

# Siblings' experiences of their brother's or sister's cancer death: a nationwide follow-up 2–9 years later

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## Abstract

**Objective:** The aim of this study was to examine siblings' experiences of their brother's or sister's cancer death and if these experiences influenced levels of anxiety 2–9 years later.

**Methods:** This nationwide survey was conducted in Sweden in 2009. All siblings who had a brother/sister who was diagnosed with cancer before the age of 17 years and who died before the age of 25 years during 2000–2007 were invited. Of those, 174 siblings participated (participation rate: 73%). Mixed data from the survey about the siblings' experiences of death were included as well as data from the Hospital Anxiety and Depression Scale. To examine the experiences, descriptive statistics and content analysis were used. Mann–Whitney *U*-test was conducted to investigate if the experiences influenced anxiety 2–9 years later.

**Results:** The siblings reported poor knowledge and experienced a lack of communication about their brother's/sister's death, for example, about the time frame, bodily changes near death, and about their own experiences. Siblings who reported that no one talked with them about what to expect when their brother/sister was going to die reported higher levels of anxiety 2–9 years after the loss. Seventy percent reported that they witnessed their brother/sister suffering in the last hours in life. Many of those who were not present during the illness period and at the time of death expressed regret.

**Conclusion:** It is important to prepare siblings for their brother's/sister's illness and death as it may decrease anxiety and regrets later on.

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## Background

Even though siblings of children who die from cancer may live through the illness experience with intensity levels similar to their parents, they often stand outside the spotlight of attention [1,2]. Until recently, little research has focused on the sibling's situation [3]. In the few published studies, cancer-bereaved siblings report several distressing problems, for example, lower self-esteem, more difficulties falling asleep, and lower levels of maturity 2–9 years after the sibling's loss in comparison with non-bereaved siblings [4]. Siblings also report a higher risk of anxiety if they perceived their need for social support as unsatisfied during their brother's/sister's last month of life [5]. Moreover, most of the siblings reported that they had not worked through their grief at all or only to some extent at follow-up [6]. Personal changes among bereaved siblings have been found, for example, changes in the personality, attitude towards and interest in school work, goals and life perspectives, and activities and interests [7].

Fear that their brother/sister would die has been found to be the most difficult aspect of the siblings' experiences during their brother's/sister's illness period, along with not knowing what was going to happen next [8]. In a qualitative study by Jenholt Nolbris and co-workers [9], siblings reported that fatal outcome had been rarely discussed. Instead, the focus of communication was on treatments and examinations. When the ill child died, siblings described having been unprepared for what was happening. This corroborates findings in the interview study by Gaab and colleagues [10], where some siblings of pediatric palliative care patients expressed a need to talk about death, the avenues through which it occurred, and its consequences. These siblings described that knowing about the impending death increased their appreciation of their brother/sister, which usually resulted in them spending more time together. Many siblings also described that they were poorly informed and even though they noticed their brother/sister getting worse, they did not expect him or her to die. Some siblings expressed that they were misled

at the end of their brother's/sister's life and that this made it harder for them to cope later on [10].

Although the volume of research on siblings in pediatric palliative care has increased, much remains to be done [3]. Current research on bereaved siblings is often limited by small samples and single-site design. To our knowledge, no nationwide study has yet explored bereaved siblings' experiences of their brother's/sister's death in order to identify avoidable and modifiable factors that can increase the siblings' wellbeing and decrease their suffering. The aims of this nationwide study were therefore to examine: (1) siblings' experiences of their brother's/sister's cancer death and (2) if these experiences influenced levels of anxiety 2–9 years later.

## Methods

This study was based on a nationwide survey in Sweden focusing on experiences of childhood cancer from the perspective of the siblings [4,11]. In 2009, all eligible siblings who had a brother/sister who was diagnosed with cancer before the age of 17 years and who died before the age of 25 years during 2000–2007 were invited to participate ( $N=240$ ). Exclusion criteria were siblings younger than 18 years old at time of data collection, siblings younger than 12 years old and older than 25 years old at the time of their brother's/sister's death, no valid address or phone number, and cognitive barrier, for example, intellectual disability. The deceased children and their siblings were traced through the Swedish Childhood Cancer Registry (where all pediatric deaths caused in Sweden can be found) and the Swedish population register (where all permanent residents in Sweden can be identified through their personal identification number). A total of 174 siblings were included (participation rate: 73%). The Regional Ethics Committee of Karolinska Institute in Stockholm, Sweden, approved the study, Dnr 2007:862-31.

Eligible siblings were sent an introductory letter describing the objectives of the study and an invitation to participate. Three to five days later, a research assistant phoned the siblings and asked whether they wished to participate. Those who agreed were mailed an anonymous questionnaire with a response letter. The response letter was supposed to be returned separately from the questionnaire to maintain anonymity. Two to three weeks later, a combined thank you and reminder card was mailed to the siblings. If the response letter was not returned, a research assistant called the siblings to ask if they needed help filling out the questionnaire.

## Measures

The questionnaire was developed using a stepwise approach described by Charlton [12] and others [4,13–16]. It consists of over 200 questions and includes two parts: the first focuses on siblings' current life situation, health,

and the experience of bereavement, and the second focuses on their brother's/sister's illness period. This study is based on a selection of questions from the survey: 19 closed-ended questions about the experiences of death with focus on communication, siblings' participation, and emotions close to their brother's/sister's death and one open-ended question ('If you want, please describe your experiences of your brother's/sister's death'). In addition, seven questions about anxiety were included from the Hospital Anxiety and Depression Scale, HADS [17], which is a validated self-reported assessment instrument for depression and anxiety [17,18]. The response alternatives score 0–3 points for each question; thus, the possible scores range from 0 to 21. A score of 0–7 indicates an acceptable level of anxiety, 8–10 indicates greater anxiety, and  $\geq 11$  indicates anxiety severe enough to need medical attention [17].

## Data analysis

In order to examine the siblings' experiences of their brother's/sister's death (Aim 1), both qualitative and quantitative analyses were conducted. Descriptive statistics were used on all questions except the open-ended one, which was analyzed with conventional content analysis [19]. First, data were read to obtain a sense of whole (all authors). Thereafter, data were read word by word to derive codes that were sorted into categories based on similarity in content (M.L.). To validate the analysis, L.J. and A.E.W. critically reviewed M.L.'s analysis documentation, which illustrated raw data and each step in the analysis process. Changes were made and discussions continued within the research team until consensus was reached. To examine the influence of the siblings' experiences of death (the closed-ended questions) on levels of anxiety 2–9 years later (Aim 2) Mann–Whitney *U*-tests were conducted. Scores for anxiety were divided in three groups accordingly to validated cut-offs as described earlier.

## Results

### Characteristics of the bereaved siblings

Fifty-eight percent of the siblings were women (Table 1). The age ranged between 19 and 33 years; 43% were married/cohabiting, and a majority had passed senior high school. There were no differences in demographic characteristics between those who answered the open-ended question ( $N=98$ ) and those who did not ( $N=76$ ) with the exception for educational level. Those who had answered the open-ended question had higher education ( $p=0.045$ , not shown in table).

### Siblings' experiences of death

First, the results from the closed-ended questions are presented below. After that, the results from the qualitative

**Table 1.** Characteristics of the bereaved siblings

	N (%)
Sex	
Man	73 (42)
Woman	101 (58)
Age	
19–23 years	88 (51)
24–28 years	59 (34)
29–33 years	26 (15)
Missing	1
Civil status	
Married	12 (7)
Co-habiting	62 (36)
Lived with parents	49 (28)
Lived with friends	4 (2)
Lived alone	46 (27)
Missing	1
Level of education	
Elementary school	27 (16)
Senior high school	124 (72)
University	22 (13)
Missing	1
Place of residence	
Rural	38 (22)
Village	36 (21)
Town	64 (37)
City	32 (19)
Missing	4
Time between diagnosis and death	
<1 year	23 (15)
About 1 year	44 (28)
About 2 years	24 (15)
About 3 years	23 (15)
>4 years	43 (27)
Missing	17
Years since loss	
2–4 years	46 (28)
5–7 years	60 (36)
8–9 years	61 (37)
Missing	7

analysis are described under three categories derived from the open-ended question.

During the last 24 h before the loss, 43% of the siblings reported getting no information about the impending death of their brother/sister from a family member. Seventy percent were not informed by one of the health care professionals (HCPs) (Table 2). Thirty-nine percent ( $N=64$ ) were either informed by a family member or by one of the HCPs (not shown in table). Seventy percent of the siblings reported that none of the HCPs informed them about the impending death during the last 24 h before it occurred. In most cases, it was not until less than 24 h before their brother's/sister's death that the sibling understood this intellectually (53%) and emotionally (76%). Fifty-three percent reported that they had an opportunity to say goodbye to their brother/sister before death. Of those who were present the last hours before death, 70% percent described that they recognized that their brother/sister was suffering. Eighty-four percent reported that nobody talked

**Table 2.** Siblings' experiences of their brother's or sister's death

	N (%)
Informed by a <i>family member</i> about the impending death during the last 24 h before it occurred	
Yes	95 (57)
No	73 (43)
Missing	6
Understood intellectually that their brother/sister was going to die (time relative to the loss)	
>24 h before	78 (46)
24 h before	72 (43)
Afterwards	19 (11)
Missing	5
Understood emotionally that their brother/sister was going to die (time relative to the loss)	
>24 h before	39 (24)
24 h before	83 (50)
Afterwards	43 (26)
Missing	9
Informed by a <i>health care professional</i> about the impending death during the last 24 h before it occurred	
Yes	50 (30)
No	117 (70)
Missing	7
Had a chance to say goodbye <i>before</i> their brother/sister died	
Yes	90 (53)
No	80 (47)
Missing	4
Noticed that their brother/sister was suffering during his or her last hours of life	
Yes	91 (70)
No	39 (30)
Missing	3
Was not present	41
Was told what to expect when their brother/sister was about to die	
Yes	28 (16)
No	144 (84)
Missing	2
Was present when their brother/sister died ( $N=95$ )	
Yes	95 (55)
No	78 (45)
Missing	1
Regret being present when their brother/sister died ( $N=78$ )	
Yes	1 (1)
No	94 (99)
Regret <i>not</i> being present when their brother/sister died	
Yes	57 (76)
No	18 (24)
Missing	3
Death came as a shock	
Yes	80 (47)
No	91 (53)
Missing	3
Saw their brother/sister after death	
Yes	155 (90)
No	18 (10)
Missing	1
Regret seeing their brother/sister after death ( $N=156$ )	
Yes	3 (2)
No	153 (98)
Regret <i>not</i> seeing their brother/sister after death ( $N=18$ )	
Yes	3 (17)
No	15 (83)
Had a chance to say goodbye <i>after</i> death	
Yes	163 (95)
No	8 (5)
Missing	3

(Continues)

**Table 2.** (Continued)

	N (%)
Saying goodbye was done in a dignified manner (N = 163)	
Yes	150 (97)
No	4 (3)
Missing	9
Talked to anyone about their brother's/sister's death	
Yes	124 (72)
No	48 (28)
Missing	2
Persons the sibling talked to <sup>a</sup>	
Family members (unspecified who in family)	34 (27)
Parents	41 (33)
Siblings	10 (8)
Other relatives	14 (11)
Friends	44 (35)
Wife/husband, girlfriend/boyfriend	8 (6)
Teacher/School nurse	10 (8)
Physician/Nurse	5 (4)
Counselor/Psychologist	12 (10)
Priest/Member of the church	4 (3)
Others, for example, 'everyone close', 'most people'	15 (12)
Content with how often the sibling was able to share his or her feelings about their brother's/sister's death with the family	
Content/satisfied	105 (61)
Wanted to talk more	61 (35)
Wanted to talk less	7 (4)
Missing	1

<sup>a</sup>More than one alternative could be selected.

to them about what to expect when their brother/sister was dying. These siblings showed significantly higher levels of anxiety 2–9 years later ( $p = 0.048$ ) compared with those who had talked to someone about what to expect (not shown in table). Around half of the siblings reported that they were present at the time of death, and only one regretted this, whereas 76% of those who were not present regretted it. Half of the siblings reported that death came as a shock for them. Almost 90% reported that they saw their brother/sister after he/she had died, but only 2% ( $n = 3$ ) regretted it. Three of 18 (17%) who did not see their brother/sister after death regretted that they did not. Ninety-five percent reported that they had an opportunity to say goodbye after their brother's/sister's death at home, at the charnel house, or in a room at the hospital together with their parents and/or with HCPs. Ninety-seven percent of those reported that it was done in a dignified way. Over one quarter of the siblings did not talk to anyone about their brother's/sister's death, and 35% wished they had talked more with their families about it.

#### Experiences shortly before death

Some siblings described their brother's/sister's deterioration as difficult for the entire family, regardless of whether the deterioration was sudden or gradual and whether they knew death was near or not (Table S1). Many siblings described their emotional reactions during this time: anxiety for their

brother's/sister's pain, powerlessness, helplessness, fear of death, jealousy towards their brother/sister, the uncertainty of waiting for death, and how distressing it was to see their brother/sister suffering. Some siblings expressed regret that they did not spend more time with their brother/sister during the illness period. Their reported explanations included that they were too busy with themselves, their own lives, or that they did not understand that their brother/sister was going to die so soon. Lack of awareness about the impending death was expressed by some siblings, and this was often related to them not realizing that death could come so suddenly.

#### Experiences at time of death

Some siblings described that their brother's/sister's death came so fast that they did not have the chance to be present or that they were on their way to their dying brother/sister but arrived too late (Table S1). Siblings who were present expressed positive feelings about it, for example, happiness and gratitude. Some described their brother's/sister's physical changes: the slow breathing or the slow heart rate as signs that death was near. More dramatic bodily changes, such as rattle breath or seizure, were scary for the siblings as they did not understand what was happening or why nobody helped their brother/sister. Some siblings described the atmosphere in the room, which in most cases was calm and beautiful with the whole family together. They expressed their sadness and the terrible feelings they experienced when their brother/sister died, but also a kind of relief because death released their brother/sister from suffering.

#### Experiences shortly after death

The siblings expressed that it was important to be together with the whole family, to say goodbye and take care of the body afterwards (Table S1). They described emptiness that they cried, were angry about death, and that they felt guilty that they were still alive. At the same time, they felt a kind of relief, as they did at the time of death, because their brother's/sister's pain and suffering had finally ended. Some siblings blamed others for the death, for example, the HCPs or the parents, for taking the wrong decisions. They described experiences that facilitated or complicated the grieving process. Facilitating factors included the knowledge that they had maintained contact with their brother/sister during the illness period and that their brother/sister looked peaceful shortly after death. Factors that complicated the grieving process included stressful situations at the time of death, for example, rapid deterioration or seizure, and that they did not show their own sadness within the family because they thought others were too busy with their own grieving process.



## Discussion

This nationwide study shows that cancer-bereaved siblings perceived that they had poor knowledge and a lack of communication about their brother's/sister's death, for example, about the time frame and bodily changes near death. Only one factor among the described experiences of death influenced anxiety later on; siblings who experienced that no one talked with them about what to expect when their brother/sister was dying showed higher levels of anxiety 2–9 years after the loss. Notably, a vast majority of the siblings reported that they witnessed their brother/sister suffering in the last hours in life. Thirty-five percent wanted to share their feelings more with their families about their brother's/sister's death. Many of those who were not present during the illness trajectory and at the time of death regretted their absence.

These results are in line with other studies, which also found that the impending death was poorly discussed with siblings [9,10,20] and that this influenced their psychological well-being [20]. Nolbris and Hellström [21] described that some siblings were not prepared that the ill child was going to die and that they did not know what was going to happen. The siblings in our study described being unprepared both for the impending death and for the bodily changes near death. Gaab and colleagues [10] found that siblings felt 'left in the dark' and expressed confusion and fear about their brother's/sister's symptoms at the end of life, as they had not been explained. To our knowledge, no scientific article addresses how to communicate about bodily changes at time of death because of cancer with children as next-of-kin. Rosenberg and co-workers [20] found that cancer-bereaved siblings who reported dissatisfaction with communication and poor preparation for death, as well as missed opportunities to say goodbye, scored higher levels of psychological distress. Research on other bereaved next-of-kin, for example, widowers poorly prepared for their wife's death, also showed an increased risk of psychological morbidity and other symptoms, for example, anxiety, sleep disorders [22], and chronic pain [23] 4–5 years after the loss.

Over one third of the siblings in this study wanted to share their feelings about their brother's/sister's death more with their families. This is in line with the findings presented by Long, Marsland [8] who found that siblings expressed a wish to have someone to talk with about their thoughts and concerns regarding treatment and death [9]. On the other hand, research has also found that parents perceive that bereaved adolescent siblings avoid revealing their feelings of sorrow to their parents [24]. It is likely that siblings hide their feelings out of respect for other family members, as we found in this study. HCPs therefore have a key role in encouraging communication within the family in order to make the siblings' feelings and thoughts visible.

Many siblings in our study regretted that they were not present during the illness period as well as at time of death. Research has shown that increased awareness about the possibility of death usually results in siblings spending more time with their brother/sister [10]. Although informing the siblings seems to be the responsibility of the parents, it is important for HCPs to support parents' communication with the siblings [25]. Current survival rates in pediatric oncology make cure the most likely outcome after a cancer diagnosis [26]; even children who die of their illness are often treated with a curative intent close to death, not least children suffering from hematological malignancies [27]. With this in mind, death can in some cases come quite suddenly for family members, and they may therefore not be properly informed. Parents, being the ones most closely involved in their child's care, are usually present even if death is sudden. However, siblings who are old enough to be independent of their parents, who are pursuing their own lives in parallel with being engaged in the life of their ill brother/sister might be at greater risk of 'missing out' on the possibility of saying goodbye, as did approximately half of the siblings in our study.

Most of the siblings (70%) witnessed their brother/sister suffering in the last hours before death, and even higher numbers have been reported previously [28,29]. However, those studies focused on parents and measured the patients' suffering in relation to symptoms the last months in the ill child's life, whereas this study focused on siblings and measured the patients' suffering in the last hours. Despite differences in study groups and time frames as well as differences in measurements, all studies [28,29], including our, showed high prevalence of suffering. Independently of whether the ill children's suffering was physical or psychological, or if the siblings' experiences were a projection of their own distress, it is necessary to further develop methods to reduce the suffering of patients and relatives.

Even if this study has strengths, for example, the high participation rate, it also has shortcomings. A qualitative design, such as narrative research, would probably have resulted in a deeper understanding about siblings' experiences of death. However, the open-ended question in this study can be seen as a complement to the closed-ended questions as it contributes to a better understanding of the numbers from the closed-ended questions.

## Implications and further research

In order to prevent anxiety and distress, it seemed particularly important to prepare the sibling for what to expect regarding their brother's/sister's death. More knowledge about symptoms at the end of life will not only give the siblings better understanding about the illness and death but might also prevent them from blaming others for their

brother's/sister's suffering and death. The results also indicate that it is important to encourage the siblings to be present during illness and at time of death and to say goodbye in time in order to prevent regrets. HCPs have an important role in enhancing communication within the family as well as between siblings and professionals in order to make the siblings visible during the illness period and after bereavement. Our study indicates that family centered interventions aiming to increase the family

communication and awareness of impending death could decrease long-term psychological suffering among bereaved siblings and their family members.

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