic regression (forward selection¹) for when information was absorbed that the child's illness was incurable

Variable	Nagelkerke's R ²	χ^2	d.f.	p
Intercept and information was given in an appropriate manner	0.12	28,989	1	<0.001
When the curative treatment ended	0.14	6,569	2	0.037
Whether the parents had someone to share their problems with during the child's illness	0.16	5,874	2	0.053

Step 1: appropriate; step 2: appropriate, treatment ceased; step 3: appropriate, treatment ceased and share problems.

¹ Please note that results were confirmed by applying backward elimination.

Eighty-six percent of mothers and 88% of fathers wanted the physician to let them know immediately when the illness was incurable. This result is consistent with previous findings from another study, which indicated that parents prefer receiving this information as early as possible [10]. Importantly, we found that parents who grasped the information that their child's illness was incurable were more likely to express their farewells before the child died.

In addition, parents who reported that they shared their problems with others during the child's illness were more likely to absorb the information about the child's incurability. It is reasonable to think that sharing problems with others may be a way to process the information and increase the chance that the information sinks in.

We found wide variability in the specific manner in which information about the child was given throughout the course of illness. Parents reported, for example, that the more severe the child's illness, the more likely it was that fathers also received the information directly from the physician, rather than through other channels. We also found that the more severe the illness, the less often the child was present during information giving by the physician. Fifty-seven percent of the parents reported that the child was present during the conversation with the physician about diagnosis, while only 39% reported that the child was present during information about recurrence and 30% when incurability was being discussed. There are studies indicating that the presence of the child, especially older children and teenagers, might be beneficial when prognostic information is being discussed [16]. Otherwise, young people may assume that the information they received was not completely honest [16]. Mack et al. [11] showed that parents were less upset when their child was present during prognostic discussion than when they were absent. This may raise the question whether prognostic discussions are more optimistic when the child is present and therefore less upsetting to parents. But this was not supported in the study. Parents were also likely to rate quality of physician care high when physicians communicated directly with the child as long as parents thought that the child was old enough [13].

Jedlicka-Köhler et al. [36] conducted a study involving 46 parents who received information about their child's diagnosis of cystic fibrosis by the child's pediatrician and found great variability in the amount of information the parents were able to retain. Thirty-three percent of these parents reported that they retained 50% or less of the information given to them [36]. The number of parents in

our study reporting that they had significant difficulties absorbing the information they received (29% of parents reporting that they were not at all or only to a certain extent able to absorb the information that their child's illness was incurable) even exceeds those numbers. This may be explained by the increased severity of the situation. Jedlicka-Köhler et al. [36] suggested as an explanation for the reduced retention that the parents' memory was disturbed by the presence of negative emotions and base their conclusion on findings of other research groups that found that powerful negative emotions can disturb memory [37]. They also conclude that depressed individuals may select and process information in a way that is consistent with their present mood state, while ignoring information that would provide a more accurate picture [38]. Though a history of depression was associated with less absorption of information about the child's incurability in our study, we do not know whether the parent was actually depressed at the time of receiving the information. Future studies should further evaluate the role of parent affect and ability to absorb distressing information.

In addition, our study found that parents of children whose curative treatment ended closer to the time of death were more likely to absorb information about the incurability of the child's disease. Additional research is necessary to better understand the implications of this finding.

This nationwide study has a high participation rate of 80%, which reduces the risk of participation bias. It also included similar numbers of mothers and fathers. Still, there are several limitations. First, it is a cross-sectional study that relies on parents reporting on issues in the past. One may wonder what parents mean when reporting that information was given in an 'appropriate' manner. Still, we believe that the parents are the only ones that can truly judge whether information was given in an appropriate way in their eyes. For future advancement of care, it is important to understand parents' perception of what is an appropriate way of delivering such sensitive information.

In summary, the findings that information given in an appropriate manner increases parents' ability to absorb the information about their child's illness being incurable is valuable for clinical practice. It supports the need for education and training for health care professionals to deliver bad news in a way that enhances understanding of the news itself. Furthermore, absorption of information has critical clinical implications for the parental preparation of their child's death. Health care profession-

als may use the findings of this study to identify parents at risk for difficulties absorbing challenging medical information and can encourage parents to discuss problems with others as an opportunity to process information throughout the child's illness.

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