Experiences and meaning of a follow-up meeting to bereaved parents in paediatric oncology: a qualitative study

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Abstract

Background Parents who have experienced the death of a child from cancer have unique bereavement needs. To support these bereaved parents a follow-up meeting with the professional caregivers of the deceased child is often scheduled in the Netherlands. Current practice suggests both parents and professionals emphasise an improvement of follow-up meetings in paediatric oncology is needed.

Aim To explore the experiences of bereaved parents at follow-up meetings with healthcare professionals in paediatric oncology, and what this follow-up meeting means to bereaved parents.

Method An explorative qualitative design was conducted with semi-structured interviews and a thematic analysis. The sample was composed of parents whose child had died from any type of cancer in the Netherlands.

Results Seven themes were identified through interviews with thirteen parents (four couples simultaneously and five mothers individually). Parents described their different stages of the grieving process and their emotions at the time of the follow-up meeting, which influenced their feelings of readiness. Feelings of readiness were also influenced by the valuable and burdensome aspects parents expect of the follow-up meeting. Most parents experienced the follow-up meeting as the last possibility to ask questions and be reassured they did everything to save their child. Additionally, during the conversation, parents and professionals retrieved memories of the child. Many parents described the possibility to provide feedback during the follow-up meeting and some parents received positive feedback that reassure them as having been a good parent. Most parents thought the conversation offered closure.

Conclusion Parents have a variety of expectations, intentions and experiences of the follow-up meeting. Parents asked unresolved questions, sought reassurance, wanted to continue contact with the professionals and experience that their child mattered. Taking these differences into consideration, professionals should try to recognise the individual needs of parents and tailor the follow-up meeting accordingly.

Keywords Bereavement, Follow-up meeting, Oncology, Paediatric, Parents

Samenvatting

Achtergrond Ouders die een kind hebben verloren aan kanker hebben unieke behoeften aan ondersteuning. Om ouders van een overleden kind aan kanker te ondersteunen, wordt vaak een nagesprek gepland met de professionals vanuit het ziekenhuis. De huidige praktijk suggereert echter dat zowel ouders als professionals denken dat deze nagesprekken mogelijk verbeterd kunnen worden.

Doel Inzicht verkrijgen in hoe ouders een nagesprek ervaren na het overlijden van een kind aan kanker en wat dit nagesprek betekent voor ouders.

Methode Een onderzoek met een exploratief kwalitatief design met semigestructureerde interviews en thematische analyse werd uitgevoerd. Een doelgerichte steekproef werd gebruikt van ouders die een nagesprek hebben gehad vanwege een overleden kind aan kanker in Nederland.

Resultaten Zeven thema's werden geïdentificeerd door interviews met dertien ouders. Ouders beschreven zichzelf en verschillende fasen van rouw en emotie wat invloed had op het gevoel van klaar zijn voor het nagesprek. Het gevoel om terug te gaan naar het ziekenhuis voor het nagesprek werd beïnvloed door de perceptie van verschillende waardevolle en bezwarende aspecten. De meeste ouders ervaarden het nagesprek als de laatste mogelijkheid om vragen te stellen en om gerustgesteld te worden dat ze alles hadden gedaan om hun kind te redden. Daarnaast werden tijdens de nagesprekken herinneringen aan het kind opgehaald. Meerdere ouders beschreven de mogelijkheid om feedback te geven tijdens het nagesprek en sommige ouders ontvingen positieve feedback van de professionals wat hen hielp in de bevestiging dat ze een goede ouder waren. De meeste ouders zagen het nagesprek als een afsluiting.

Conclusie Ouders hebben verschillende verwachtingen, intenties en ervaringen met het nagesprek. Tijdens de nagesprekken stelden ouders vragen, zochten geruststelling, wilden contact continueren en weten dat hun kind geen nummer was. Gezien de verschillen is het belangrijk dat professionals individuele behoeften van de ouders herkennen en nagesprekken aanpassen aan deze behoeften.

Trefwoorden Rouw, nagesprek, oncologie, kinderen, ouders

Introduction

Approximately 550 children (aged between 0-18 years) are annually diagnosed with cancer in the Netherlands.[1] Although survival rates have improved to more than 75 percent, every two to three days a child dies from cancer in the Netherlands.[1] This makes cancer the leading cause of non-accidental death of children over the age of two years.[2,3] Losing a child is one of life's most difficult experiences.[4-6] Feelings of grief affect individuals differently.[4-6] Grief is defined as the main emotional reaction to bereavement, incorporating diverse psychological, physical, social and behavioural reactions.[6,7] Parental grief has been recognised as more intense and longer lasting than other types of grief[8,9], with increased risks of physical illness[7,10], psychological illness[7,10], adverse social outcomes[5,7,10], and mortality[5,11]. Therefore, the World Health Organization emphasises the importance of bereavement care in palliative care.[12,13]

Qualitative studies exploring the global needs of bereaved parents show beneficial effects for parents of an ongoing relationship with the professional caregivers of their deceased child.[14-19] Parents need less time to work through their grief and feel more supported.[14-19] In addition, they are prevented from feelings of secondary loss and abandonment.[14-19] Despite the widespread recognition of increased risks to bereaved parents and beneficial effects of an ongoing relationship, little empirical evidence exists to guide professionals in paediatric oncology in supporting parents.[20]

In the Netherlands, following the death of a child in paediatric oncology, the professional caregivers of the child often arrange a formal follow-up meeting with the bereaved parents. These follow-up meetings are usually scheduled for six weeks after the child's death, and can be conducted with those professional caregivers who were intensively involved in the health care process, such as paediatric oncologists, nurses or general practitioners, either individually or jointly. Current practice suggests both parents and professionals emphasise an improvement of follow-up meetings in paediatric oncology is needed.

Research evaluating follow-up meetings in paediatrics from the parental perspective is scarce. Only studies exploring the parental interest or hypothetical important topics that should be discussed during the follow-up meeting are described.[21,22] Bereaved parents expressed their interest in the follow-up meeting because they experienced multiple unresolved needs surrounding the bereavement process.[21,22] Parents who experienced the sudden death of their child within a Paediatric Intensive Care Unit (PICU) sought reassurance and the opportunity to voice complaints and express gratitude.[22] Parents who experienced the death of a child from cancer thought topics such as siblings, sharing stories and emotional support were of most interest, whereas topics such as financial issues, the child's medical record and cause of death were of least interest.[21] Currently, however, there are no existing studies examining parents' experiences after follow-up meetings in paediatric oncology and expectations of a follow-up meeting might not correspond with actual experiences.

To improve the content of follow-up meetings in paediatric oncology, insights from parents' experiences and perspectives are required. Therefore, a better understanding of the bereaved parents' experiences of the follow-up meeting in paediatric oncology is needed.

Aim

The objective of this study was to explore bereaved parents' experiences of a parent-healthcare professional follow-up meeting following their child's death in paediatric oncology, and what this follow-up meeting means to them. A better understanding of the parents' perspective concerning a follow-up meeting after child loss facilitates a better attunement of the parents' needs and the identification of strategies to improve follow-up meetings.

Method

Design

An explorative qualitative design[24,25] was conducted with semi-structured interviews[24,25] using thematic analysis[26]. A qualitative study design allows in-depth exploration of a topic and is therefore most appropriate to explore the experiences and meaning of a follow-up meeting to bereaved parents in paediatric oncology.[24,25]

Sample

The population of interest were parents whose children (aged between 0-18 years) died from any type of cancer in the Netherlands. A purposeful sample was composed of parents who had a follow-up meeting with one or more professional caregivers of their deceased child. Parents were eligible to participate if the follow-up meeting occurred within the past three years before the commencement of this study. Parents who were unable to speak Dutch, lived abroad, or aged under eighteen were excluded. Maximum variation was sought with respect to disease duration, place of death, and type of cancer. This maximum variation approach maximises differences at the beginning of the study, which increases the likelihood that results reflect different perspectives.[24,27]

Parents were sought using a website announcement and the social media of a patient organisation for childhood cancer. Additionally, two mothers were actively approached by the patient organisation to participate. Parents were free to choose the location of the interview. If both parents were interested in participating in the study, the researcher suggested interviewing both parents together regarding their interpersonal relationship and their perspective of the follow-up meeting.[28]

Data collection

Data collection consisted of a background questionnaire and a semi-structured interview. The background questionnaire was used to gain insight into the characteristics of the participants, the deceased child, and the disease process. To explore the parents' experiences, semi-structured interviews were conducted. Semi-structured interviews ensure that the researcher obtains all the information required, and the participants have freedom to provide as many explanations as they wish.[28] The topic list of the interview was based on literature[22,21,30,34] and the knowledge of experts in palliative care, including a paediatric oncologist, a representative of the patient organisation, and the researchers (appendix 1). Topics were: expectations, experiences, meaning, satisfaction, and positive and negative aspects. All interviews were conducted by the main researcher (RD), were audio-taped, and transcribed verbatim. Data collection was conducted between February and May 2016.

Data analysis

The data analysis followed the analytical process of thematic analysis as described by Braun & Clarke.[26] This approach was chosen due to the inductive systematic procedure for identifying, analysing, and reporting patterns within data retrieved in an explorative study.[26] The systematic procedure consists of six phases (presented in table 1): familiarising yourself with the data, generating codes, searching for themes, reviewing themes, defining themes, and producing the report. Additionally, during data analysis the software program NVivo 11 (QRS International) was used.[35] An iterative process between data collection and data analysis existed, whereby the information of the analysed interviews resulted in new topics for subsequent interviews.[25] The study aimed for datasaturation.[36,37]

< insert table 1 phases of thematic analysis by Braun & Clark >

Rigour

Several methods for ensuring trustworthiness were selected based on the criteria of Lincoln & Guba[38]. Credibility was ensured through the use of maximum variation[39] of bereaved parents and a pilot interview[40,41] was conducted with a purposefully selected participant prior to the start of the study. In response, small adjustments were made to the questions and background questionnaire. Additionally, a second researcher peer-reviewed the interview style of the first researcher to enhance the quality of data collection. To increase dependability, the first four interviews were independently coded by the two researchers (RD,MK). Further interviews were analysed primarily by the first researcher (RD). Themes were discussed between the researchers to reach consensus about the content of themes and interpretations.[25] Confirmability was promoted by written observational and methodological memos, which served as an additional aid during the analysis.[24,25] Furthermore, a bracketing session was held and reflective memos were written to provide insight into the process of reflexivity.[24,25] Transferability was enhanced by a clear description of the sampling procedure, respondents, data collection and analysis in accordance to the consolidated criteria for reporting qualitative research (COREQ).[42,43] Additionally, thick descriptions were collected and the findings were presented with appropriate quotations.[39]

Ethical issues

The Medical Ethical Committee was consulted to obtain a release from the Medical Involving Human Subjects Act prior to the study.[44] Interested parents received written and oral information and were assured that they were free to withdraw from the study at any time. Written informed consent was obtained from participating parents.

Results

Sample

A total of thirteen parents (nine mothers and four fathers) of nine deceased children were interviewed, four couples simultaneously and five mothers individually. For characteristics see Table 2. The majority of the deceased children had been diagnosed with a brain tumour. The children died within eight to 54 months after diagnosis, six children died at home and three at the hospital, including two children within the PICU. Time between the follow-up meeting and the interview ranged from nine to 36 months. All interviews were conducted at the home of the parents and lasted between one and two hours.

< insert table 2 baseline characteristics respondents and deceased children >

Main results

Seven themes were identified in the interviews: readiness and timing*,* returning to the hospital, medical treatment and decisions, good parenting, identity and uniqueness of the child and the situation, feedback to the professionals, closure and continuing connected.

Readiness and timing

Some parents described themselves as still in shock at the moment of the follow-up meeting, while other parents considered themselves able to have the follow-up meeting. Parents described themselves in different stages of the grieving process and emotions at the time of the follow-up meeting which influenced their feeling of readiness. Several parents described how, if the follow-up meeting was scheduled too soon, they were too busy arranging things and were unaware of what the professionals would say during the conversation (Box 1, quote 1). For a few parents, the follow-up meeting was scheduled more than three months after their child's death. These parents described several reasons why the follow-up meeting should be scheduled within a shorter period after the child's death. For example, they wanted to go on with life, felt more reluctant for the conversation, or did not expect the follow-up meeting any longer. Some parents conformed to the time represented by the professionals because they believed this period was chosen for a scientific reason that was probably good for them (Box 1, quote 2). Many parents suggested that the timing should be left to the parents to decide when they feel ready. It is the responsibility of the professional to contact the parents, several times if necessary.

Box 1, theme readiness and timing

'Then it is still very briefly and you're still kind of in a dream state …. And it is like your life is living you instead of the other way around... If I had to go again now, then I would experience it much more intense, you become more aware.' (R7, mother)

'I think you, you should leave it to the professionals, there will be a good reason why that's normal after three months? Yes, there will be a good theory behind it…' (R3, Mother)

Returning to the hospital

Some parents experienced returning to the oncology department as very pleasant, they felt a sense of belonging in familiar surroundings. These parents wanted to hold on to this feeling because the familiarity and connection suddenly fell away after the death of their child. They experienced the oncology department as their world, where people understood them and they wanted to connect with the professionals once more (Box 2, quote 1). For some parents, the experience of the follow-up meeting was a huge confrontation with the disease process and death of their child. They felt like they had to go back to the place where bad things had happened and associated with wearisome memories (Box 2, quote 2). Being able to have the confrontation with the hospital, department or professionals was related with the perception of burdensome and valuable aspects associated with it. Parents who found it difficult to have the conversation emphasised the importance of going to the follow-up meeting because many of them had unresolved questions that needed answering.

Box 2, theme returning to the hospital

> *'After she passed away, many people will never know her anymore. Then you are just a mother of two children. But for the people who knew her, like there in the hospital, you are a mother of three children. And it is nice to be able to share that with people who knew her.' (R6, mother)*
>
> *'You don't want to go back, but you know you need to go back to that place and as long as you have not have had that follow-up meeting, every time you are reminded that this moment is still to come.' (R3, mother)*

Medical treatment and decisions

Unresolved questions of parents affected which professionals the bereaved parents wanted to meet. Most parents indicated they preferred to meet with the professionals who were extensively involved with their child, and could answer unresolved questions. Some parents said the appointed professionals did not attend at the follow-up meeting, which they found tiresome, because questions remained unanswered (Box 3, quote 1).

Most questions were frequently addressed by discussing the chronological review of the treatment process and critical decisions made. Parents felt this approach was beneficial as it ensures potential questions were adequately addressed and explained, if necessary. Some parents wanted to verify if they remembered the disease-related information correctly. Other parents wanted to put the disease within context, to compare their child with other children or the literature. Additionally, parents sought for reassurance by asking the 'what if' questions that arose out of counterfactual thinking. For examples: 'have we done everything to save our child?' and 'what if we had chosen a different treatment?' Parents hoped to hear answers that gave them a good feeling about the choices they made (Box 3, quote 2). Most parents thought the professionals gave reassuring answers, such as there being no other options for treatment, or that their child had not suffered. Some parents felt reassured that they had done everything to save their child, meaning some parents could better accept the death of their child after these explanations. Some parents, however, believed such reassuring answers were offered only to help them cope, or to make life more bearable, therefore some parents doubted the honesty of some answers. Although, these parents were unsure whether they would have preferred hearing more realistic answers, considering knowing the truth might make them feel even worse or guiltier. For example, if they find out whether they or the professionals badly influenced their child's prognosis (Box 3, quote 3). Some parents, thinking about it, did not continue these questions, while others kept asking themselves what answer it was they wanted to hear. In addition, parents understood that most of the questions that arose from counterfactual thinking fall within a grey area where the professional cannot provide all the answers. This caused some of these parents to experience the follow-up meeting as unsatisfactory (Box 3, quote 4). Some parents mentioned that 'what if' questions are 'anyway pointless'. They experienced their professionals as always open to questions during treatment, where these questions were discussed during the treatment process.

Most parents experienced the follow-up meeting as the last possibility to ask questions to professionals. They sought reassurance by discussing the chronological treatment process and asking 'what if' questions. While some parents felt reassured, other parents doubted the honesty of some answers.

Box 3, theme evaluation of the medical treatment and decisions made

> *'Our oncologist told us she would combine the follow-up meeting with the PICU physician, because I had a lot of questions for them both. When we entered the room the oncologist told us the PICU physician could not attend, he had no time for the follow-up meeting. I found it annoying, I had questions for him as well that would not be answered.' (R9, mother)*
>
> *'I really needed to know whether everything was done within the treatment process and if every option was considered. I think I needed this information for my grieving process, knowing everything was done. You cannot bring back your child, however as a parent you still have questions…' (R6, mother)*
>
> *'Whether that drug was the cause of her death, he could of course not answer… What if we had not given her that drug, had it not happened? But he did not believe… But they cannot confirm or deny it. So that is a bit of a grey area and we actually still have no answers. So what do you want? Partially, you want to know, but if it was the drug, you would feel even worse, because who has administered that drug to her for months? The doctor also said do not make yourself feel guilty about it, but you still do after the death of your child. You will still doubt, have we done enough for her?' (R1, mother)*
>
> *'It is very striking, because you ask a question, you get an answer, but that answer is still not satisfactory. Because it does not help you, but it is very strange, what do we want to answer then really?' (R10, father)*

Good parenting

A few parents described how the professionals gave positive feedback about the role of the parents during the disease of their child's treatment. Compliments that parents received were, for example: that they were extensively involved during care, that parents had coped well with the situation, and that the professionals valued the parents. Parents considered these compliments as normal however, thought of them as nice and helpful. They helped reassure parents that they had been a good parent (Box 4, quote 1).

Box 4, theme good parenting

> *'If your child goes to high school, which a lot of parents experience, so you can ask, how do you do that? You can talk about that, but in this situation there are few people with whom you can discuss how you do it well. …. So it was nice that the professionals gave compliments on how we had done it. (R5, mother)*

Identity and uniqueness of the child

Many parents described how they reminisced about their deceased child during the follow-up meeting. Some professionals helped retrieve these memories by telling anecdotes and stories about the deceased child. This gave parents a sense that the professionals knew their child, and that the death of their child mattered to the professionals. Parents consider their child as unique and special, and want the professionals to recognise that (Box 5, quote 1). They do not want their child to be just one of many who died. Parents experienced such recognition as helpful with accepting the loss of their child. If the professional cared, showed emotions and ensured that the child and the follow-up meeting is special for them too, this made the parents feel that they and their child mattered.

Box 5, theme identity and uniqueness of the child and the situation

> *'I really wanted that they would not forget my daughter, it is of course my daughter ... so… unique! I found it almost unbearable that others might think that this is one of so many children who died.' (R8, mother)*

Feedback to the professionals

During most follow-up meetings the professionals asked the parents to reflect upon the treatment process. Parents appreciated it when professionals gave them the opportunity to offer feedback during the conversation. Most parents felt comfortable giving feedback and speak freely to the professionals, due to the good relationship they had with them. One mother considered the follow-up meeting as the most important moment to provide feedback to the medical team (Box 6, quote 1). In contrast, other parents still found it difficult to provide feedback to the professionals; they also needed consolation and wanted the conversation to be harmonious, and thought this was not possible if they confronted the professionals with negative feedback.

Box 6, theme feedback to the professionals

> *'And if I spoke to my child's doctor when she was alive, I had other questions, and my daughter was there. There was no right moment to provide feedback about how I experienced it, and I did not know how they would react. There might arise a conflict of interests. After the death of my daughter I experienced the possibility to provide feedback and to speak freely, considering I did not expect anything of the professionals anymore.' (R8, mother)*

Closure and continuing connected

Many parents described the follow-up meeting as a closure moment for both the professional and the parent. Some parents thought of it as a distinct closure of the hospital period. They explained how ‘it feels like the end of a specific period’ when some parents may have left this period behind. Other parents experienced the meeting as a necessity. Life goes on, they feel they need to return to the hospital and actively seek closure. Sometimes, contact with professionals was continued after the follow-up meeting. This arose from the parents, professionals, or certain circumstances, and was experienced as valuable. Many parents indicated that they would like to meet the professionals of their deceased child again. The majority of these parents, however, considered it as inconvenient to contact the professionals after the follow-up meeting (Box 7, quote 1). Some parents sought a connection with the hospital through memorial services or visiting fellow-sufferers where some parents hoped to encounter the professionals again.

Box 7, theme closing and continuing connected

> *‘I think I want to go back again to the hospital to retrieve memories. At the memorial site they have a book with a page for my son, I would like to see that page. (…) And I think I want to meet the professionals again. However, it feels uncomfortable to contact them again. It ended there for us, while their lives continue and there are a thousand of new children diagnosed in that time. I think I wanted to retain a feeling. (R7, mother)*

Discussion

The aim of this study was to explore the experiences of bereaved parents in follow-up meetings, and to discover what this follow-up meeting meant to them. Seven themes were identified: readiness and timing, returning to the hospital, medical treatment and decisions, good parenting, identity and uniqueness of the child, feedback to the professionals, closure and continuing connected. The current study showed that parents experience follow-up meetings very differently. Parents have different intentions with regard to the follow-up meeting, for example: asking questions, being reassured, providing feedback and talking about their unique child. Whereas many parents described the follow-up meeting as a moment of closure, some parents indicated they still wanted to meet the professionals again.

The majority of parents in this study preferred the follow-up meeting to happen within the first three months of their child’s death, which is in line with other studies. [21,22,45,46] Other consistent findings were: experiencing unresolved questions before the follow-up meeting[21,22,45,47], searching for reassurance[22,45], wanting to continue contact with the professionals[47-49], and the need to feel that they and their child mattered[45]. This shows that results are partly generalisable as far as expectations of follow-up meetings in paediatric oncology and sudden death are concerned.

By discussing the chronological treatment process and critical decisions during the follow-up meeting with the professionals, some parents felt reassured that they had done everything to save their child, and that there were no other options. These results are in line with studies about follow-up meetings after the sudden death of children.[22,47] Conversely, these studies suggest that one of the parents' top priorities is complete and honest information about their deceased child.[22,47] This study shows some parents have ambivalent feelings about the reality of the situation and the need to be reassured, believing the honest story might make them feel guilty. Guilt is included in several classic grief measures and is a known emotion in bereavement. It is also mentioned in other studies about follow-up meetings.[45,50-53] Importantly, that literature suggests that guilt is especially prevalent among some vulnerable subgroups and is associated with maladaptive health outcomes.[51] Therefore, professionals should not increase feelings of guilt and should be sensitive enough to recognise these feelings during the follow-up meeting and determine whether support is needed.

The other studies confirming the need for reassurance did not remark upon the ambivalent feeling about the realistic situation and reassurance.[22,47] These studies involved parents who reflected about what they expected of a follow-up meeting, or parents whose child had died suddenly, and were conducted by survey or by telephone interviews.[21,22,47] This might explain why ambivalent feelings were only described by some parents in this study. It is unclear, however, whether parents develop these feelings before the follow-up meeting or during later reflection.

The findings of this study should be considered within the context of several limitations. First, it is not clear whether data saturation has been fully achieved, therefore the results should be considered with caution. Second, selection bias might be introduced by the self-selection of parents for this study. These parents might be more motivated to give their opinion and this reflected some inherent bias in the characteristics, considering the large number of parents with a high education level. Nevertheless, this sampling technique ensured geographic diversity of parents and hospitals. Another limitation is that maximum variation could not be actively achieved, due to a low response rate, though variation was attained with place of death and disease duration. The maximum variation on type of cancer is low, considering most children in this study were diagnosed with a brain tumour, which has the highest mortality rate in the Netherlands.[3] Finally, parents were interviewed within the first three years of the follow-up meeting. The experiences of the follow-up meeting, and its meaning to parents may evolve over time and, furthermore recall bias may alter the accuracy of the experiences. Reflections, written memos and peer review during the study helped to prevent further bias. Another strength is the use of in-depth interviews, which allow parents to discuss their personal experiences and perspectives of the follow-up meeting, rather than choose or rank responses of a predefined list. Additionally, several methods enhancing the rigorous design were used such as: a pilot interview, analysing interviews based on consensus within the research team, memos and a transparent description of the study in accordance to COREQ.

Conclusion

Parents have a variety of expectations, intentions and experiences of the follow-up meeting. They described their different stages of grieving which influenced their feelings of readiness for the conversation. Parents associated the follow-up meeting with different burdensome and valuable aspects. During the conversation, parents asked unresolved questions, sought reassurance, wanted to continue contact with the professionals and wanted to know that their child mattered. Many parents described the possibility to provide feedback during the follow-up meeting and some parents received positive feedback that reassure them as having been a good parent. Most parents felt that the conversation offered closure. Taking the variety of expectations, intentions and experiences into consideration, professionals should try to recognise the individual needs of the parents and tailor the follow-up meeting accordingly.

Recommendations

This study recommends allowing parents to decide who they want as interlocutors and to determine the optimal timing of the follow-up meeting, with the professional having the responsibility to contact the parents. Regarding the different intentions and needs professionals need to be very sensitive and tailor the follow-up meeting to the individual needs of parents. Professionals should ask questions, reminisce, provide positive feedback about the coping style and show their personal emotions about the child’s death and the conversation. Combining future research exploring the professionals’ perspective a framework could be constructed to assist paediatric oncologists and other professionals in conducting follow-up meetings. Additionally, it would be interesting to conduct further research on the ambivalent feelings that some parents described regarding the reality of the situation and the need to be reassured.

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Table 1, Phases of thematic analysis by Braun & Clark.[26]

Phase	Description of the process
1. Familiarizing yourself with your data	Transcribing data, reading and re-reading the data, noting down initial ideas.
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report	The final opportunity for analysis. Selection, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a report of the analysis.

Table 2, Characteristics of respondents and their children

Characteristics parents N= 13 (100%)	n	%
Gender		
Male	4	30
Female	9	70
Age		
<40 year	4	30
40– 45 year	8	62
>50 year	1	8
Cultural background		
Dutch	13	100
Marital status		
Cohabiting	4	30
Married	8	62
Divorced	1	8
Education*		
Low	1	8
Mediate	3	3
High	9	69

Characteristics children N= 9 (100%)	n	%
Gender		
Boy	5	56
Girl	4	44
Age at diagnosis		
0 – 5 year	4	45
5 – 10 year	2	22
10 – 15 year	3	33
Type of disease		
Brain tumor	7	78
Bone tumor	1	11
Leukemia	1	11
Tumour-targeted treatments		
Operation	6	67
Chemotherapy	7	78
Radiotherapy	6	67
Proton therapy	1	1
Time between diagnosis and no chance of cure		
0 – 6 months	1	11
6 – 12 months	4	45
12 – 24 months	1	11
>24 months	3	33
Time between diagnosis and death		
6 – 12 months	2	22
12 – 24 months	4	45
>24 months	3	33
Place of death		
Home	6	67
Hospital	3	33
Time between death and follow-up meeting in the hospital		
0 – 6 weeks	2	22
7 – 12 weeks	4	45
13 – 18 weeks	0	0
> 19 weeks	3	33
Number of follow-up meetings in the hospital		
1	7	78
2	2	22
Time between follow-up meeting and interview		
0 – 12 months	2	22
13 – 24 months	2	22
> 25 months	5	56

* Low = primary school, lower secondary general, lower vocational; middle = higher secondary general education, intermediate vocational education; high = higher vocational education, university.

Appendix 1

Topiclijst interviews ouders Versie 1 13-12-2015

Openingsvragen

Kunt u vertellen hoe het met u en uw kind gegaan is vanaf het moment dat [naam kind] ziek werd?

Kunt u iets vertellen over hoe het nagesprek is verlopen?

Thema's en vragen ter verkenning of verdieping

1. Verwachtingen nagesprek

Relatie met hulpverlener	- U heeft het gesprek gehad met een [type hulpverlener], hoe lang was deze [type hulpverlener] al bij de zorg van uw kind betrokken? - Hoe was de relatie met de [type hulpverlener]?
Informatie vooraf	- Wie heeft het initiatief genomen om dit gesprek aan te gaan? - Heeft u vooraf informatie ontvangen over het nagesprek? - Van wie heeft u deze informatie ontvangen?
Voorbereiding	- Heeft u het gevoel gehad zich te kunnen voorbereiden op het gesprek? - Hoe heeft u zich voorbereid op het gesprek? - Heeft u er over getwijfeld om het nagesprek af te zeggen?
Verwachtingen	- Welke verwachtingen had u van het nagesprek? - Waren deze verwachtingen positief of negatief? - Had u vooraf verwachtingen over welke onderwerpen aan bod zouden komen? - Welke onderwerpen wilde u aan bod laten komen?

2. Ervaringen nagesprek

Vormgeving gesprek	- Met wie was u aanwezig bij dit gesprek? - Had u achteraf gezien nog andere mensen mee willen nemen naar het gesprek? - Waar vond dit gesprek plaats? - Hoe lang heeft het nagesprek ongeveer geduurd? - Had u voor uw gevoel voldoende tijd voor dit nagesprek?
Inhoud gesprek	- Welke onderwerpen heeft u tijdens dit gesprek besproken met [type hulpverlener]? - Hoe kwamen deze onderwerpen voor het gesprek tot stand? Had u hier zelf invloed op? - Zijn uw onderwerpen aan bod gekomen?
Ervaring	- Hoe voelde u zich tijdens het nagesprek - Hoe heeft u het nagesprek ervaren? - Was deze ervaring positief of negatief? - Wat heeft er voor gezorgd dat u dit zo ervaren hebt?

3. Betekenis nagesprek

Betekenis	- Hoe voelde u zich tijdens het gesprek? - Weet u nog welke betekenis het nagesprek voor u had op dat moment? - In hoeverre heeft het nagesprek iets veranderd in het verlies van uw kind? - Wat zorgde er voor in het nagesprek dat dit veranderd is? - Bent u na het nagesprek anders omgegaan met het verlies van uw kind? - Denkt u nog wel is terug aan het nagesprek?

4. Tevredenheid nagesprek

Tevredenheid	- Kwamen uw verwachtingen en ervaringen overeen? - Hoe tevreden was u over dit nagesprek? - Vindt u het prettig dat u dit nagesprek met [type hulpverlener] gehad heeft?

	- Heeft het ziekenhuis voldoende aan nazorg geboden?
5. Goede aspecten en verbeterpunten	
Goede aspecten	- Wat vond u positief aan het nagesprek? - Wat vond u waardevolle onderwerpen in het nagesprek?
Verbeterpunten	- Zouden hulpverleners het nagesprek op bepaalde punten kunnen verbeteren? - Hoe zou dit verbeterd kunnen worden? - Had u nog graag een nagesprek gehad met een andere hulpverlener? Zo ja, welke hulpverlener en waarom? - Wat vond u van het moment waarop u het gesprek had?