

# Parental experiences and perspectives of end-of-life decision-making in allogeneic paediatric stem cell transplant

*A RETROSPECTIVE, MULTI-CENTRE, GROUNDED THEORY APPROACH*

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## INTRODUCTION

The outcomes of paediatric allogeneic stem cell transplantation (SCT) have improved over time. Despite this improvement a number of children die post-transplant (1,2). For children with hematologic malignancies and some non-malignant diseases, SCT is a potentially curative treatment (3,4). Complications may arise post-transplant, e.g. infections, graft versus host or transplant related toxicities. Children suffer from nausea, diarrhea, mucositis, fatigue and pain. Some children are admitted to the Intensive Care Unit (ICU) and all experience some form of physical and social isolation. Compared with non-SCT children with cancer, SCT children with cancer spend more days in hospital in their last month of life. They are more likely to be intubated in the last 24 hours of life and to die in the ICU, with less opportunity for end-of-life (EOL) preparation (5). EOL refers to the period when all curative options have been used and care is focused on preparing for an anticipated death (6). Parents of SCT children with cancer are more likely to have a primary goal of cure during the EOL period and at time of death compared with parents of non-SCT children with cancer in the EOL period (5). On behalf of their seriously ill child, parents have to make EOL related decisions while hoping for cure after SCT. Such decisions may involve complex treatment, ICU admission, withdrawing or withholding of life sustaining treatment or the decision not to resuscitate (7-10).

Literature about parental EOL experiences in paediatric SCT is scarce. In a grounded theory thesis (11) the parental EOL decision-making has been described as a process of 'the realization of the parental knowing' with four categories; developing trust, committed to seeing it through, facing my worst fear, acceptance of self (11). Experiences from a comparable group (4) learn that parents in paediatric oncology consider EOL decisions the most difficult they have to face (12). Qualitative studies demonstrate that these decisions are affected by factors as the child's quality of life, the child's chance of improving, perceptions of their child's wishes (13), hospital staff's advice (13,14), or spending more time with their child (15).

During SCT of their child parents experience intense distress and disorientation (16,17). Bereaved parents of children who died after SCT show higher levels of depression, anxiety and stress (18), and are at greater risk of decreased psychological well-being (19) in comparison with those whose children died from cancer but did not receive SCT. In clinical practice has been observed that mortality caused by complications post-SCT made it difficult to prepare for the upcoming death. Patient and parents live with hope for cure and are willing to do everything what is possible for a last chance for cure. Treatment is focussed on cure

and the change to EOL care is often abrupt. It is unclear how parents get insight in the child's situation, and which EOL decisions they are confronted with. Healthcare professionals (HCP's) try to support parents in decision-making but in clinical practice HCP's search for wisdom for this support. Therefore insight is needed in parental EOL decision-making in paediatric SCT.

## **PURPOSE**

The aim of this grounded theory study is to investigate the parents' experiences with EOL decision-making in paediatric SCT. A better understanding of the parents' perspectives can help HCP's to support parents in decision-making and can help to improve (after)care.

Research question

'How do parents experience and perceive EOL decision-making after allogeneic paediatric SCT?'

## **METHODS**

### **DESIGN**

In this retrospective, qualitative, multi-centre study, Grounded Theory was used in order to analyse data and abstract theory that reflects the parental EOL decision-making post-SCT. Grounded Theory (20) was chosen because of its theory developing character. The intention of a Grounded Theory study is to move beyond description (20). The intention of this study was to understand the parental EOL decision-making, which may help explain practice (21). In this thesis categories were identified, abstracting theory will follow in a later stage.

### **SAMPLE**

A criterion sample was used. Parents of children who died within a year after allogeneic SCT were asked to participate, because of the expectation that they can provide maximum information about the studied experiences. Parents were eligible to participate when their child passed away within last year, to prevent for recall bias and possible changes in parental coping. Parents were included not earlier than six weeks after their child died, after an aftercare conversation with HCP's. This was done to avoid disturbance of the early bereavement process. Parents who were unable to speak and read Dutch or who lived abroad were excluded. Participants were recruited from the only two Dutch paediatric centres for allogeneic SCT's, which together perform 70 SCT's per year. Potential participants were identified by the local staff. An invitation letter from the program director of the SCT unit or

treating physician was sent to parents of twelve children together with study information. After one week the researcher contacted the parents. Parents of two children did not agree to participate because of a too burdensome period; parents of three children required more time and they indicated they could be approached later. Twelve parents of seven children participated; saturation was not reached, further inclusion will take place at a later stage. From two children one parent was included, due to single partnership or because one of the parents lived abroad. Children died 11-262 days post-SCT, from whom two after a second SCT. One child died on the planned SCT day and did not receive the transplant. This case was included due to a limited accessible population and due to comparable decision-making. For further characteristics see [table 1](#).

The study protocol was approved by the medical ethics committee of Leiden University Medical Centre. Prior to the interview written informed consent was obtained from all parents according to the declaration of Helsinki (22). Each participant was assigned to a unique code. Data were coded and anonymized. Participation required efforts from parents; the researcher paid attention to it by giving contact information and when indicated referring to (consisting) social support.

## DATA COLLECTION

Data collection consisted of a short questionnaire and an interview. The questionnaire was used to gain insight in family, child and treatment characteristics and was completed during the interview appointment.

When parents agreed to participate, the in-depth open interview was scheduled. In-depth open interviews provided the opportunity for the parents to share their story and perspectives (23). Parents were free to choose the interview setting they felt most comfortable in. In line with their preference most face to face interviews were held at home of the participants. One couple chose to be interviewed in the hospital for practical reasons. Participants were interviewed by an experienced SCT nurse (HM). Due to possible differences in perception and coping of couples interviews were conducted separately. One couple was interviewed together. Interviews were conducted between May and August 2014 and took one to two hours. The interviews took place between 100 days to one year after the child's death. A topic list drafted on the basis of preliminary studies in EOL decision-making (14,24-28) and knowledge of the researchers, was used to make sure that all topics ([table 2](#)) were discussed. Interviews were audio-taped and transcribed verbatim.

The researcher wrote observational memos subsequent to each interview about the most central research question, important themes, context and atmosphere, to serve as a reminder and as basis for data analysis (23,29). In one case a report was written directly after the interview, because of audio-tape problems. For ethical reasons parents were not asked for a second interview or member check. Member validation was also not performed because it probably does not add to the credibility and validity because of changes in mind and poor recall (30-32). Feasibility and interview quality were tested by separate evaluation of the four first interviews by the researcher (HM) and the principal investigator (MK), followed by discussion, to improve the topic list and interviews.

## DATA ANALYSIS

During analysis two strategies were used; coding and thinking theoretically (20). As advanced by Strauss and Corbin (20) coding in Grounded Theory consists of three phases; open, axial and selective coding. All interviews were read thoroughly to become familiar with the data (33). The first four interview transcripts were coded and categorized individually by the researcher (HM) and the principal investigator (MK). Further interviews were analysed primarily by the researcher (HM). Codes were discussed until consensus was reached (open coding). While examining the interviews and memos, segments of the text were organized into groups. Groups of codes were combined, categorized and described. Review took place by discussing the code tree and theoretical insights on a regular basis with the principal investigator (MK) to reach consensus about the content and interpretations, to increase the reliability (23) (axial coding). Selective coding followed in a later stage. Coding was supported by software program NVIVO 10 (QRS Australia). Analysis required the ability of theoretical thinking, which refers to interpreting data and distracting themes from data. This process was supported by writing theoretical memos and audit trail during analysis (23), which enhanced validity. Data collection and data analysis was an interactive process and a constant comparison approach was used. When data of 2-3 interviews were collected and coded, a new set of interviews took place. The researcher searched for new information to fill the already identified categories and to reach saturation. New, rising ideas were tested in further data collection (23).

## RESULTS

The parents explained experiences and perceptions about EOL decision-making during the interviews. Three categories were identified; dealing with decision-making, making the most of opportunities and being a good parent. For illustrative quotes, see [table 3](#).

## DEALING WITH DECISION-MAKING

Parental decision-making was emotional and intellectual difficult to address; the four themes listed below played a role.

### *TRUSTING IN AND HOPING FOR VICTORY*

Parents did not experience the SCT as a choice, but as a last resource. Parents mentioned they were informed about possible serious complications, but also about the opportunity for cure. Consequently parents emphasized they trusted in a positive outcome. The choice to withhold transplant was not an option, because the child certainly would die in most cases. Even when chances for survival were rated low, parents would choose this opportunity. Parents focussed on positive aspects like a good donor, this nourished trust. Worries decreased when positive results persist. When it seemed all curative options had been used, trust in a good outcome decreased and hope for it increased, because parents did not want to hear their child would die. Parents increased hope by remembering victories from the past, when the situation of their child was worse, like during earlier ICU admissions.

### *DEVELOPING A FRAME OF REFERENCE*

During SCT most parents did not experience they had to make decisions. After explanation they followed the HCP's in decision-making. Parents realized the team is qualified and knowledgeable concerning disease and treatment. They mentioned having no frame of reference about SCT and felt not capable of taking decisions. Some parents developed a frame of reference by searching for information, looking at earlier experiences, experiences of other SCT patients, but it mostly was formed by information of HCP's. Most parents were able to focus attention on the fact that the process of their child could be positively different.

### *STRUGGLING WITH SUFFERING*

During EOL parents get insight in the child's condition by looking at the physical and mental deterioration. One parent indicated that she could not see the wounds of her child and protected herself by not looking at it. Some parents expressed they realize their child was very ill, but they did not notice the deterioration, because they became accustomed to the situation. Suffering of the child was expressed to be one of the hardest things for parents; often they were able to resist these feelings to support their child keep fighting. When it became clear that all hope was gone, it was important for parents that care aimed to avoid further suffering. In most cases the period of realizing the child would die was short, some hours or a few days, with little or no opportunity to prepare for the upcoming death. During

EOL, parents had to make decisions about ICU admission, stopping medication, stopping treatment, autopsy and when possible about the place of death.

#### *PREVENTING ANTICIPATED REGRET*

When there were still options for cure parents intended to do everything for cure and were not able to withhold treatment, like no ICU admission. Parents did not want to be responsible for initiating the possible death of their child. Parents indicated they would not be able to live with that knowledge and prevented themselves from anticipated regret.

#### **MAKING THE MOST OF OPPORTUNITIES**

Parents considered using maximum opportunities for survival of their child. Consequently parents had to trust HCP's and had a critical attitude.

#### *TRUSTING THE HEALTH CARE PROFESSIONALS*

The knowledge that the team was specialized in SCT and worked hard for their child provided trust for using maximal opportunities. Parents felt their child was in hands of the treating team. Parents trusted them because of a consistent, regularly explanation of taken decisions, unambiguity and the experience that their concerns were heard. It helped parents when the SCT period was made as bearable as possible by helping them to keep going by using humor, distraction, involvement, honesty, tender care and humanity of HCP's.

#### *HAVING A CRITICAL ATTITUDE*

Parents wanted to get the most out of treatments to retain curation. Therefore parents had a critical attitude in thinking along in the treatment, estimating risks and discussing treatment options, worries and doubts. During EOL parents needed confirmation that their child would really not recover.

#### **BEING A GOOD PARENT**

Parental decision-making was influenced by the wish to be a good parent, which were described in subsequent paragraphs with use of four themes.

#### *FOLLOWING THE CHILD*

A parental consideration during SCT was how the child felt about the situation. When the child wanted to do everything for a possible survival, parents followed their child's wish. One parent indicated she did this, even though she had no trust in the treatment herself. For

parents it was important that children were involved in decision-making. Most parents indicated they would have followed their child if the child had wished to stop further treatment at a later stage of treatment; which occurred in one case. For parents it was important to preserve a future for their children and they advocated their wishes in the way they thought their child wished or would have wished.

### *KEEPING GOING*

The parental job was to help their child keep fighting and showing not to give up. As a result, there was sometimes no space to discuss their own fears; this would have disrupted too much. Being there for their child was crucial for parents, and they did everything possible, like helping in personal care, cooking, distraction, not discussing matters and keeping the child's spirit up. In addition, parents felt their children tended to protect them from worries in not showing pain or sleeplessness. Parents illustrated that the hope, strength and optimism of their child supported them. Parents kept themselves going by keeping their child and family going, being positive, hopeful and living day by day. Support from friends, family, HCP's or employers who offered the opportunity to stay with their child, helped parents. Quality time at home pre-SCT helped families to prepare for SCT.

### *FEELING RETROSPECTIVE DOUBTS*

Retrospectively parents experienced doubts and these addressed timing of treatment, medication, hearing more results, communication between HCP's, taken risks like kind of donor, future perspectives of medical care, time being with their child and talking with their child. In hindsight, treatment decisions made with hope for cure and resulting in suffering were experienced as meaningless after the child died. Parents wondered what they did to their child. Parents allowed themselves to feel this afterwards; before and during treatment they could not think about it, since the treatment had an important goal. They realized that they did not want to hear that their child would die. In retrospect most parents declare they would have made the same decisions. One parent of a child with a hematological disease explained that he would not decide for SCT again.

### *EXPERIENCING FEELINGS OF LOSS*

Feelings of loss played a role during the whole SCT process. Parents felt anxious or had bad feelings while realizing that SCT was a treatment with certain risks. One parent explained she had no trust in the treatment due to the seriousness of the disease. The EOL period in most cases was experienced as a rollercoaster, with a lot of complications and suffering,

what made parents feel powerless. In hindsight parents struggled with doubts, the lack of psychological contact, the suffering, anxiety and they experienced intense feelings of loss.

## **DISCUSSION**

This study shows that parents did not experience decision-making during SCT as something they had to do. Parents wanted to preserve a future for their child. Consequently all possible treatment options were used and parents helped their child to keep going. In most cases EOL was experienced as a rollercoaster, with a rapid sequence from hope for cure to death, in which it was difficult to make conscious EOL decisions. Some parents experienced decision-making during EOL, like stopping further treatment. In this and earlier stages of treatment parents followed HCP's in what they offered and decided. Parents experienced intense feelings of loss when the treatment did not lead to survival since in most cases the upcoming death was not anticipated.

The expressed feelings of loss confirmed what was found in studies where parents experienced intense stress, anxiety and grief during or after SCT (16-18). Feelings of loss played also a role in paediatric oncology, within a struggle between preservation and letting go where parents stepwise learned to deal with the loss of their child and to anticipate on the upcoming death (25,26,28). Compared to these studies feelings of loss were more intense in the current study. It is proposed that this is caused by the experienced EOL rollercoaster, in which was little time for parents to let their child go and to prepare for the upcoming death. Findings of current study confirmed what was found in an evaluation of parental perspectives about EOL care after SCT (5). Both studies found that parents' goal during EOL was cure, children suffered highly from treatment and parents had little time to prepare EOL. Current study added a description of the parental meaning on these aspects. Described categories in this study were comparable to those found in a similar study, where all parents described an acceptance of self as outcome of the process (11). This was not found in current study, but rather feelings of loss.

This study has strengths and limitations. This study provides new insight in parental EOL decision-making. Strength is the ability to speak with parents within a year after the loss of their child, what prevents for recall bias. Due to the feelings of loss a narrative approach during interviews was chosen, which made it difficult to gain deep insight in parental considerations. Reflections during the study helped to prevent further bias. During SCT and EOL parents searched for positive aspects and sometimes worries from HCP's were not

heard. HCP's views, which may have provided more insight in how things are really said, were not investigated.

Knowledge about parental decision-making can help HCP's to support parents. Supporting parents in EOL care after paediatric SCT demands an individual approach in which the HCP should be sensible to doubts and questions of parents.

## **CONCLUSION**

During SCT parents did not experienced they had to make decisions, but they followed all possible treatment options offered by the HCP's. During EOL some parents had to decide to stop further treatment and parental considerations aimed to avoid further suffering. Parental EOL decision-making after SCT was difficult to distinguish from decision-making during SCT because in most cases the period of EOL was very short and abrupt after a period of fighting for survival. Hope for cure during treatment and little time to prepare EOL seemed to be factors that influence parental feelings of loss.

## **RECOMMENDATIONS**

Supporting parents demands reflection of HCP's in what way and when they inform parents and children about an eventually upcoming death during SCT. Transparency and dialogue about possible EOL decisions in the future, considerations, limitations, possibilities and preferences should be part of the whole SCT process. HCP's should be honest when it seems hope for cure decreases, making clear that parents possibly have to let their child go. During EOL parents should be offered some control. When possible, parents could be involved in timing of stopping further treatment and place of death, for example the choice for a ward they feel most comfortable in. HCP's should be aware of and weigh possibilities for parents to stay with their child and without isolation. To gain more insight in how support in decision-making is offered and perceived more research is needed. Ethnographic, prospective research with HCP's, parents and perhaps the involved patients is suggested.

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## **CONFLICT OF INTEREST**

No conflict of interest.

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## TABLES

Table 1 Characteristic of parents interviewed (n=12) and patients (n=7)

Characteristics	N	%
<b>Gender parents</b>		
male	6	50
female	6	50
<b>Age parents</b>		
≥40	12	100
<b>Cultural background parents</b>		
Dutch	11	91.7
Mixed (Dutch and other)	1	8.3
<b>Marital status parent</b>		
married/cohabiting	10	83.3
married/living apart	1	8.3
single	1	8.3
<b>Education parent</b>		
low <sup>1</sup>	1	8.3
middle <sup>2</sup>	8	66.7
high <sup>3</sup>	3	25
<b>Gender child</b>		
male	4	57.1
female	3	42.9
<b>Type of disease child</b>		
Aplastic Anaemia	1	14.3
Leukaemia or lymphoma	4	57.1
Myelodysplastic syndrome	1	14.3
B-thalassemia	1	14.3
<b>Age child at diagnosis</b>		
10-11	1	14.3
12-16	4	57.1
≥16	2	28.6
<b>Type of SCT<sup>4*</sup></b>		
cord blood (unrelated/related)	2	33.3
HLA <sup>5</sup> identical donor	2	33.3
matched unrelated donor	2	33.3
<b>Treatment during EOL</b>		
ICU <sup>6</sup> admission	5	71.4
chemotherapy	1	14.3
transfusions	7	100
experimental study participation	1	14.3
<b>Time between SCT and death</b>		
< 100 days	4	66.67
100 days- 1 year	2	33.33
<b>Age child at death</b>		
12-16	4	57.1
≥16	3	42.9
<b>Place of death</b>		
at home	2	28.6
hospital		
SCT unit	1	14.3
ICU	4	57.1

<sup>1</sup> low: primary school, lower secondary general, lower vocational;

<sup>2</sup> middle: higher secondary general education, intermediate vocational education;

<sup>3</sup> high: higher vocational education, university

<sup>4</sup> SCT=stemceltransplantation

<sup>5</sup> HLA= Human leukocyte antigen

<sup>6</sup> ICU=Intensive Care Unit

\* counted for 6 cases, due to one case did not receive SCT

**Table 2 Interview topics**

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<b>Interview topics</b>
1 How do parents get insight in the child's condition and treatment options?
2 With which EOL decisions are parents confronted?
3 What are parent's considerations concerning the EOL decisions?
4 Which factors influence the parents' decision-making in the EOL process?
5 What kind of support helped parents in EOL decision-making?

**Table 3 Illustrative quotes**

<b>Theme</b>	<b>Situation</b>	<b>Illustrative quotes</b>
<b>DEALING WITH DECISION-MAKING</b>		
<b>Trusting in and hoping for victory</b>	Father of Emma 16 years old, about decreasing trust and increasing hope during EOL.	Trust is, knowing that you can jump 1:50 meter and hope is hoping you get the 2 meter.
<b>Developing a frame of reference</b>	Mother of Daniel, 14 years old, about SCT	You accept the information, because you do not know that matter. So at that time I had to, I am again engrossed in the matter of stem cell. And that's very different matter than the chemo.
<b>Struggling with suffering</b>	Mother of Emma, 16 years old, about suffering	She suffered so much and it led to nothing. When you fight and receive a trophy, than suffering has had a goal. But if you suffer and the stem cell did not get a chance. We have fight so hard for it.
<b>Preventing anticipated regret</b>	Father of Daniel, 14 years old, about treatment options	You will take every opportunity, even if there is a chance of 1%. In case you do not take the opportunity you will have compunction, which will consists.
<b>MAKING THE MOST OF OPPORTUNITIES</b>		
<b>Trusting the Health Care professional</b>	Father of Marten, 16 years old, about the death of his son due to unexpected complications	The doctor did the best he could do, it told everyone. The doctor is a professional.
<b>Having a critical attitude</b>	Father of Davitha, 16 years old about thinking along	You have to convince me, if you say if is different, you have to tell me why and if you have good arguments or a good statement, then I will be ok with it. But not without that discussion.
<b>BEEING A GOOD PARENT</b>		
<b>Following the child</b>	Mother of Luke, 13 years old, about choosing for treatment	If Luke said I want to go home to die, I had taken him home, but it was his wish to get well again, so we have to stay.
<b>Keeping going</b>	Father of Davitha, 16 years old, about how to endure as parent	The little things that you do, where you are positive about: 'yes we have reached this yet'. And so from day to day, always one step by step..
<b>Feeling retrospective doubts</b>	Father of Pascal, 15 years old, about questions he has to deal with	Sometimes I have my questions..., Then you have something like; you become angry, you get angry, you blame yourself a little bit...
<b>Experiencing feelings of loss</b>	Mother of Pascal, 15 years old, about the second SCT	I have not had such a good feeling as the 1st time. Despite all good care and information. It is all about you child. It just was not good the 2nd time, it was just not good for me.

Quotes are somewhat edited in for legibility and anonymity.

## DUTCH SUMMARY

**Titel** Ervaringen en percepties van ouders over de besluitvorming tijdens het levenseinde van hun kind na allogene stamceltransplantatie.

**Inleiding** Een stamceltransplantatie (SCT) is mogelijk levensreddende behandeling, sommige kinderen overleven het echter niet. Begrip van ouderperspectief over besluitvorming tijdens het levenseinde ontbreekt.

**Doel en onderzoeksvraag** Een beter begrip van het ouderperspectief over besluitvorming tijdens het levenseinde na een SCT bij kinderen, kan hulpverleners helpen ouders te ondersteunen in de besluitvorming en de (na)zorg te verbeteren.

**Onderzoeksvraag** Hoe ervaren ouders de besluitvorming tijdens het levenseinde van hun kind na een stamceltransplantatie en hoe kijken ze hierop terug?

**Methode** Een retrospectief, kwalitatief onderzoek aan de hand van Grounded Theory. Persoonlijke, diepte interviews met twaalf individuele ouders zijn op een kwalitatieve wijze geanalyseerd. Interviews werden gecodeerd, gecategoriseerd en thema's beschreven.

**Resultaten** Drie categorieën over ouderervaringen zijn geïdentificeerd: 1) 'omgaan met besluitvorming' met thema's: vertrouwen in en hopen op overwinning, het ontwikkelen van een referentiekader, worstelen met het lijden, het voorkomen van geanticipeerde spijt; 2) 'het benutten van kansen' met thema's: vertrouwen in de hulpverlener, een kritische houding hebben; en 3) 'een goede ouder zijn' met thema's: volgen van het kind, staande blijven, gevoelens van retrospectieve twijfels, gevoel van verlies ervaren.

**Conclusie** Tijdens SCT ervaren ouders niet dat zij beslissingen moeten nemen; zij volgen alle mogelijke behandelopties aangeboden door hulpverleners. Tijdens het levenseinde moesten sommige ouders besluiten om verdere behandeling te stoppen en ouders overwogen dan het verdere lijden te vermijden.

**Aanbevelingen** De ervaringen van ouders bieden inzicht voor hulpverleners hoe zij ouders kunnen begeleiden in het nemen van besluiten. Dit vraagt teamreflectie over de wijze waarop en wanneer ouders worden geïnformeerd over een eventueel naderende dood gedurende de SCT. Etnografisch, prospectief onderzoek, onder hulpverleners, ouders en wellicht betrokken patiënten wordt aanbevolen om verder inzicht te verkrijgen.

**Trefwoorden:** Levenseinde; Besluitvorming; Stamceltransplantatie; Kind; Perspectieven.

## ENGLISH ABSTRACT

**Title** Parental experiences and perspectives of end-of-life decision-making in allogeneic paediatric stem cell transplant (SCT).

**Background** SCT is a potentially curative therapy, yet some children will die. There is little knowledge about parental perspectives on end-of-life (EOL) decision-making.

**Aim and research questions** A better understanding of parental perspectives about EOL decision-making after paediatric SCT can help healthcare professionals (HCP's) to support parents in decision-making and to improve (after) care.

Research question: How do parents experience and perceive EOL decision-making after allogeneic paediatric SCT?

**Method** A retrospective, qualitative study using Grounded Theory. Face to face, in-depth open interviews with twelve individual parents were conducted and analysed qualitatively. Interviews were coded and categorized; derived themes were described.

**Results** Three categories about parental experiences were identified: 1) 'dealing with decision-making' with themes: trusting and hoping for victory, developing a frame of reference, struggling with suffering, preventing anticipated regret; 2) 'making the most of opportunities' with themes: trusting the Health Care professional, having a critical attitude; and 3) 'being a good parent' with themes: following the child, keeping going, feeling retrospective doubts, experiencing feelings of loss

**Conclusion** During SCT parents did not experienced they had to make decisions, but they follow all possible treatment options offered by the HCP's; during EOL some parents had to decide to stop further treatment and parental considerations aimed to avoid further suffering.

**Recommendations** The parental experiences provide insight for HCP's in how to support parents in taking decisions. It demands reflection of the team about when and in what way they inform parents and children about an eventually upcoming death during SCT. Ethnographic, prospective research with HCP's, parents and perhaps the involved patients is suggested to gain further insight.

**Keywords** End-of-life; Decision-making; Stem cell transplant; Paediatric; Perspectives.