



# Parental experiences in end-of-life decision-making in allogeneic pediatric stem cell transplantation

## “Have I been a good parent?”

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### Abstract

**Background:** In pediatric hematopoietic stem cell transplantation (HSCT), the end-of-life (EOL) phase and the loss of the child is often characterized by a sudden deterioration of the child following a period of intensive curative treatment. This demands a fast transition for parents. Therefore, an understanding of the parents' perspective on decision-making in such a complex situation is needed. This study aims to gain insight in parental experiences in EOL decision-making in allogeneic pediatric HSCT.

**Methods:** A qualitative descriptive study was performed among parents of eight families. Data were thematically analyzed.

**Results:** All parents were aware of their child's deterioration. Six families were confronted with a rapid deterioration, while two families experienced a gradual realization that their child would not survive. Parental EOL decision-making in pediatric HSCT shows a reflective perspective on the meaning of parenthood in EOL decision-making. Two central themes were identified: “survival-oriented decision-making” and “struggling with doubts in hindsight.” Six subthemes within the first theme described the parents' goal of doing everything to achieve survival.

**Discussion:** Parents experienced EOL decision-making mainly as a process guided by health care professionals (HCPs) based on the child's condition and treatment possibilities. The decision-making is characterized by following opportunities and focusing on hope for cure. In hindsight parents experienced doubts about treatment steps and their child's suffering. HCPs can strengthen the parental role by an early integration of palliative care, providing timely support to parents in the process of imminent loss. Advance care planning can be used to support communication processes, defining preferences for future care.

### KEYWORDS

decision-making, end-of-life, experiences, hematopoietic stem cell transplantation, parental, pediatric

Abbreviations: EOL, end-of-life; HCP, health care professional; HSCT, hematopoietic stem cell transplantation; ICU, intensive care unit.

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## 1 | INTRODUCTION

For an increasing group of children, hematopoietic stem cell transplantation (HSCT) offers an opportunity for cure. In Europe, annually over 5000 pediatric HSCTs are performed, of which 75% are allogeneic.<sup>1</sup> Despite improved HSCT outcomes over the last decades,<sup>2-7</sup> a significant number of pediatric patients still die after a HSCT because of recurrence of initial disease or HSCT complications. Survival rates ranged widely from 45 to 95% based on the initial disease and transplant modality.<sup>2-7</sup>

Parents are confronted with their child's somatic and psychosocial distress during HSCT<sup>8-10</sup> and they experience intense distress and disorientation themselves.<sup>11-13</sup> Their focus during the child's end-of-life (EOL) period includes mainly cure<sup>14</sup> and it has been shown that bereaved parents are at great risk of decreased psychological well-being.<sup>15,16</sup> In HSCT, the EOL phase is often characterized by a sudden deterioration of the child following a period of intensive curative treatment. Pediatric and young adult HSCT patients are more likely to suffer highly during their last month of life as compared to non-HSCT patients, including intubation in the last 24 h of life and dying in the intensive care unit (ICU).<sup>14,17</sup> As a consequence, initiating EOL preparation and providing support to patients and parents is limited or lacking<sup>14,17</sup>; this demands a fast transition for parents. Therefore, an understanding of the parents' perspective on EOL decision-making in such a complex situation is needed. In this study, EOL refers to the period when curative options become exhausted and care is focused on quality of life and on preparing for an anticipated death.<sup>18</sup> This study aims to gain insight in parental experiences in EOL decision-making in allogeneic pediatric HSCT.

## 2 | METHODS

### 2.1 | Design

In order to provide in-depth insight into the parents' experiences concerning EOL decision-making, a qualitative descriptive study was conducted.<sup>19</sup> The study is reported in accordance with the COREQ checklist (Table S1).<sup>20</sup>

### 2.2 | Sample

Parents of children that died within a year after allogeneic HSCT were selected. Parents were eligible to participate within a 2-year period after the loss of their child. To prevent disturbance of the early bereavement process, parents were not included until 6 weeks after their child's death and not until a routinely aftercare meeting with their health care professional (HCP) had taken place. Parents with insufficient proficiency in Dutch or who lived abroad were excluded. Participants were recruited from the two Dutch centers for pediatric allogeneic HSCT. The local staff identified eligible participants and sent a mail invitation to parents of 19 children. After 1 week, parents were approached by phone. When parents agreed to participate a face-to-face appointment was scheduled at a convenient moment for them.

**TABLE 1** Interview topics

#### Interview topics

Opening question:  
When is the stem cell transplantation first discussed and how did it go from then on?

1 How did parents get insight in the child's condition and treatment options?

2 What end-of-life decisions were parents confronted with?

3 What were the parent's considerations concerning the end-of-life decisions?

4 What influenced the parental decision-making in the end-of-life process?

5 What kind of support helped parents in end-of-life decision-making?

Due to difficulties with recruitment, we enlarged the initial inclusion criterion of up to 2 years after the child's death. Written informed consent was obtained from all parents. The research ethics committee of the Leiden University Medical Centre approved the study protocol (P14.013). All data were coded by assigning the respondents a unique code.

### 2.3 | Data collection

Data collection implied in-depth face-to-face individual interviews and a background questionnaire. All interviews were performed in Dutch. During the interviews open questions were asked; the interviewer started with an open and broad question to provide the opportunity for parents to tell their story. The interviewer used a topic list based on literature<sup>21-26</sup> and expert knowledge, as guidance to guarantee the research questions could be answered (Table 1). No time restrictions to answer all questions were used. Observational memos were written after each interview to grasp the interviewer's impression of the context, atmosphere, and important themes. Interviews were conducted by an experienced HSCT nurse (HM), who was not involved in the care of the participating families. An open atmosphere was experienced during all interviews in which feelings of loss were present, but not disrupting the interview process. Interviews were recorded and transcribed verbatim. Feasibility and interview quality were tested by separate evaluation and subsequent discussion of the four first interviews by two study team members (HM, MK).

### 2.4 | Data analysis

Data were thematically analyzed.<sup>27,28</sup> The observational memos served as a starting point for data analysis.<sup>27,29</sup> All interviews were read thoroughly to become familiar with the data.<sup>27</sup> The first four interview transcripts were coded and categorized independently by two study team members (HM, MK) and further interviews primarily by one member (HM). Coding was supported by software program NVIVO10 (QRS Australia). During analysis two intertwined strategies were used; coding and thinking theoretically. Coding consists of segmenting data in meaningful parts and providing summarizing labels to these parts. This process was followed by comparing codes within

**TABLE 2** Characteristics

Characteristics on family, patient, and parent level	N
Participating families	8
Type of disease child	
Bone marrow failure	2
Malignancy	4
Hemoglobinopathy	1
Primary immune deficiency	1
Treatment during EOL	
PICU admission	6
Chemotherapy	1
Transfusions	7
Experimental study participation	1
Time range between HSCT and death <sup>a</sup>	
<100 days	5
100 days-1 year	2
Place of death	
At home	2
Hospital	
HSCT unit	1
PICU	5
Gender child	
Male	5
Female	3
Age child at diagnosis	
4-12 years	2
12-16 years	4
≥16 years	2
Year of (last <sup>b</sup> ) transplantation	
2012	1
2013	6
2014	1
Age child at death	
<12 years	1
12-16 years	4
≥16 years	3
Cause of death	
Relapse	1
(HSCT-related) complication	7
Gender parents <sup>c</sup>	
Male	7
Female	7
Age parents	
≥40 years	14
Cultural background parents	
Dutch	13
Mixed (Dutch and other)	1

(Continues)

**TABLE 2** (Continued)

Characteristics on family, patient, and parent level	N
Marital status parent	
Married/cohabiting	12
Married/living apart	1
Single	1
Education parent	
Low <sup>d</sup>	1
Middle <sup>e</sup>	8
High <sup>f</sup>	5
Time range between child's death and interview	
3-6 months	5
7-12 months	4
13-23 months	5

Abbreviations: HSCT, hematopoietic stem cell transplantation; PICU, pediatric intensive care unit.

<sup>a</sup>One child died shortly before HSCT.

<sup>b</sup>Three children died after a second HSCT.

<sup>c</sup>From one child only a father participated and from one child only a mother.

<sup>d</sup>Low: Primary school, lower secondary general, and lower vocational.

<sup>e</sup>Middle: Higher secondary general education, intermediate vocational education.

<sup>f</sup>High: Higher vocational education, university.

cases and between cases, resulting in a list of categories. Data collection and data analysis alternated to find new information, to fill and develop already identified categories. After interviewing and analyzing two to four interviews, another round of interviews and analysis took place. Analysis required theoretical thinking,<sup>30-32</sup> which refers to interpreting data and describing the meaning of the categories.<sup>28</sup> Coding and theorizing were regularly discussed by two study team members (HM and MK) to reach consensus about the content and interpretations.<sup>27</sup> Analysis was performed in Dutch. Quotations were translated in English and edited by a native English speaker. Saturation in data analysis<sup>27</sup> was reached on a conceptual level after inclusion of 12 parents. Saturation refers to the point that further data analysis did not add to the described categories.<sup>27</sup>

### 3 | RESULTS

Of the invited parents of 19 children, parents of eight children (42%) participated in the study between May 2014 and March 2015 (Table 2). Of six children both parents participated and of two children only one parent participated. Interviews took place between 3 and 23 months (mean 9.5 months) after the child's death. Interviews were mostly taken at participants homes. One couple preferred to be interviewed in the hospital. Interviews lasted 1-2 h and were conducted individually, except for one couple. In one case, a detailed report was written immediately after the interview due to recording problems.

All parents expressed to have been aware of their child's deterioration. Two processes could be identified. Six families were confronted with a rapidly worsening condition of their child following serious

complications. Time to realize their child was terminally ill varied from hours to a few days. All these children died in the hospital and most of them in the pediatric ICU, with a mean of 41 days post-HSCT. Parents faced decisions on stopping medication, ending treatment and eventually consenting for autopsy. Two families reported having gradually realized their child would not survive. Of these children, one suffered from a relapse malignancy and one from a HSCT complication; both died at home on average 222 days post-HSCT. The parents made EOL decisions together with their child and HCPs on where to die, continuation of transfusions, chemotherapy, pain medication, or sedatives. Both groups of parents felt the threat of losing their child during the whole HSCT process, since they realized this was a treatment with serious risks. These anxious feelings were intensified when realizing chances for survival became less or when facing the deteriorating situation of their child.

Parents' descriptions of the EOL decision-making process in pediatric HSCT revealed a reflective perspective on the meaning of parenthood during this process. From the parents' reflections two central themes came forward: survival-oriented decision-making and struggling with doubts in hindsight. For illustrative quotes, see Table 3.

### 3.1 | Survival-oriented decision-making

Parents did not feel having made specific decisions, but rather being involved in a HCPs-guided decision-making process. Parents followed the advised HSCT as a well-considered opportunity for cure; they stated that the decision for HSCT was a logical step in line with standards of care. Withholding transplantation was perceived by most parents as a choice that would result in their child's death and therefore not considered a realistic option, even in those cases where chances for survival were rated low. Parents experienced most decisions as cure directed and they followed the treatment flow and associated decisions, guided by the child's HCPs. The subsequent described themes reflect the parental role in the EOL decision-making process and served the parental goal of doing everything to achieve survival.

#### 3.1.1 | Developing a frame of reference

Parents experienced the complexity of the treatment as hard to understand and felt unable to take decision-making responsibility. As such they searched for a frame of reference and this helped the parents to get control over the HSCT situation and to safeguard chances for survival. Understanding of the HSCT was mainly obtained from communication with their HCPs. Parents themselves worked hard to develop their frame of reference using different strategies, including active searching for information, comparing the current situation with earlier experiences and peer experiences. When parents were confronted with new deteriorating situations during HSCT, they relied on previous worrisome disease-related experiences. It appeared to be difficult for parents to get grip on these specific situations and the formed frame of reference proved inadequate. One mother explained she was highly focused on being offered the same interventions as in an earlier deteriorating situation and it took much doubts and time to realize this time the situation was different. Frames of reference were developed

during the process and provided some control, which supported parents in recapture confidence and hope.

#### 3.1.2 | Having confidence in and hope for a good outcome

Given the curative aim of the HSCT, parents experienced confidence and hope. Confidence can be described as trusting the child will survive and be cured. Hope was explained as an uncertain positive expectation, which became manifest as an intense parental feeling focused on the child's survival. Initially parents had confidence in a good outcome by using all possible opportunities based on the treatment and trust in the competence of the specialized HSCT team. Parents felt supported by a consistent, regularly explanation of treatment decisions and the feeling they were heard in their concerns. Confidence in a good outcome was nourished when positive results were heard. On the contrary, when parents faced their child's situation deteriorating, their confidence in a good outcome decreased. During the treatment trajectory, hope was always present and became more intense when parents perceived a worsening situation. Parents nourished hope by keeping successes from the past alive, such as when their child had recovered after a comparable life-threatening situation. During EOL, hope was focused on small improvements that could be the start of a turnaround of the worsening situation or on protecting the child from further suffering. Confidence and hope both functioned as fundamental principles for parents during the treatment phase and as having a positive orientation concerning the survival of their child. When a good outcome could not be expected anymore, confidence disappeared and only hope remained.

#### 3.1.3 | Preventing anticipated regret

Preventing anticipated regret refers to following all offered treatment chances in order to prevent decisional regret in the event of the child's death. Parents would have blamed themselves in case their decisions would have led to a worsening scenario or even death. Parents stated they could not live with that kind of remorse. As a consequence, their decision-making was characterized by following HCPs' advices. During the treatment process, the parental perspective on preventing anticipated regret was focused on survival. When it became clear that the child would die soon, the perspective changed to avoidance of further suffering.

#### 3.1.4 | Advocating getting the most out of treatment

Many parents mentioned their intention to get the most out of treatment. The goal of this intention was to become and stay convinced that the chosen treatment would be the most successful and that everything possible to help their child survive would be done. This resulted in active involvement during the transplantation process, discussing treatment options, worries, and doubts with the transplant team. Two main strategies were identified: participation and information. Some parents actively participated in daily care to control the situation as much as possible, where others searched actively for information about the best treatment. Although differently approached, a cure

**TABLE 3** Illustrative quotes

The meaning of parenthood in end-of-life decision-making			
(1) Survival-oriented decision-making			
Theme	Definition	Situation <sup>a</sup>	Illustrative quotes <sup>b</sup>
A. Developing a frame of reference	The parents' process of gaining knowledge about the specific content of HSCT in order to get some grip on the situation.	Mother of Daniel (14 years old, MD) about the transplantation as new treatment.	"You accept the information, because you do not know that subject. So, at that time I had to gain insight into the subject of stem cell. And that's a very different subject than the chemo."
B. Having confidence in and hope for a good outcome	The parents' trust in the survival and cure of their child and their uncertain positive expectation, focused on the child's survival.	Father of Emma (16 years old, MD) about decreasing trust and increasing hope during end-of-life. Father of Marten (16 years old, NMD) about the loss of his son due to unexpected complications.	"Trust is; knowing that you can jump 1.50 meter and hope is; hoping you will reach 2 meters." "The doctor did the best he could, I told everyone. The doctor is a professional."
C. Preventing anticipated regret	The parents' intention to follow all offered treatment opportunities in order to prevent decisional remorse in the event of the child's death.	Father of Daniel (14 years old, MD) 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 remorse, which will consist."
D. Advocating getting the most out of treatment	The parents' confidence in having done everything possible to live up to survival.	Father of Davitha (16 years old, NMD) about thinking along.	"You have to convince me, if you say it 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."
E. Keep going	The parents' job in moving their child and themselves forward.	Father of Davitha (16 years old, NMD) about how to endure as parent. Mother of Emma (15 years old, MD) about keeping her daughter fighting.	"The little things that you do, which you are positive about: 'yes we have reached this yet'. And so, from day to day, always step by step." "I had to make sure she kept on fighting."
F. Following the child's wishes	The parents' advocating role regarding their child's wish to take all opportunities for cure.	Mother of Luke (13 years old, MD) about following her son's wish for treatment.	"If Luke had said; 'I want to go home to die', I had taken him home, but it was his wish to get well again, so we had to stay."
(2) Struggling with doubts in hindsight			
	Definition	Situation	Illustrative quotes*
	The parents' questioning whether all survival possibilities were used.	Father of Pascal (15 years old, NMD) about questions he had to deal with. Mother of Emma (15 years old, MD) about doubts in hindsight regarding suffering.	"Sometimes I have my questions.... Then you have something like; you become angry, you get angry, you blame yourself a little bit..." "When they changed the dressings, I choose another position. I was not able to look at her wounds. It was too confronting to see her suffering, the deterioration. I protected myself against it....When we had received a trophy, it would have served a purpose."

Abbreviations: MD, malignant disease; NMD, nonmalignant disease.

<sup>a</sup>Quotes are somewhat edited for legibility and anonymity.

<sup>b</sup>All names are fictitious.

directed, advocating intention gave the parents an active role to safeguard maximum chance for survival.

### 3.1.5 | Keep going

The parent's job during the HSCT process and related decision-making, was to keep both their child and themselves going. Parents explained that by being with their child they tried to move their child forward. Being present for their child enabled parents to focus on supporting their child's coping, on advocating to provide maximum comfort, and on navigating the child's perspective toward survival. Despite parents

thought their children protected them by not showing pain or sleeplessness, their child's hope, strength, and optimism helped parents not to give up on doing everything they could to assure their child's survival. Parents kept themselves going by focusing on their own situation, being positive, hopeful, and living day by day. Consequently, parents did not allowed themselves to express their own worries and fears, because this would have disrupted themselves too much. Guidance from HCPs in making the treatment trajectory as bearable as possible and keeping the hope alive supported parents to keep going and to focus on decision-making, aiming for cure.

### 3.1.6 | Following the child's wishes

For decision-making guidance, parents referred to their child's wish to take all opportunities for cure. In following the child's wishes, parents acted according to their parental role of doing everything to preserve a future perspective for their child. Although parents appreciated age-appropriate information for their child, they reported to have the decisive role themselves. Within this role, parents advocated for specific wishes of their child, for example, sedation. The focus of the advocating role was sustaining the child toward survival. Once death was considered unavoidable, the focus shifted toward quality of life. In those cases where the children died at home, parents followed the child's wishes regarding EOL decisions. This was different for parents of children who died in the hospital, for whom the opportunity for EOL preparation lacked.

### 3.2 | Struggling with doubts in hindsight

In hindsight most parents struggled with doubts about treatment decisions made. First, they worried about decisions that could have been turning points toward recovery. Parents doubted whether a different treatment or timing, better communication between HCPs, or access to (future) improvements of medical care would have saved their child. Second, treatment decisions made with hope for cure but resulting in increased suffering were in hindsight felt as useless and one of the hardest remembrances to cope with. A mother explained that her child had suffered while striving for survival. Facing the loss of her child, it was difficult to cope with this suffering: "When we had received a trophy, it would have served a purpose." Parents explained how they were able to avoid feelings triggered by their child's suffering in order to remain able to support their child. Some parents mentioned they had grown accustomed to the deteriorating situation. For others, it was too hard to face the worsening in order to maintain hope for cure. Parents allowed themselves to face the child's suffering only after the child's death. Despite this, most parents declared they would have made the same decisions. A parent of a child with a nonmalignant disease explained that in hindsight he would have decided differently, but realizing this only can be said afterwards. To keep going after their child passed away, parents needed to convince themselves that everything possible was done and that everyone had fought hard for a treatment with the intention to cure.

## 4 | DISCUSSION

In this study, all parents were aware of their child's deterioration. Six families were confronted with a rapid worsening and two families experienced a more gradual course. "*Survival-oriented decision-making*" and "*struggling with doubts in hindsight*" are identified as themes reflecting parental EOL decision-making in pediatric HSCT. Both aspects reflect on the meaning of parenthood in EOL decision-making, serving the goal of striving for survival. Parents experienced EOL decision-making mainly as a process guided by HCPs, based on the child's condition and treatment possibilities, in which they did not make clear EOL decisions

themselves. Parental thoughts were determined by their own ambition for survival and their attitude was focused on everything necessary to achieve this. In hindsight, parents experienced doubts about treatment steps and the suffering of their child. However, most parents still felt they had been on the right track by trying to do everything to save their child's life.

The process of decision-making for HSCT, being the preferred treatment strategy of the HCPs to achieve cure and not felt as a parent driven decision, is in line with a study about decision-making for HSCT in oncology patients, suggesting to describe it as "agreeing to a plan."<sup>33</sup> In our study, parents reflect on the meaning of parenthood serving the goal of protecting, but particularly to keep their child alive. Both aspects of good parenthood in EOL decision-making were described previously.<sup>23-25,34-37</sup> Kars et al showed that parenthood was focused on being of meaning to the child and preserving the parent-child relationship during the EOL phase at home.<sup>25</sup> Hinds et al defined the meaning of being a good parent in multiple illness contexts, including ICU settings, and also described the protecting and life-saving direction.<sup>34,35,38</sup> The intensive cure directed treatment and rapidly deteriorating situation in most families can explain the mainly keeping-alive attitude in our study. From studies in pediatric oncology and pediatric HSCT, it is known that parents experience EOL decision-making as a struggling transition process in which at a certain point it became clear they had to let their child go.<sup>24,39</sup> In our study, the transition process toward EOL was in most cases very short, resulting in less preparation to let the child go. The question arises whether the best interest of the child could be overlooked by the focus on survival and becoming accustomed to the child's suffering. In hindsight parents struggled with doubts about the suffering, but also questioned themselves whether everything possible was done in light of keeping their child alive. These doubts may be related to the intensive curative treatment and the often sudden character of the loss. Despite the fact that parents experienced the threat of loss already during treatment, their hope was focused on survival, which left them less prepared for their child's death.

This study can help HCPs to support parents in exploring what good parenthood might be in EOL decision-making. Two approaches can strengthen the parental role. First, an early integration of palliative care. This approach includes identifying values, wishes, needs, worries, and care goals important for the child and family in an early stage to guide (EOL) decision-making, often referred to as advance care planning. In pediatric HSCT, this approach showed to be feasible and satisfactory<sup>40</sup> and was associated with less intensive treatment during EOL, such as no invasive ventilation, dying outside an ICU setting and more room for preparing families for EOL.<sup>41,42</sup> An important condition is the openness from HCPs toward providing curative and palliative care simultaneously. HCPs need to integrate this approach before they can guide parents toward it. Second, when it seems cure is not feasible anymore, HCPs can help parents to timely prepare to let the child go. This letting-go attitude could affect the child's well-being and parenthood positively.<sup>24,39</sup> For HCPs, this means a need to address communication about the suffering and both directions of being a good parent, keeping alive and protecting. Therefore, we suggest a "go

for the best, prepare for the worst” approach at an early stage during HSCT. HCPs need to give a realistic explanation of the difference between hope and confidence for a good outcome in deteriorating situations. Furthermore, they need to help families to focus on reduced suffering and increased quality of life.

This study provides new in-depth insight in the meaning of parenthood in EOL decision-making in pediatric HSCT, especially in rapidly worsening situations. A strength of the study was the opportunity to interview the parents within 2 years after the loss of their child. This provides a direct insight given the difficulty of studying this vulnerable population. We used several methods in accordance with the standards of qualitative research to strengthen the credibility and trustworthiness of the study, including attention to the vulnerability of the parents and a study team of experts in the field. Due to the observed respondent’s intense feelings of loss during the interviews, a narrative approach was used rather than strictly following the interview topics. The parent’s vulnerability has led to a possible selection bias since parents of 11 children refused to participate because they considered the interviews too burdensome. Of the nonparticipating families, the majority of the children had malignancies as compared to half of the children in the participating families and a higher percentage died from relapse as compared to the participating families. Nevertheless, the results showed a generic response of parents, independent from their child’s underlying disease or reason of death. Furthermore, we achieved saturation in the data analysis from a varied sample.

In conclusion, we showed that parents experienced EOL decision-making mainly as a process guided by HCPs in which they did not make clear EOL decisions themselves. Support needs to focus on guiding parents throughout the illness and EOL course with a focus on supporting good parenthood in considering and deciding on what is in the best interest of their child. Future studies may include HCPs views and can focus on implementing advance care planning in pediatric HSCT, and its effects on psychosocial well-being during and post-HSCT.

## CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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