

ORIGINAL ARTICLE

Teenagers want to be told when a parent's death is near: A nationwide study of cancer-bereaved youths' opinions and experiences

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ABSTRACT

Background. We aimed to investigate cancer-bereaved youths' opinions and experiences of being told about a parent's imminent death from cancer and of barriers to this communication.

Material and methods. This nationwide population-based survey included 622/851 (73%) youths (aged 18–26) who at age 13–16, 6–9 years earlier had lost a parent to cancer.

Results. In total 595 of 610 (98%) of the participants stated that teenage children should be informed when the parent's death was imminent (i.e. a matter of hours or days, not weeks). 59% stated that they themselves had been told this, 37% by the parents, 7% by parents and healthcare professionals together and 8% by professionals only. Frequent reasons for why the teenager and parents did not talk about imminent death before loss were that one (n = 106) or both (n = 25) of the parents together with the teenage child had pretended that the illness was not that serious, or that none of the parents had been aware that death was imminent (n = 80). Up to a couple of hours before the loss, 43% of participants had not realized that death was imminent.

Conclusion. In this population-based study virtually all youth who at ages 13–16 had lost a parent to cancer afterwards stated that teenagers should be told when loss is near, i.e. a matter of hours or days, not weeks. Many stated that they had not been given this information and few were informed by professionals, with implications for future improvements in end-of-life care of patients with teenage children.

Evidence suggests that while most young people eventually will recover from the loss of a parent to death there is an increased risk of serious outcome, e.g. [1]. Communication and family cohesion are important means to ease the negative impact on the minor family members [2–5]. Communication in terms of talking about death with a dying child, and awareness and preparedness for the impending death of a spouse, have been shown to alleviate suffering and long-term harm in cancer-bereaved adults [6,7].

Nevertheless, providing end-of-life information is a challenge to healthcare professionals even when only adults are involved and there are several reasons for why it is not completed, ranging from denial on the part of the recipient to failure on behalf of the provider of information [8].

Research about communication in cancer-struck families with children (<18) has predominantly focused on the providers of information and almost exclusively on the parents [9,10]. Several

barriers to open parent-child communication have been identified, including the highly comprehensible parental attempts to protect their children from distress [9]. Even parents who believed in the benefit of open communication balanced their ambition to tell the truth against trying to protect the children from the harm this information could cause [10].

Research about teenage recipients of information about a parent's serious cancer disease and death, is scarce [11–13]. In a nationwide project we leveraged the Swedish population-based registries to identify children that at age 13–16, 6–9 years earlier had lost a parent to cancer. In this study we present descriptive data on participants' opinions about being told that a parents' death is imminent, if and from whom they had received this information, barriers to communication with the parents and when the bereaved teenagers had become aware of the different points of the increasingly more serious disease trajectories.

Methods

Setting

This nationwide population-based survey was conducted between February 2009 and March 2010 in Sweden.

Participants

Children who at age 13–16, in 2000–2003 lost a parent to cancer (ICD10;C:00-96). The Swedish National Causes of Death Register was used to identify parents and the Multi-generational Register to identify their teenage children. Participants had to have lived with both parents at the time of loss, have one living parent at the time of survey and an identifiable telephone number.

Questionnaire development

Semi-structured interviews with 16 children (cancer-bereaved between the ages of 13 and 25, recruited through newspaper advertisement), the research groups' previous findings, the child bereavement literature and discussion with experts inspired the research questions of this project. Study-specific single-item questions and response-options were tested for face validity to ensure that the questions were understood as intended and that the response-options were all-embracing. This was carried out on a one-to-one basis with 15 individuals who had been 13–16 at the time of loss (six from the original interview sample and an additional nine recruited through a new newspaper advertisement). The final questionnaire

included in total 271 items of which 24 were used for the present study. The routines for questionnaire development have been described in details elsewhere [14].

Measures

To measure participants' opinion we asked "When it is possible to predict that death is imminent, do you think teenage children should be informed that their parent has a short time left to live (that is a matter of hours or days, not weeks)?" (No/Yes). For experiences we asked "Did anyone tell you that the end now was near (that your parent was dying, that it was now a matter of hours or days, not weeks)?" (No/Yes/I don't remember). If the answer was "Yes", participants were asked by whom. We asked if the teenager and the dying and the other parent respectively had talked about imminent death in the final week of the dying parent's life, providing the response options "Yes", "No, we had already talked", "No, there was no need to talk", "No, he/she tried to but I refused", "No, I tried to but he/she refused", "No, we both pretended that death was not imminent", "No, none of us realized that death was imminent", "I don't remember", and, for the dying parent, "No, he/she was too ill to communicate". We asked about the length of time before the loss that the teenager had: 1) known that the parent had cancer; 2) realized that the disease was incurable; and 3) realized that the parent was going to die. Response options ranged from "Never/afterwards" to "More than 2 years". We further asked "For how long did you realize that your parent's death was imminent", and "For how long do you believe that your parent/your other parent/the physicians, respectively, realized that death was imminent" with response options ranging from "Never/afterwards", to "3 days or more".

Procedure

Eligible individuals were successively approached first by an introductory letter with information about the overarching aim of the study, research ethics, i.e. the right to abstain from participation at any point in time, contact information to the research team and the information that we would call them in a few days to allow for questions and ask if they were willing to participate. We avoided to make contact during anniversaries, family holidays and vacations and sent a questionnaire, with a separate reply card to ensure anonymity, only to those who explicitly agreed. We posted a combined thank-you-and-reminder card a few weeks after the questionnaire and later made reminder phone calls only to those whose reply cards we had not received and who had agreed to be called. All materials, i.e. the questionnaire, letter and infor-

Table I. Characteristics of the study population.

	Bereaved children no. (%)
Confirmed eligible ¹	851
Not reachable	55 (6)
Declined to participate	66 (8)
Agreed initially but did not return questionnaire	108 (13)
Providing information	622 (73)
Participant gender (role)	
- Male (son)	309 (50)
- Female (daughter)	312 (50)
- Not stated ²	1
Year of birth (age at survey)	
- 1988–1990 (18–20)	210 (34)
- 1986–1987 (21–22)	286 (46)
- 1984–1985 (24–25)	123 (20)
- Not stated	3
Current employment status (at ages 18–26, more than one alternative is possible)	
- Studying at high school level	24/614 (4)
- Adult education at high school level	31/613 (5)
- Studying at university level	187/613 (31)
- Employed or self-employed	355/616 (58)
- Unemployed	91/616 (15)
- On parental leave	9/613 (1)
- On sick leave	7/613 (1)
Residential region	
- Rural	54 (9)
- Small village or town	113 (18)
- Medium sized town	283 (46)
- City of more than 500 000	166 (27)
- Not stated	6
Gender of deceased parent (role)	
- Male (father)	337 (54)
- Female (mother)	284 (46)
- Not stated	1

¹All those identified in registers who met inclusion criteria; ²The group “not stated” are not included in tests for significance or in calculations of proportions.

mation sheet, included information that encouraged participants to call us on our free-of-charge telephone number if they needed any help with the questions or support for feelings aroused by the questionnaire. We have no indications of having caused any harm by our procedure or the questions asked, neither from the pilot or the main study. The project was approved by the Regional Ethical Review Board, Karolinska Institutet, Stockholm.

Statistical analyses

We present responses in numbers and percentages. Log-binomial regression was used to calculate risk ratios (RRs) and 95% confidence intervals (CIs). Statistical analyses were done in SAS (version 9.2, SAS Institute Inc., Cary, NC, USA).

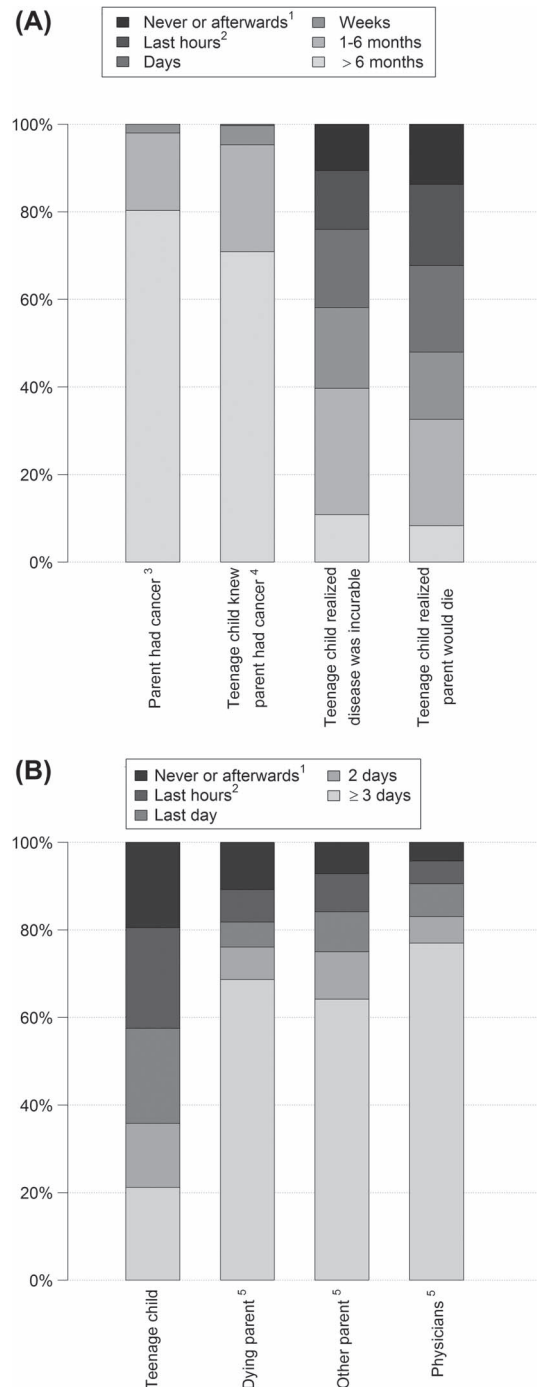


Figure 1. Cumulative percentages for length of time before the loss; (A) that the cancer-bereaved youths report to have known about different phases of the disease and dying trajectory; (B) when cancer-bereaved youth themselves and when cancer-bereaved youths believe that parents and physicians respectively, had realized that death was imminent (a matter of hours or days, not weeks). Missing values were not included in calculations. (1) A combination of “Not applicable, I never realized this” and “After the loss”, (2) A combination of “At time of loss” and “A couple of hours before the loss”, (3) As reported by cancer-bereaved youths. 55 individuals responded “I don’t know”, (4) Response-options shorter than “a couple of days” were not available, and (5) Length of time before the loss that cancer-bereaved youth’s believed that adults had been aware that death was imminent.

Table II. Number and percentage of responses to the question if the cancer-bereaved youth had talked with the dying parent and the other parent respectively about imminent death in the final week before the loss.

No.	Yes	No, we had already talked	No, we had no need to talk	No, my other parent tried but I didn't want to	No, I tried but my other parent didn't want to	No, we pretended that death was not imminent	No, none of us realized that death was imminent	I do not remember	Total no. (%)
No, my dying parent was too ill to communicate	52	10	15	14	1	11	13	12	128 (22)
Yes	46	1	6	4	2	9	2	3	73 (12)
No, we had already talked	11	9	2	1			1	5	29 (5)
No, we had no need to talk	31	7	34	2	1	3	3	9	90 (15)
No, my dying parent tried, but I didn't want to	3		1	14		3	4	2	27 (5)
No, I tried but my dying parent didn't want to				1		1			2 (—)
No, we both pretended that death was not imminent	26		2	4	1	25	4	9	71 (12)
No, none of us realized that death was imminent	1	1	2	3		6	80	5	98 (17)
I do not remember	20		1	9	2	2	5	33	72 (12)
Total no. (%)	190 (32)	28 (5)	63 (11)	52 (9)	7 (2)	60 (10)	112 (19)	78 (13)	590

The first column shows the response-options to the question if the teenager had talked with the dying parent about imminent death in the final week before the loss; The first row shows the response-options to the question if the teenager had talked with the other parent; Grey areas highlights a diagonal corresponding to the number of cancer-bereaved youth reporting the same reason for communicating or not for both parents. For example, 80 cancer-bereaved youths responded that they had not realized that death was imminent when referring to both the dying and the other parent.

Results

Altogether, 851 cancer-bereaved youth were eligible for the study whereof 622 (73%) completed the questionnaire, 50% were women and 46% had lost a mother. Reasons for non-participation were that individuals either could not be reached (6%), declined to participate (8%), and that the questionnaire was not returned (13%). Table I lists the characteristics of participants.

In total 595 (98%) participants stated the opinion that teenage children should be told when a parent's death from cancer is imminent. Of 617 respondents, 367 (59%) reported that they had been told: 226 (37%) by parents, 42 (7%) were told by parents and healthcare professionals together and 50 (8%) had been told about imminent death by healthcare professionals alone. Thirty percent of participating cancer-bereaved youth reported that no one had told them that death was imminent and 11% did not remember (Supplementary Figure 1, to be found online at <http://informahealthcare.com/doi/abs/10.3109/0284186X.2014.978891>).

We found a general tendency of increased risks for not being told about the parent's imminent death among those whose parents had had the cancer diagnosis for a shorter time than two years, and among youths who knew about the disease for a shorter

time than two years (Supplementary Table I, to be found online at <http://informahealthcare.com/doi/abs/10.3109/0284186X.2014.978891>). The rows and columns of Table II shows for both parents, respectively, whether the bereaved youth had been talking to the parent about imminent death in the final week before the loss and, if not, the reason why. A total of 218 cancer-bereaved youths (37%) reported having talked with the other parent about imminent death and 102 (17%) had talked with the dying parent, 17% if the dying parent was a mother and 16% if the dying parent was a father (data not shown). In total 182 (22%) reported that the dying parent had been too ill to communicate. The diagonal of Table II shows the numbers of cancer-bereaved youth reporting the same reason for both parents. Mutual pretending with both parents was reported by 25 participants, unawareness that death was imminent was reported by 80 participants, and 14 indicated to have refused to talk with both parents about imminent death despite parental attempts to talk.

Figure 1 shows how many participants that at different time-points before the loss had been aware of the increasingly more serious prognosis (A), and the points in time when participants realized that death was imminent and when they believed that the dying parents, the other parents and the physicians

respectively realized that death was imminent (B). A couple of days before the loss, the cumulative proportion of participants that had realized that their parent's disease was incurable was 76%, while 67% had also realized that the parent would die from the disease. Two days before the loss the cumulative proportion of cancer-bereaved youths that had realized that loss was imminent (i.e. a matter of hours or days) was 36% while at this point in time they believed that 75–76% of both dying and other parents, and 83% of physicians, had realized that death was imminent. The number of youths who realized that death was imminent increased to 57% during the final day and reached an accumulated 80% a couple of hours before the loss (Figure 1).

Discussion

This Swedish nationwide study of youth who during their teenage years, 6–9 years earlier in 2000–2003, had lost a parent to cancer, showed that virtually everyone thought that teenage children should be told when the parents death is near, i.e. a matter of hours or days, not weeks. Three of five reported to have been given this information, predominantly by the parents and seldom in the presence of healthcare professionals. Prevalent reasons for not talking with the parents about imminent death in the final week of the dying parents' life were mutually pretending that the situation was not that serious and unawareness that death was imminent. Many teenagers had been unaware of the imminent loss until the very last day or hours but believed that parents and professionals had known it longer.

To our knowledge this is the first nationwide population-based study of cancer-bereaved teenagers' opinions about and reception of information about a parent's imminent death from cancer. Several reasons for the almost unanimous desire for information about parental imminent death can be hypothesized, including the wish to be prepared, avoid unexpectedness, have the chance to talk and say farewell, and to increase understanding and coping. For example, in a Swedish nationwide study of 691 widowers, low preparedness for the loss was associated with an increased risk of perceiving death as shocking [7]. Another Swedish nationwide study of 449 parents found that when there was no forewarning of the child's death or when forewarning was not absorbed this lowered the chance of coming to a closure and say farewell [15]. Harris [16] reported from a qualitative study of 11 parentally bereaved American teenagers that all spontaneously reflected on the issue of having said goodbye, a precious and comforting memory if they had, but associated with anger, disappoint-

ment and guilt if not. In 449 Swedish cancer-bereaved parents it was found that 27% of parents who did not talk about death with their child still regretted this 4–9 years afterwards [6]. A qualitative study from the UK points to distress in parentally bereaved resulting from lack of accurate, timely and age (i.e. maturity) appropriate information [5]. Possibly, when information is not withheld the teenagers are comforted that the truth is shared with them and they are provided with the knowledge and vocabulary needed to understand and mentally process the trauma, thus improving coping and adjustment [17]. Speculatively, non-prediction of imminent death might decrease the trust in healthcare professionals. In our previous report we found end-of-life medical information to the family before (and preferably both before and after) the loss to be associated with higher trust in the health care provided which in turn was associated with a lower risk of depression [4].

We found that 43% had been told when death was imminent by a parent which compares with the 40–50% of parents who talked about death with children (aged > 9) dying from malignancies [6]. In accordance with results from a Swedish qualitative study [11] we found that most often the information was provided by the other parent. In the present study, we found that around three of five teenagers reported that they had been told and an additional one of five that they had realized without being told that loss was near before it occurred. According to our participants the parents and physicians had been aware of the situation somewhat longer than the children. Presumably, this reflects a parental need for own space to comprehend and cope with the situation first before being able to tell the children [18,19]. We are not aware of any other study documenting the prevalence of various reasons for why parent-teenage talk about imminent death is not taking place. Different scenarios leading to family unawareness of imminent death might be distinguished, including problems in both giving and receiving information, e.g. [15] and prognostic failures. Possibly, family unawareness is more prevalent or persistent when the patient is young and has minor children. In an American study of 668 advanced cancer patients, those who were parents of dependent children had more panic and anxiety. In addition, they were more likely to favor a course of treatment aiming for life extension rather than for pain relief compared to patients without dependent children [20].

Pretending is a recognized strategy in both adults and children to protect significant others from the painful news that one of them is dying [21,22]. In our study, 10% attributed the reason for absence of parent-teenager communication about imminent

death to mutual pretending. In comparison, pretending between adults was reported in 5% of UK families, 4% of Irish families, and 15% of Italian families [23].

The high participation-rate and identifying participants through population-based registers to reduce potential selection-related problems are major strengths of the study.

To minimize measurement errors, we used questions derived from semi-structured preparatory interviews and tested for face validity by those concerned. Acquiring information through self-assessment of retrospective single-item questions can be viewed both as strength (i.e. getting information directly from those concerned) and limitation (e.g. participants might have been told but unable to absorb the information). We have no knowledge about if or how age and the passing of time, i.e. 6–9 years, might have influenced the responses.

In conclusion, we found that bereaved youths believe that teenagers should be informed when a parent's death from cancer is a matter of hours or days, but many had not been told and had realized what was about to happen very late. Some may argue that the responsibility to tell children about a parent's serious disease and imminent death falls upon the parents. However, the situation is likely to be both completely novel and, quite understandably, extremely stressful for the parents. It has repeatedly been documented that telling the children is a major challenge and throughout the disease trajectory many parents express a need for professional support in reasoning around the issues of who, when, what and how to talk with the children [9,19,24–26]. Simultaneously, it is acknowledged that these children constitute a vulnerable group. In Sweden, and several other Nordic countries, an amendment was made to the health-care legislation in 2010 that healthcare professionals must consider the needs for information and support of children of parents that are seriously ill and unexpectedly dies. Family unawareness and mutual pretending are distinguished examples of situations where assistance is warranted from the professionals involved in the health care of the parent. To ensure that bereaved-to-be teenagers are forewarned when death is near, in accordance to the wishes expressed in this investigation, the healthcare professionals involved can motivate and support parents to have this conversation with their children, by themselves or together with the professionals.

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Supplementary material available online

Supplementary Figure 1 and Table I to be found online at <http://informahealthcare.com/doi/abs/10.3109/0284186X.2014.978891>.

Supplementary material for Bylund-Grenklo T, et al. Teenagers want to be told when a parent's death is near: A nationwide study of cancer-bereaved youths' opinions and experiences. *Acta Oncol* 2014; doi: 10.3109/0284186X.2014.978891

Supplementary Table I. Potential predictors for reporting on not having been told about the parent's imminent death from cancer¹.

	No. /total (%) of not being told	RR (95% CI)
Participant gender (role)		
• Female (daughter)	90/280 (32)	0.9 (0.7–1.2)
• Male (son)	94/270 (35)	1.0 (reference)
Year of birth (age at follow-up)		
• 1988–1990 (19–21)	66/184 (36)	1.3 (0.9–1.9)
• 1986–1987 (22–23)	87/252 (35)	1.2 (0.9–1.8)
• 1984–1985 (24–25)	31/112 (28)	1.0 (reference)
Age at loss		
• 13	32/110 (29)	1.0 (0.7–1.4)
• 14	50/132 (38)	1.2 (0.9–1.8)
• 15	56/150 (37)	1.3 (0.9–1.7)
• 16	43/145 (30)	1.0 (reference)
Year of loss		
• 2000	44/144 (31)	0.7 (0.5–1.0)
• 2001	42/128 (33)	0.8 (0.6–1.1)
• 2002	36/123 (29)	0.7 (0.5–1.0)
• 2003	59/145 (41)	1.0 (reference)
Birth order		
• Oldest child	46/124 (37)	1.0 (reference)
• Middle child	45/135 (33)	0.9 (0.6–1.3)
• Youngest child	86/270 (32)	0.9 (0.6–1.1)
• No siblings	7/22 (32)	0.9 (0.4–1.6)
Residential region		
• Rural	19/47 (40)	1.3 (0.8–1.9)
• Small village or town	37/103 (36)	1.1 (0.8–1.6)
• Medium sized town	80/246 (33)	1.0 (0.8–1.4)
• City of more than 500 000	48/151 (32)	1.0 (reference)
Religious or spiritual		
• No, not at all	128/382 (34)	1.5 (0.8–2.8)
• Yes, a little	34/92 (37)	1.7 (0.9–3.2)
• Yes, moderately	14/41 (34)	1.5 (0.7–3.2)
• Yes, much	8/36 (22)	1.0 (reference)
Gender of deceased parent (role)		
• Female (mother)	91/252 (36)	1.2 (0.9–1.5)
• Male (father)	93/298 (31)	1.0 (reference)
Deceased parent's year of birth (age at death)		
• 1960–1969 (31–43)	26/71 (37)	0.9 (0.6–1.3)
• 1955–1959 (41–48)	51/157 (32)	0.8 (0.6–1.1)
• 1950–1954 (46–53)	36/148 (24)	0.6 (0.4–0.8)
• 1936–1949 (51–67)	60/147 (41)	1.0 (reference)
Deceased parent's educational level		
• Middle school (years ≤ 9)	37/102 (36)	1.1 (0.8–1.5)
• High-school (years 10 ≤)	71/213 (34)	1.0 (0.8–1.3)
• University	69/206 (34)	1.0 (reference)
Other parent's year of birth (age at loss of spouse)		
• 1960–1969 (31–43)	29/93 (31)	0.8 (0.6–1.2)
• 1955–1959 (41–48)	63/176 (36)	0.9 (0.7–1.3)
• 1950–1954 (46–53)	51/170 (30)	0.8 (0.6–1.1)
• 1936–1949 (51–67)	34/90 (38)	1.0 (reference)
Other parent's educational level		
• Middle school (years ≤ 9)	34/98 (35)	1.0 (0.7–1.3)
• High-school (years 10 ≤)	70/227 (31)	0.8 (0.7–1.1)
• University	71/196 (36)	1.0 (reference)

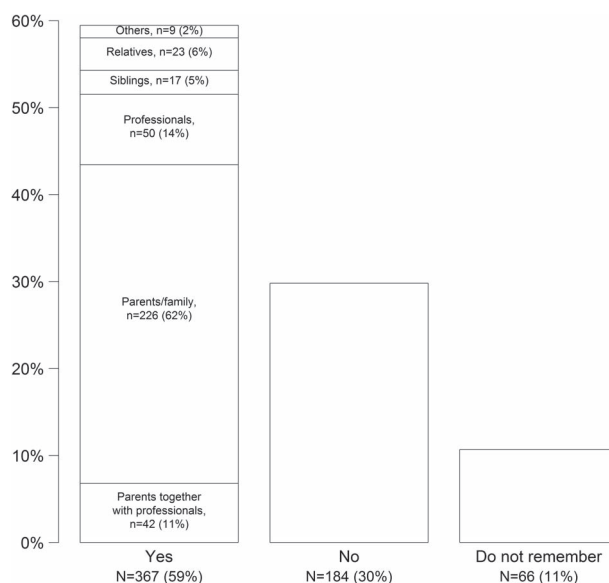
(Continued)

Supplementary Table I. (Continued)

	No. /total (%) of not being told	RR (95% CI)
Cancer site		
• Breast, gynecological	33/107 (31)	0.9 (0.6–1.3)
• Urinary tract, Prostate	7/24 (29)	0.9 (0.4–1.7)
• CNS	14/61 (23)	0.7 (0.4–1.1)
• Skin, Sarcoma	14/37 (38)	1.1 (0.7–1.8)
• Hematological	8/35 (23)	0.7 (0.3–1.3)
• Lung, head-neck, thyroid	32/78 (41)	1.1 (0.8–1.7)
• Unknown primary	5/10 (50)	1.5 (0.7–2.9)
• Don't know, don't remember	17/51 (33)	1.0 (0.6–1.6)
• Gastrointestinal	38/111 (34)	1.0 (reference)
Length of time before loss that the parent had cancer (estimated by the teenage child)		
• A couple of weeks	5/10 (50)	1.9 (1.0–3.8)
• A couple of months	9/27 (33)	1.3 (0.7–2.3)
• 4–6 months	19/55 (35)	1.3 (0.8–2.1)
• 7–12 months	23/70 (33)	1.3 (0.8–1.9)
• 1–2 years	62/168 (37)	1.4 (1.0–2.0)
• More than 2 years	43/165 (26)	1.0 (reference)
• Don't know	20/50 (40)	1.5 (1.0–2.3)
Length of time that the teenage child knew the parent had cancer		
• A couple of days	0/2	³
• A couple of weeks	11/24 (46)	1.8 (1.1–3.0)
• A couple of months	22/59 (37)	1.5 (0.9–2.6)
• 4–6 months	28/66 (42)	1.7 (1.1–2.5)
• 7–12 months	26/78 (33)	1.3 (0.9–2.0)
• 1–2 years	60/172 (35)	1.4 (1.0–1.9)
• More than 2 years	37/145 (26)	1.0 (reference)

CI, confidence interval; RR, relative risk ratio.

Log-binomial regression was used to calculate RRs and 95% CIs: ¹Participants reporting not to remember if anyone told them about imminent death are excluded from calculations; ²Deaths and losses occurred between the years of 2000–2003; ³Not calculated because of low numbers.



Supplementary Figure 1. Answers to the questions “Did anyone tell you that your parent’s death was imminent (a matter of hours and days, not weeks)?”, and “Who told you?”.