<http://www.diva-portal.org>

Postprint

This is the accepted version of a paper published in *Death Studies*. This paper has been peer-reviewed but does not include the final publisher proof-corrections or journal pagination.

Citation for the original published paper (version of record):

Jalmsell, L., Kontio, T., Stein, M., Henter, J., Kreicbergs, U. (2015)

On the child's own initiative: parents communicate with their dying child about death.

Death Studies, 39(2): 111-117

<http://dx.doi.org/10.1080/07481187.2014.913086>

Access to the published version may require subscription.

N.B. When citing this work, cite the original published paper.

Permanent link to this version:

<http://urn.kb.se/resolve?urn=urn:nbn:se:uu:diva-237041>

ON THE CHILD'S OWN INITIATIVE

- PARENTS COMMUNICATE WITH THEIR DYING CHILD ABOUT DEATH

Authors: Li Jalmsell, Taru Kontio, Maria Stein, Jan-Inge Henter & Ulrika Kreicbergs

Abstract: 99 words

Tables: 3

Figures: 1

Research support:

This study was financed by the Swedish Childhood Cancer Foundation

Running head:

Parents communicate with their dying child about death

Previous presentations of the manuscript:

The manuscript has not been presented elsewhere.

Potential conflicts of interest:

The authors have no potential conflicts of interest to declare.

Acknowledgments

We thank the parents who made this study possible by bravely sharing their experiences with us.

ABSTRACT

Open and honest communication has been identified as an important factor in providing good palliative care. However, there is no easy solution to if, when and how parents and a dying child should communicate about death. This paper reports how bereaved parents communicated about death with their child, dying from a malignancy. Communication was often initiated by the child and included communication through narratives such as fairy-tales and movies and talking more directly about death itself. Parents also reported that their child prepared for death by giving instructions about his or her grave or funeral and giving away toys.

INTRODUCTION

The incidence of childhood mortality in western countries is low nowadays so most parents do not have to face the possibility of surviving their own child. Having a child with a severe and potentially life-threatening illness forces families to recognize that life is not endless, and that even children and young adults might die. Being told that one's child is likely to die is undoubtedly among the worst fears of any parent, and losing one's child has been described as one of the most stressful life-events possible (James & Johnson, 1997; Wheeler, 2001). Parents may be faced with the difficult task of balancing their desire to keep their child alive as long as possible with their desire to protect their child from unnecessary suffering.

We have previously reported that four to nine years after the loss of their child, bereaved parents still experienced increased levels of anxiety and depression compared to non-bereaved parents (Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004a). Open and honest communication about disease and prognosis between health care practitioners, parents and children has been proposed as an important factor in improving and providing good palliative care (Beale, Baile, & Aaron, 2005; Mack & Grier, 2004) whereas poor communication has been seen as a factor that increases distress for both the sick child and his or her parents (N. A. Contro, Larson, Scofield, Sourkes, & Cohen, 2004; N. Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Mack & Grier, 2004). Open communication has also been shown to prevent long-term psychological morbidity in bereaved parents and siblings (Eilegård, Steineck, Nyberg, & Kreicbergs, 2012).

If and when the ill child's condition deteriorates, the parents have to choose whether and how to communicate with their child about death. More specifically, they must decide whether they should talk about their own child's approaching death, and if so, how best to do that. We

have previously reported on bereaved parents who made this difficult decision (whether and how to talk with their child about death) and if they later regretted their decision. In summary, no parent who had talked to his or her child about death regretted it, whereas a few parents who had not talked to their child about death had regrets (Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004b).

The child's understanding of death develops with age (Pettle & Britten, 1995; Piaget, 1929); hence one of the challenges with talking with children about death is to adapt the conversation to the child's level of understanding. It has also been proposed that children with severe or life-threatening illnesses have a better understanding of these matters than their peers (Raimbault, 1981; Spinetta, 1974). In the present paper, we report on ways in which bereaved parents communicated with their dying child about death. To our knowledge there are no previous studies that have reported on this. Increased knowledge in this area could help health care providers working in palliative care to support families during this difficult time.

METHOD

The national study reported here has been described earlier (Jalmsell, Kreicbergs, Onelov, Steineck, & Henter, 2006; Kreicbergs et al., 2005; Kreicbergs et al., 2004a, 2004b). The study included parents whose child died from a malignancy during a six-year period in Sweden. We now have done a secondary analysis with the same participants. The parents were asked to report on the communication they had had with their child about death (Figure 1). The following questions were asked: "Did you talk about death with your child at any time?" (the answer to this question has been more thoroughly explored earlier (Kreicbergs et al., 2004b)), "Did you and your child communicate about death in any other way than by using the word death?", the parents could choose one or several of the answers, a) "Not relevant, we didn't

communicate about death,” b) “Yes we communicated about death through fairy tales,” c) “Yes we communicated about death through drawings,” d) “Yes we communicated about death through films,” e) “Yes we communicated about death through music,” f) “Yes we communicated about death through other activities.” In addition, parents were asked to elaborate on their answer with written comments to an open-ended question: “If you talked or communicated in any way with your child about death, please feel free to describe how you talked or communicated.” The present paper reports on findings from an analysis of the parents’ written responses to this question.

The deceased children and young adults were all diagnosed with a malignancy before their 17th birthday and died before the age of 25. They were identified through the Swedish National Register of Causes of Death linked to the Swedish National Register of Cancer. All diagnoses were verified by the child’s former physician and/or the medical records. Individuals registered as the guardian of the child/young adult at time of diagnosis were regarded as parents. Parents were eligible if they (1) were born in any of the Nordic countries, (2) had a listed phone number and (3) spoke and understood Swedish. The Research Ethics Committee of the Karolinska Institute, Stockholm, Sweden approved the study. Eligible parents were invited to participate by an introductory letter in which the objective of the study was briefly described. Ten days after this letter was sent, the parents were contacted by telephone and asked whether they would like to receive the questionnaire. Parents who agreed to participate were sent a questionnaire that was returned anonymously.

The written comments were subjected to qualitative content analysis to identify and characterize themes. The analysis was performed systematically following the steps of systematic text condensation described by Malterud (Malterud, 2012). The following four

steps were used: 1) All comments were read through several times to formulate an overall impression of the data, while bracketing preconceptions. 2) Meaning units related to the phenomenon studied (how parents had communicated with their child about death) were identified and assigned a descriptive code. Codes relating to similar themes were grouped together in descriptive categories reflecting relevant themes in the data. 3) Systematic condensation and abstraction of the meaning in each descriptive category was carried out, and then expressed as if it were a story told by one of the bereaved parents. 4) The essence in each category was summarized in general descriptions of how parents communicated with their child about death. The result was validated by rereading the original written comments and extracting quotes to illustrate each category. The first three authors (LJ, TK, MS) each performed an individual initial analysis of the data, results were discussed together with the senior researchers (UK, JIH), after which the final analysis was conducted and summarized by the first author (LJ). All authors have read and approved of the final analysis.

RESULTS

In total 449 parents returned the questionnaire. The sample represents both mothers (56%) and fathers (43%), although more mothers (76%) than fathers (24%) are included in the content analysis as they chose to elaborate more frequently on how they communicated with their child about death. The children and young adults died between the age 0 and 24 from all types of malignancies, the most common being leukemia and brain tumors (Table 1). 147 parents reported that they had talked about death with their child prior to his or her death. This aspect has been presented in greater detail in an earlier publication (Kreicbergs et al., 2004b). Many parents chose to communicate with their child about death indirectly, without using the word “death”, most commonly by using fairy tales or movies. Regardless of the age of the

dying child or young adult, communication through fairy tales was the most commonly reported mean of communication. No parents with a child younger than 4 years reported using music to communicate about death and only one parent reported using drawings, this being more commonly used in older children, especially with children and young adults over the age of 9 (Table 2).

Sixty-seven parents provided written comments about how they communicated with their child. One theme and four categories emerged in the analysis of the written comments (Table 3). The overall theme was *communication on the child's own initiative*, and the categories were: 1) *communicating about death by using narratives*, 2) *talking about friends and family that had died, or about death itself*, 3) *talking about life after death*, and 4) *preparing for death through practical preparations*.

Communication on the child's own initiative

Irrespective of the means of communication, many parents reported that they believed that their child was well aware of his or her situation and that the communication [about death] was often initiated by the child/young adult him/herself.

Communicating about death by using narratives

Many parents expressed that they communicated with their child through children's literature and/or movies. By using fairy tales, books and movies as carriers of the conversation, the subject of death seem easier to talk about. By using stories, the parents as well as the child or young adult, could talk about the difficult subject of death without specifically referring to the child's imminent death. For some families, this opened up a conversation that would otherwise be deemed too difficult. One might also assume that fairy tales describing death in

some way might help younger children understand the concept of death. The mother of a 6-year-old boy wrote: *“David didn’t like ‘The Brothers Lionheart’ but the last month he often watched that movie and talked about it. He was also fond of ‘House of Angels’. The last day of his life he stopped the movie at the point where Erik is in his coffin with a satin pillow under his head, and he said that he wanted that same pillow for himself.”* Another mother, with a 13-year-old daughter wrote: *“We watched ‘The Brothers Lionheart’ as a movie. It was important that the whole family saw it. Sophie said ‘I believe I will ride a brown horse’.”*

Narratives were used as a means for communication in both children as well as in the group of young adults. A father of a 19-year old wrote: *“Our conversations about death did often relate to episodes in fairy tales or movies.”* Another father, with an 18-year old child wrote: *“Sometimes we discussed around fairy tales or other literature that concerned death about what could happen. Further, our child sometimes wanted me to sing or play songs that regarded death.”*

Talking about friends and family that had died, or about death itself

When choosing to discuss death, several parents chose to talk about someone else’s death, e.g. that of a relative or a friend. Some also reported being as direct as possible with their child about his or her impending death, taking into account the child’s level of understanding. The mother of a 10-year-old boy wrote: *“The last day at home, Patrik and I talked about that he would probably die soon due to his disease. It was he who raised the question and I answered as honestly as possible.”* Several parents pointed out that their child appeared more aware of life and death than peers and that he or she knew that death was coming. The mother of a 10-year-old girl wrote about her daughter: *“She wished for her own death and didn’t want to live*

the last two weeks of her life. She asked if we would get another child after she died. We told her that she could never be replaced.”

In younger children this type of conversations had to be adjusted to the child’s level of understanding, and a mother of a 3-year-old boy wrote: *“Since our son was quite young, it is hard to tell how much he understood about our conversations about death, but we wanted him to understand as much as possible.”* Another mother of a 3-year-old girl wrote: *“She was always together with me and cried if I went anywhere without her. But this time she told me that I couldn’t come with her. She told me that she had flowers growing in her stomach.”*

In older children and young adults, conversations were usually more direct. A father of a 16-year-old girl wrote: *“We talked straight forward about death, even long before she got ill.”* A mother of a 17-year old boy wrote: *“We talked a lot about children that we knew that had died, as well as about his grand-parents. He told me that ‘I’m not afraid of dying, since I will then be with Jesus’.”*

Talking about life after death

Another way of talking about death was to talk about the after-life. This approach was used to comfort the child by explaining that someone was already waiting (on the other side) for the child/young adult and thus he or she would not have to be alone. Additionally, the child was assured that the family would be reunited later on and that their separation was only for a limited amount of time. The father of a 7-year-old boy wrote: *“It was usually Tim who asked: what happens when you die? And I answered: you come to a place where you are no longer sick, and where you’re not in pain. A place where you can do what you like.”* Some parents also reported that it was their child who reassured the family that he or she would still be with

them, even after death. The mother of a 17-year-old boy wrote: *“Our son often said, ‘but then I’ll be with you all.’ ‘Father – when you’re out hunting. Mother – when you’re cooking. Sister – when you’re using your nice perfume. Sister – when you’re out traveling.’”*

Even with younger children parents communicated about life after death. A father of a 4-year-old wrote: *“We talked about things in general and got talking about heaven.”* A mother of a 3-year-old wrote: *“Since my daughter’s father died just before she got ill, we talked a lot about him. [...] The fear of dying almost disappeared for her since she knew that her father would take care of her if she died. She was more sad about missing her next birthday.”*

Preparing for death through practical preparations

Parents also reported that they communicated with their child about death by making practical preparations. This more practical approach occurred less commonly with young children, although a mother of a 3-year old boy wrote: *“My son asked if his carcass/peel could stay at home once he was dead. He also told my husband that he wanted him to take care of his favorite bears once he was gone.”* All parents describing practical preparations stress the child’s own initiative of preparing either gifts for others or practical arrangements for his or her own funeral. The mother of an 18-year-old boy wrote: *“Our son died in the beginning of December. During the fall he gave a lot of time and thought to Christmas gifts for us and for his sisters. He chose gifts from a catalogue and when the gifts arrived I had to wrap them in Christmas paper. When he got worse, he wanted me to put the gifts where he could see them. I believe that he was well aware that he was not going to be there with us during Christmas but that he still wanted us to see and understand that he thought of us. These gifts became so much more important than those given or received other years.”* Apart from the practical arrangements made, these responses also suggest that the child was well aware of his or her

imminent death. This might also represent an emotional preparation. The mother of a 6-year-old girl wrote: *“We often visited the grave of her grandfather. At those times my child told us how her tomb would look when she died. She also told us which flowers she thought would be the most beautiful to have close to the grave: harebell and lily of the valley.”*

DISCUSSION

We found that the dying child or young adult often was the one that initiated the conversations about death, and that scenarios in fairy tales, literature or movies triggered conversations. In our study, many parents expressed thankfulness for these narratives that made it easier to talk about death with their child. In line with previous studies several parents mentioned that the child's own awareness of his or her impending death was what triggered the conversation (Beale et al., 2005). When death was being discussed more directly, the parents reported talking about the death of others, as well as their child's own death, in terms corresponding to the child's level of understanding. Furthermore, some parents described how their child or young adult prepared for death through practical activities, such as saying goodbye to close friends and relatives, sorting out or giving away possessions, or preparing for the funeral.

The question of if and how a child with a severe illness should be informed about the possibility of death and dying has long been regarded as one of the important questions in caring for these children (Hurwitz, Duncan, & Wolfe, 2004). In Western cultures there is a general support for informing the child, even younger ones about his or her disease and prognosis (even in the case of a poor one). Some parents might wish to withhold a poor prognosis from their child in order to protect them from bad news and to not take away the child's hope. This is more common in Asian cultures where family usually takes priority over

individuals and a child is regarded the parents' responsibility (Hatano, Yamada, & Fukui, 2011). Occasionally, this perspective is also seen in Western cultures where it often leads to ethical conflicts between parents and members of the health care team who hold to the norm of truth telling and respect for individual autonomy (Hatano et al., 2011; Pergert & Lutzen, 2012). One of the difficulties suggested in providing general guidelines for such communication, apart from being aware of cultural differences, is to factor in the child's individual understanding of death (Hurwitz et al., 2004). For caregivers, the important issue is not the question of talking or not talking, but rather of being willing to assess and inquire about the families' needs and wishes, and abide by them (Waechter, 1971).

The understanding of the concept of death is believed to evolve with age, and the finality of death has been assumed to be fully understood sometime after the age of 10 (Pettle & Britten, 1995; Piaget, 1929), although studies focusing on children suffering from severe or life-threatening illnesses often report that children may reach such understanding at an earlier age (Raimbault, 1981; Spinetta, 1974). Many studies have also described the terminally ill child's own awareness of the gravity of his or her situation and the possibility of forthcoming death, often manifested through remarks or conversations at unexpected times (Beale et al., 2005; Chapman & Goodall, 1980; Hinds et al., 2005; Spinetta, 1974; Spinetta, Rigler, & Karon, 1973).

An earlier study found that no parent who had talked to his or her child about death regretted having done so (Kreicbergs et al., 2004b), and it has been proposed that health care practitioners should support families in their efforts to talk with their child about death, in particular if the child seems aware that he or she is going to die (Himmelstein, Hilden, Boldt, & Weissman, 2004; Hinds et al., 2005; Hurwitz et al., 2004).

Parents are usually the ones closest to the child and thus in the best position of judging their child's awareness and understanding of his or her situation and what is to come. At the same time, parents are often torn between doing what is best for their child and safeguarding the emotional welfare of the entire family. In our study, we focused on how parents who did choose to communicate with their child about death, accomplished this difficult task. To our knowledge, these findings have not been previously reported.

The question of how parents communicate with a severely ill child or young adult about death could be more thoroughly explored through a study using one on one interviews. Since our findings come from secondary analysis of written comments in a larger questionnaire, we did not have the ability to follow-up to clarify certain answers; nor were we able to provide a complete and thorough analysis of how conversations took place. Instead, we carefully examined parents' written comments to identify different ways in which they communicated with their dying child about death. With secondary analysis from a population-based study of parents who had lost a child to a malignancy during a 6-year period, we were able to analyze written comments from many parents, and thus identify a broad spectrum of views. Still, there is a risk of recall bias, and a prospective observational study of families with terminally ill children would probably have yielded less biased results. Furthermore, the questionnaire included both close- and open-ended questions, and one must acknowledge that the choices provided in the close-ended questions might have influenced the respondents' written comments. Hence, answers relating to other categories might have been underrepresented. With this in mind, the results should not be regarded as telling the whole story about how parents communicate about death with their severely ill child, but instead be seen as a sample of how these communications take place, and as a basis for future studies.

Health care practitioners working with children suffering from life-threatening illnesses are in a unique position to listen to the concerns and thoughts of terminally ill children and their parents, and to openly communicate with them throughout the child's deterioration. We conclude that parents communicate about death with their child in several different ways. Talking about the child's own forthcoming death should not be regarded as the only possible way, nor automatically considered as the optimal way. The best way for a specific family to communicate with their child about death should take into account both culture and family preferences. We believe that our findings are of importance for health care providers in helping families to find their own way of communicating, and in supporting them in their efforts.

Based on our results, we stress the need for health care practitioners to be curious about the families' preferred means of communication. For some parents, an emotionally non-verbal communication might be enough, and caregivers need to support that approach, while other parents might need support in talking openly about the child's imminent death. Since the parents in this present study reported that books and movies facilitated their conversations, and also that sometimes their child broached the topic of death him or herself, one way of helping the families to initiate such difficult conversation might be to provide appropriate literature and, if possible, movies, on the hospital wards and other facilities where these children and families are cared for. Which specific books and movies would be useful would no doubt differ with country and culture, and may also to some extent be time-specific. Such literature and movies could easily be placed on a bookshelf with other storybooks, thus not forcing anyone to choose them but simply being available for those who want them. It might also be helpful, if well-known characters from relevant children's books are displayed as

pictures or paintings. Having these subtle triggers present might help both care providers and families to initiate a conversation about death on the child's own terms, especially if he or she seems aware of imminent death. Taking such simple measures might facilitate conversations about death at minimal risk of causing harm.

References

- Beale, E. A., Baile, W. F., & Aaron, J. (2005). Silence is not golden: communicating with children dying from cancer. *J Clin Oncol*, 23(15), 3629-3631. doi: 10.1200/jco.2005.11.015
- Chapman, J. A., & Goodall, J. (1980). Helping a child to live whilst dying. *Lancet*, 1(8171), 753-756.
- Contro, N. A., Larson, J., Scofield, S., Sourkes, B., & Cohen, H. J. (2004). Hospital staff and family perspectives regarding quality of pediatric palliative care. *Pediatrics*, 114(5), 1248-1252. doi: 10.1542/peds.2003-0857-L
- Contro, N., Larson, J., Scofield, S., Sourkes, B., & Cohen, H. (2002). Family perspectives on the quality of pediatric palliative care. *Arch Pediatr Adolesc Med*, 156(1), 14-19.
- Eilegård, A., Steineck, G., Nyberg, T., & Kreicbergs, U. (2012). *The impact of communication prior to and after the loss of a brother or sister to cancer - a nationwide long-term follow-up*. Karolinska Institutet. The loss of a child to cancer - focusing on siblings. Thesis by A. Eilegård
- Hatano, Y., Yamada, M., & Fukui, K. (2011). Shades of truth: cultural and psychological factors affecting communication in pediatric palliative care. *J Pain Symptom Manage*, 41(2), 491-495. doi: 10.1016/j.jpainsymman.2010.12.002
- Himelstein, B. P., Hilden, J. M., Boldt, A. M., & Weissman, D. (2004). Pediatric palliative care. *N Engl J Med*, 350(17), 1752-1762. doi: 10.1056/NEJMra030334
- Hinds, P. S., Drew, D., Oakes, L. L., Fouladi, M., Spunt, S. L., Church, C., & Furman, W. L. (2005). End-of-life care preferences of pediatric patients with cancer. *J Clin Oncol*, 23(36), 9146-9154. doi: 10.1200/JCO.2005.10.538
- Hurwitz, C. A., Duncan, J., & Wolfe, J. (2004). Caring for the child with cancer at the close of life: "there are people who make it, and I'm hoping I'm one of them". *JAMA*, 292(17), 2141-2149. doi: 10.1001/jama.292.17.2141
- Jalmsell, L., Kreicbergs, U., Onelov, E., Steineck, G., & Henter, J. I. (2006). Symptoms affecting children with malignancies during the last month of life: a nationwide follow-up. *Pediatrics*, 117(4), 1314-1320. doi: 10.1542/peds.2005-1479
- James, L., & Johnson, B. (1997). The needs of parents of pediatric oncology patients during the palliative care phase. *J Pediatr Oncol Nurs*, 14(2), 83-95.
- Kreicbergs, U., Valdimarsdottir, U., Onelov, E., Bjork, O., Steineck, G., & Henter, J. I. (2005). Care-related distress: a nationwide study of parents who lost their child to cancer. *J Clin Oncol*, 23(36), 9162-9171. doi: 10.1200/jco.2005.08.557
- Kreicbergs, U., Valdimarsdottir, U., Onelov, E., Henter, J. I., & Steineck, G. (2004a). Anxiety and depression in parents 4-9 years after the loss of a child owing to a malignancy: a population-based follow-up. *Psychol Med*, 34(8), 1431-1441.
- Kreicbergs, U., Valdimarsdottir, U., Onelov, E., Henter, J. I., & Steineck, G. (2004b). Talking about death with children who have severe malignant disease. *N Engl J Med*, 351(12), 1175-1186. doi: 10.1056/NEJMoa040366
- Mack, J. W., & Grier, H. E. (2004). The Day One Talk. *J Clin Oncol*, 22(3), 563-566. doi: 10.1200/jco.2004.04.078
- Malterud, K. (2012). Systematic text condensation: a strategy for qualitative analysis. *Scand J Public Health*, 40(8), 795-805. doi: 10.1177/1403494812465030
- Pergert, P., & Lutzen, K. (2012). Balancing truth-telling in the preservation of hope: a relational ethics approach. *Nurs Ethics*, 19(1), 21-29. doi: 10.1177/0969733011418551

- Pettle, S. A., & Britten, C. M. (1995). Talking with children about death and dying. *Child Care Health Dev*, 21(6), 395-404.
- Piaget, J. (1929). The child's conception of the world. *Routledge & Kegan Paul LTD London*.
- Raimbault, G. (1981). Children talk about death. *Acta Paediatr Scand*, 70(2), 179-182.
- Spinetta, J. J. (1974). The dying child's awareness of death: a review. *Psychol Bull*, 81(4), 256-260.
- Spinetta, J. J., Rigler, D., & Karon, M. (1973). Anxiety in the dying child. *Pediatrics*, 52(6), 841-845.
- Waechter, E. H. (1971). Children's awareness of fatal illness. *Am J Nurs*, 7(6), 1168-1172.
- Wheeler, I. (2001). Parental bereavement: the crisis of meaning. *Death Stud*, 25(1), 51-66. doi: 10.1080/07481180126147

Figure 1. Overview of the questions as well as corresponding answers from the questionnaire, analyzed in the present paper

<p>Did You talk about death with your child at any time?</p> <ul style="list-style-type: none"> - Tick the answer that you consider to be most correct. - Also tick the correct answer to the right. 			
☐ No ☐ Yes	→ →	<p>Do you wish You had done so?</p> <p>Do you wish You had <u>not</u> done so?</p>	☐ Yes ☐ No ☐ Yes ☐ No
<p>Did you and your child communicate about death in any other way than by using the word death?</p> <ul style="list-style-type: none"> - Tick the answer(s) that you consider to be correct 			
☐ Not relevant, we didn't communicate about death ☐ Yes we communicated about death through fairy tales ☐ Yes we communicated about death through drawings ☐ Yes we communicated about death through films ☐ Yes we communicated about death through music ☐ Yes we communicated about death through other activities.			
<p>If you talked or communicated in any way with your child about death, please feel free to describe how you talked or communicated.</p>			
<hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>			

Table 1: Characteristics of the parents answering the questionnaire and their children

	<i>All parents</i>	<i>Parents whose answers are included in the content analysis</i>
<i>Characteristics of the parents returning the questionnaire</i>		
	No. (%)	No. (%)
Parent		
Biological parent	438 (98)	66 (99)
Non-biological parent	9 (2)	1 (1)
Not stated	2 (<1)	0
Gender		
Male	191 (43)	16 (24)
Female	251 (56)	51 (76)
Not stated	7 (2)	0
Parent's age at child's diagnosis		
<30 yrs	66 (15)	9 (13)
30-39 yrs	232 (52)	36 (54)
40 yrs or older	146 (32)	21 (31)
Not stated	5 (1)	1 (1)
Number of children at child's diagnosis		
1	82 (18)	13 (19)
2	192 (43)	16 (24)
3	116 (26)	23 (34)
4 or more	54 (12)	14 (21)
Not stated	5 (1)	1 (1)
<i>Characteristics of the children</i>		
Age of child at diagnosis		
0-3 years	165 (37)	15 (22)
4-9 years	128 (29)	25 (37)
10-16 years	149 (33)	26 (39)
Not stated	7 (2)	1 (1)

Age of child at death

0-4 years	132 (29)	11 (16)
5-8 years	95 (21)	17 (25)
9-15 years	103 (23)	20 (30)
16-24 years	106 (24)	17 (25)
Not stated	13 (3)	2 (3)

Type of malignancy in child

Leukemia	129 (29)	25 (37)
Lymphoma	20 (4)	4 (6)
Brain tumor	157 (35)	18 (27)
Osteosarcoma	36 (8)	5 (7)
Soft tissue sarcoma	17 (4)	3 (4)
Neuroblastoma	40 (9)	6 (9)
Other malignancy	46 (10)	5 (7)
Not stated	4 (1)	1 (1)

Table 2. How parents communicated with their child about death (no. (%))**Did you talk about death with your child at any time?*

	All parents	Parental gender			Age of child at death				
		Male	Female	Not stated	0-4	5-8	9-15	16-24	Not stated
Yes	147 (33)	54 (29)	92 (39)	1	20 (16)	33 (36)	48 (51)	43 (41)	3
No	282 (63)	132 (71)	146 (61)	4	108 (84)	58 (64)	46 (49)	63 (59)	7

Did you and your child communicate about death in any other way than by using the word death?

Not relevant, we didn't communicate about death	262 (58)	130 (67)	129 (52)	3	104 (78)	53 (51)	46 (45)	57 (58)	2
Yes we communicated about death through fairy tales	54 (12)	17 (9)	37 (15)	0	11 (8)	21 (20)	11 (11)	9 (9)	2
Yes we communicated about death through drawings	15 (3)	5 (3)	10 (4)	0	1 (0)	3 (3)	8 (8)	3 (3)	0
Yes we communicated about death through films	31 (7)	8 (4)	23 (9)	0	5 (4)	12 (12)	10 (10)	4 (4)	0
Yes we communicated about death through music	21 (5)	11 (6)	10 (4)	0	0	5 (5)	8 (8)	8 (8)	0
Yes we communicated about death through other activities	60 (13)	22 (11)	38 (15)	0	12 (9)	9 (9)	20 (19)	17 (17)	2

* Summation of percentages may not equal 100 due to rounding

Table 3. Presentation of the results with themes and categories (no. (%)*)

<i>Main theme</i>	<i>Category</i>	<i>N^o of quotes</i>	<i>Parental gender</i>		<i>Age of child at death</i>				
			<i>Male</i>	<i>Female</i>	<i>0-4</i>	<i>5-8</i>	<i>9-15</i>	<i>16-24</i>	<i>Not stated</i>
Communication on the child's own initiative	Communication about death by using narratives	19 (28)	4 (25)	15 (29)	3 (27)	6 (35)	5 (25)	4 (24)	1
	Talking about friends and family that had died, or about death itself	18 (27)	5 (31)	13 (25)	4 (36)	4 (24)	5 (25)	5 (29)	0
	Talking about life after death	18 (27)	5 (31)	13 (25)	3 (27)	4 (24)	7 (35)	4 (24)	0
	Preparing for death through practical preparations	12 (18)	2 (13)	10 (20)	1 (9)	3 (18)	3 (15)	4 (24)	1

* Summation of percentages may not equal 100 due to rounding