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## Being a Parent of a Child With Cancer Throughout the End-of-Life Course

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**D**eath can be anticipated for most children with progressive cancer. Parents often are aware of their imminent loss (Kars et al., 2011) and enter an end-of-life (EOL) phase in which all curative options have been exhausted and care is focused on preparing for the anticipated death (Nuss, Hinds, & LaFond, 2005). In most western countries, EOL care increasingly comprises cancer-directed therapy to prolong life or phase I or II studies (Liben, Papadatou, & Wolfe, 2008; Ulrich, Grady, & Wendler, 2004). In contrast, care for the dying is referred to as terminal care.

Because of the preferences of the child, parents, and medical staff, the EOL phase increasingly occurs at home (Davies et al., 1998; Vickers & Carlisle, 2000). In the Netherlands, 63% of children who die from cancer pass away at home (Pousset et al., 2010). Whether nurses are involved in palliative care provided at home depends on the individual situation.

In the authors' experience within the Dutch care system, palliative care for children who reside at home is provided primarily by the regular healthcare institutions that are responsible for home care. As a consequence, all children and their parents transfer from the multidisciplinary team of the pediatric oncology ward (with nurse specialists as their primary caregivers) to the general practitioner. Once at home, parents can call on homecare nurses or nurses from technical homecare services. In practice, care arrangements at the EOL vary from no nursing care at all to the simultaneous involvement of nurses from all sources: transmurial care by specialist nurses from the oncology ward, nurses that provide technical support, and regular homecare nurses.

The role of parents as decision makers and care providers at home is extensive (Martinson, 1996; Molenkamp, Abu-Saad, & Hamers, 2002). Previous research has focused on their problems and needs. Parents

**Purpose/Objectives:** To elucidate parents' experiences when caring at home for their child with incurable cancer and to show how parents give meaning to their experiences throughout the end-of-life (EOL) phase.

**Research Approach:** Interpretative qualitative study.

**Setting:** Five academic pediatric oncology centers.

**Participants:** 42 parents of 22 children with incurable cancer, cared for at home.

**Methodologic Approach:** An inductive thematic analysis of single and repeated open interviews using phenomenological techniques.

**Findings:** Four EOL stages were identified: becoming aware of the inevitable death, making the child's life enjoyable, managing the change for the worse, and being with the dying child. The essence of parenting during those stages was captured by the notion of being meaningful to the child and preserving the parent-child relationship. Parents were able to cope better with the EOL phase and to sustain their parenting role because of their ability to postpone grief, enjoy their child's expressions of happiness, see the child's identity despite physical impairment, and enjoy the rewards they experienced from being there for their child.

**Conclusions:** Parenting while losing a child brings parents to the point of an existential crisis. The child's deterioration forces parents to redefine their traditional parenting role. Although the way parents give meaning to their caregiving experience helps them cope, it can decrease their ability to acknowledge the child's needs.

**Interpretation:** Nurses can help parents to face the reality of their child's situation and redefine their role accordingly, such as by providing information and alternative perceptions that fit the child's changed needs while preserving the parent-child relationship. Attention to signals indicating stress disorders is needed.

report EOL decisions to be the most difficult treatment-related choices they face during their child's cancer experience (Bluebond-Langner, Belasco, Goldman, & Belasco, 2007; Hinds et al., 1997). However, parents

stress their need to have their views taken into account when decisions are made (Carnevale, 2004; Contro, Larson, Scofield, Sourkes, & Cohen, 2002). In addition, parents need honest information and open communication to provide adequate care (Freeman, O'Dell, & Meola, 2000; Monterosso & Kristjanson, 2008). Finally, parents find having access to care providers they can trust and with whom they feel a bond to be helpful (James & Johnson, 1997). Parents felt positive as a result of nursing their child themselves (Collins, Stevens, & Cousens, 1998; Saiki-Craighill, 2002). However, several problems have been reported, including inadequate symptom management (Theunissen et al., 2007; Wolfe et al., 2008; Wolfe, Grier, et al., 2000), the child's distress (Hechler et al., 2008), and the parents' own fears of the moment of death (Collins et al., 1998).

Most research conducted from the parents' perspective is retrospective. Studies have indicated that the perspective of bereaved parents often changes. In hindsight, a substantial number of parents evaluate parenting themes such as discussing death with their child or continuing cancer-directed treatment during EOL differently or even regret their approach (Hechler et al., 2008; Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004; Mack et al., 2008). The few prospective EOL studies revealed that parenting at EOL is not guided solely by objective medical arguments or by clearly defined child-centered goals such as improving the child's quality of life or relieving suffering. Kars, Grypdonck, Beishuizen, Meijer-van den Bergh, and van Delden (2010) described that parents' abilities to let their child go is influenced by factors concerning their relationship with their child or how they give meaning to their role as parents. Also, parents' difficulties with abandoning a curative approach or the late shift to symptom-directed therapy is influenced by the meaning parents attribute to gaining more time with their child as a result of life-prolonging curative or palliative cancer-directed treatment (Bluebond-Langner et al., 2007; Hechler et al., 2008; Wolfe, Klar, et al., 2000). Parenting at the EOL increasingly is believed to be influenced by existential issues and meaning giving (Bluebond-Langner et al., 2007; Kars et al., 2010; Monterosso & Kristjanson, 2008). Parents may fare better in this experience by finding meaning in what they are going through (Liben et al., 2008). Therefore, a better understanding of how parents give meaning in these circumstances is important to improving pediatric EOL care. As a result, the authors conducted the current study to increase the understanding of the process that parents go through when caring at home for their child with cancer and to study how parents give meaning to their experiences in the EOL phase.

## Methods

The authors conducted an interpretative qualitative study using an inductive thematic analysis (Kvale,

1996). Analytical techniques that are common in phenomenological research were used to gain insight into the parents' main experiences and meaning giving during EOL (Giorgi, 1997). The aim was to improve the understanding of the EOL experience from the parents' perspective (Creswell, 2003).

## Sample

Parents were recruited from five university pediatric oncology centers, which together cover 80% of all Dutch pediatric patients with cancer. Parents of children aged 16 years or younger with all types of cancer were considered eligible after the oncologist had informed them that the remaining treatment options could not provide cure. Parents who spoke Dutch and cared for their child at home were enrolled, irrespective of whether their child was receiving cancer-directed (including phase I or II study medication) or symptom-directed therapy. The oncologist asked permission for the researcher to contact the parents. Data indicated that parents were not asked to participate when the oncologist estimated the child would die within one week or when communication was complex because of relational or cultural problems. In three cases, parents refused to participate either because they found the study to be too great a burden or because the study's palliative undertone did not fit their interpretation of the situation. Forty-two parents (22 mothers and 20 fathers) of 22 children (aged six months to 16 years) participated (see Table 1).

## Data Collection

Individual in-depth open interviews were held at the patients' homes. In seven cases, second interviews with one or both parents took place, and in one case, a third. Interviews were conducted from August 2005 to November 2007, lasted one to two hours, and occurred from two days to one year before the child's death. Ten parents could be interviewed only after their child had died. In five cases, the parents preferred to give attention to their child first. Of those, three children died within one week. In one case, parents who learned about the study spontaneously volunteered to participate after their child had died. This resulted in 55 interviews at different moments during or soon after the EOL phase. A topic list based on the literature, expert knowledge, and previous studies of the research group was used at the end of each interview to ensure that all areas were discussed. Topics included parental care and goals, parent-child relationships, parting and loss, coping, family life, and professional care. Interviews were tape-recorded and transcribed verbatim. The study was approved by the medical ethics committee of the University Medical Centre Utrecht. Written informed consent was obtained from all participating parents.

**Table 1. Participant Characteristics**

Characteristic	n
<b>Gender</b>	
Male	20
Female	22
<b>Age (years)</b>	
29 or younger	2
30–39	27
40 or older	13
<b>Marital status</b>	
Married or cohabiting	39
Divorced or not cohabiting	3
<b>Education</b>	
Primary, lower secondary general, or lower vocational	13
Higher secondary general or intermediate vocational	17
Higher vocational or university	12
<b>Child's age at first interview (years) (N = 22)</b>	
Less than 1	2
1–4	9
5–11	6
12–15	4
16	1
<b>Child's type of cancer (N = 22)</b>	
Leukemia or lymphoma	9
Central nervous system tumor	5
Neuroblastoma	2
Renal tumor	1
Hepatic tumor	2
Bone tumor or soft tissue sarcomas	3
<b>Time from first interview until child's death (N = 32)</b>	
1–7 days	4
1–2 weeks	4
3–4 weeks	4
1–3 months	10
4–6 months	6
7–9 months	2
10–12 months	2
<b>Time from child's death until first interview (weeks) (N = 10)</b>	
4	1
5	1
6	4
7	2
10	2

N = 42 unless otherwise noted

## Data Analysis

Data analysis conducted according to the Giorgi (1997, 2005) method was aimed at understanding meaning by identifying themes and patterns. The research team had four members who read transcripts to obtain a sense of the narrative as a whole. Secondary units of meaning were then identified. The meaning of the separate parts was determined by the meaning of the interview as a whole (Kvale, 1996). The team worked toward a consensus in interpretation—comparing meaning units within and between cases. The first author checked themes and patterns identified against existing data and new material. This iterative process constituted researcher triangulation and increased both the depth and reliability of the analysis.

The software program NVivo 7 was used to increase insight into the content, meaning, and recurrence of themes. The transparency of the analytical process and verifiability of the research was enhanced by using memos to explain provisional interpretations and conclusions. During the analysis, the authors found that the EOL phase consisted of four stages from the parents' perspectives. The code tree was redesigned accordingly. Subsequently, common themes for each stage were identified. Data collection was finished when saturation was reached. Peer review was undertaken by discussing the initial results with Dutch pediatric oncology experts.

## Findings

During the interviews, parents explained their position and perspective by reflecting on previous experiences and by referring to what could be expected. Four stages were identified in the EOL phase from the parents' perspective: becoming aware of the inevitable death, making the child's life enjoyable, managing the change for the worse, and being with the dying child.

### Becoming Aware of the Inevitable Death

**Inevitability of death:** The first stage was marked by the oncologist's announcement that the child could not be cured (see Figure 1). Hearing this made parents feel as though they could no longer ignore the inevitability of death. They were on their way to losing their child: "It was suddenly clear that he wouldn't get better and that we would have to prepare ourselves for his death. That really broke our hearts." Parents were aware the perspective had changed, irrespective of whether they were able to manage this switch in thinking: "Then you know you've crossed the border—you're on the wrong side of the line."

Once the inevitable truth of the approaching death finally had been revealed, parents felt as if an emotional wound had at last been opened, exposing a raw nerve. They could not avoid anticipating what was to come. Parents had vivid images of their child's deterioration and suffering. They were occupied with concrete funeral arrangements such as what clothes to wear or whether the church would be large enough to accommodate all attendees. Whether or not parents had anticipated the bad news, the reality of imminent death in this stage was experienced as signifying the collapse of their parenthood. For example, parents with only one child referred to not being parents anymore once their child had died. One mother anticipated what to say when people ask her about her children: "You really realize she will soon be lost. Do I then say I have one child or two?" Parents spoke of future prospects now lost, such as their child's first day at school or first love. Their child was meant to survive them, possibly have children

Roy was a seven-year-old boy with renal tumor. His mother was interviewed two weeks after the doctor announced that treatment had failed (eight weeks before Roy's death).

### **Inevitability of Death**

It was last year that Roy had his very last treatment. Of course we knew—I mean that it would be the very last time—so that after that there would be no opportunity whatsoever to treat Roy, even if it came back.

Doctor Smit said it straight away: "This is not good news. I'm afraid the lymph nodes are enlarged and that points to a return of . . . the tumor." We thought, OK, it's been said and we're going to lose Roy, but then they had also said that they were going to see if there were any other possibilities for specialist treatment. I mean, we knew it wouldn't cure him, but it did give us some hope for the time being, at least for that weekend.

### **Open Awareness and Discussion of Reality**

Because those are just your first questions, what now? What's going to happen? How long has he got left? Of course, they can't answer that at that point. So, yeah, you know that so you ask them what's going to happen at the end.

### **Taking Responsibility While Lacking a Model**

Doctor Smit said: "I want to see you in a week's time." But she said we didn't have to come if it wasn't convenient when the time came. That week of accepting and trying to believe that terrible news was true—that was not easy, to put it mildly. . . . And, you know, the most difficult moment of all is when you get to the point where the oncologist says that it's all up to us now. . . . We have to decide what the next step is going to be.

### **Having Done Everything to Save Their Child**

I can't just stand by and watch. I just can't do that. So I went to a homeopath and I went to . . . one of those alternative medical people . . . paranormal something or other, doesn't matter what it's called. As long as someone tells me that they can give Roy energy—just do it. And I'm still hoping . . . at the back of my mind, there is still a possibility. . . . Who knows, maybe it's not such a serious case as they think. After all, they haven't even taken a biopsy, they don't do that.

Note. Quotes were edited for readability. Names are fictitious.

### **Being Strong to Be There**

You cry. You are completely out of it. You know that it's over. But you just don't want to believe it. So, I think you're in a kind of vacuum, walking around in a daze. . . . You're just completely stunned. And then you just go home. And Roy started to choose the nicest CDs in the car and just sat in the back singing along with them. And of course you want to put on a brave face for Roy. And it sounds mad, I know, but you feel really strong at that point.

### **Positioning Bad News**

And Doctor Smit said it really nicely to Roy. . . . She didn't actually say—we can or we can't do anything, but that it may be possible to do something. And straight away we both said: Roy must not know what the consequences will be. Certainly not in the near future. Because we don't want to take his future away from him, even if it's only six months. **We don't want his happiness, his childhood taken away from him.**

Of course, we know Roy's not stupid and he sees our sadness and how sad his grandma and grandpa are. . . . But we explain that to him as follows: "Roy, of course we're sad, for heaven's sake, after all you've been through—we're fed up with that horrible tumor, those nasty cancer cells have come back again." He's still taking medication to protect him. I am so scared that if we stop giving him the medication that Roy . . . well, you know, at that moment will realize very quickly and that he'll ask me, "Mum, why aren't we doing anything anymore?"

Because . . . look, I'll tell you that it is just so incredibly difficult for us to take that path. **You're sort of in two minds about everything.** . . . On the one hand, you don't want to tell him, you don't want him to realize. On the other hand, however, sometimes you would like him to know, because then you could ask him, "What are all the things you still want to do?"

## **Figure 1. Illustrative Quotes of Stage 1: Becoming Aware of the Inevitable Death**

and, as such, offer parents the opportunity to become grandparents. Therefore, parents were not only losing their child, but also a vital part of themselves.

**Open awareness and discussion of reality:** Once the inevitability of death had been disclosed, parents discussed it relatively openly. This often was manifest in their active searching for concrete details: Is there anything we can still do? How much time is left? What will be the actual cause of death? In retrospect, parents who were confronted with decisions that incorporated an acceptance of death, such as a no-resuscitation order, were amazed by their ability to discuss those themes. Openness toward the outside world also was seen. Parents expressed that cure had failed and they had to face the reality of death.

**Taking responsibility while lacking a model:** A striking similarity was found among parents' feelings that from the moment they learned their child's cancer was incurable, they were given back the responsibility for the further life of their child. Beforehand, when a

cure was still realistic, parents had felt directed by their child's oncologist and treatment protocols. Now that the child could not be cured, medical staff invited parents to decide the remaining treatment options themselves. Many parents expressed the feeling that once things became difficult and unpredictable, the oncologist stopped providing guidance and counseling concerning what was best for their child, and decisions regarding the rest of their child's life were left to the parents. Despite their disappointment about being forced to rely on their own resources, parents appreciated recognition of the importance of their perspective. Parents perceived this as the moment when they had to retake responsibility. Sometimes that was reinforced by a need to distance themselves from medical staff and prioritize their own wishes: "They [medical staff] were in charge for years without success, now I want to make my own decisions." Hearing that their child could not be saved almost seemed to strengthen parents' actorship, meaning they regained initiative in directing and regulating the

situation. At the same time, parents felt a deep lack of a model: "You've never been in this situation before." They felt a need to find new anchor points.

**Having done everything to save their child:** The most pressing concern was to explore remaining medical options. Participants related how they weighed the medical facts and the pros and cons of further treatment options while, in the end, making decisions based on their relationship with the child as parents. The pros and cons were experienced as incomparable quantities and, as parents, they had to account for their child's chances and EOL course. Parents expressed that they would never forgive themselves if they had not tried everything to save their child. Some parents experienced treatment decisions as a choice between doing "something" and doing "nothing." For most, doing "nothing" was equivalent to letting their child die. They considered "doing something" as a sign—particularly to their child—of not giving up. Doing something also provided the possibility of prolonging their child's life and, therefore, prolonging parents' time with their child. Some parents brought the dilemma to another level by speaking about the tensions between their own wish to prolong life and their responsibility to face reality and safeguard their child's well-being during the EOL phase. Irrespective of whether parents decided to focus on cancer-directed treatment to prolong life or shift entirely toward symptom treatment, making a decision helped them to regain control. Having set a new goal seemed to serve as an anchor point.

**Being strong to be there:** Despite needing to admit to their emotions to alleviate their own suffering, parents emphasized that they felt responsible for providing stability for their child. To fulfill this task, parents forced themselves to keep going: "I can't collapse now because I have to be there for him." Some parents felt an almost supernatural strength to do this. Most parents expressed the uniqueness of their parenting role: Only they felt the unconditional love that enabled them to stay with their child. Parents experienced tension between their wish to "be there" and the need to manage the disruption of their own lives. At this stage, activities of daily life offered them the necessary stable baseline: "You have to eat; your other children have to go to school." To parents' surprise, following the routine of daily life gave them the strength to continue, allowing them to address the more challenging parenting tasks now required.

**Positioning bad news while protecting their child from breaking down:** Most children were informed that they could not be cured. When parents spoke about the moment their child was informed, they all referred to having felt how hard the experience was for the child. Some parents described their child's efforts to stay calm. Others had witnessed a moment of complete breakdown. Most parents indicated they

rationally understood the necessity of informing the child, but doing so had been emotionally disruptive for them as a parent. Witnessing their child's response to the bad news made parents feel powerless, reducing their role to providing comfort while being unable to change the situation.

Parents felt encouraged by medical staff to be open and honest with their child, but in a way that considered the child's stage of development and coping. Parents took this challenge seriously and reported attempts to let their child understand his or her own situation and help the child to position the bad news in his or her life. Doing so demanded much from their parenting skills. To prevent their child from breaking down, parents often shifted to a more careful or avoidant approach. One mother said she initially had tried to talk about death with her four-year-old son. She had created a positive image by saying death meant that he would go to a star with a big playground. She had felt uneasy because she had not told him the most important thing: "He had to go alone." At first, he had asked her every day about when to leave. Later, she felt relieved that he no longer asked and concluded that talking about death was senseless because her child did not yet understand the concept. In addition, she was not able to provide comfort for the aspect of death she considered to be most threatening for her son: going alone. Some parents continued the initial openness and succeeded in creating togetherness in facing the EOL and death. In talking about death, these parents offered their child a reassuring picture of the afterlife that they believed the child would find helpful. One mother, for instance, constructed a life after death in which her daughter, Dianne, could still see her family and the family could still feel Dianne's presence. Dianne's parents also spoke about her fears concerning the dying process and the measures that could be taken to resolve them.

**Facilitating the continuation of life:** Parents paid a lot of attention to opportunities for their child to resume his or her usual life. They considered continuing life without obstacles important to the child's happiness. Family, friends, and school were informed and advised on how to behave so the child would appreciate participation. A kind of balance developed, which appeared to be the start of the second stage.

### **Making the Child's Life Enjoyable**

**Not experiencing the child as very ill:** The second stage was characterized by the perception of the child's physical condition as fragile but relatively stable and predictable (see Figure 2). Treatment, symptoms, and complications were manageable in such a way that the child could participate in normal life to a degree. Although the malignant process was life threatening, parents did not experience their child as very ill. They felt relatively certain tomorrow would be the same as today.

Dianne was a 10-year-old girl with acute myelogenous leukemia. Her father and mother were interviewed 12 weeks before and two weeks after her death.

### **Not Experiencing the Child as Very Ill**

**Father:** And she keeps saying to herself gosh, I don't understand it at all. I don't feel anything, I don't notice anything. You can see that her blood levels aren't good. But when you look at her, well, you can't see anything. Yes, okay, she does get bruises very easily and sometimes a nosebleed. But, okay, if you didn't know any better, you would just think there was nothing wrong with her.

### **Being There and Enjoying Life**

**Mother:** She has two friends and is very close to one of them. She's here almost all the time, day and night, and that is very important to her. Normally, you would just say sorry, not today. But now I think, yeah, of course you can be here today as well if you want. Try and make something of every single day. That isn't really difficult. You do it for her, and it gives you a good feeling.

**Mother:** That she always knows that I am there for her . . . that however difficult it is to let her go, that you know how fragile she is, for example, at the moment she has really low thrombos but I still let her go out if she wants. **I do make agreements with her. She's got a mobile phone, and if anything happens, she has to phone me. So that I don't get too over worried . . . but that she does know I am there.**

### **Cherishing the Child's Identity and Wholeness**

**Father:** Now you just have to try and enjoy the moments together with her. **Just enjoy how she is, her spontaneous nature. And annoying me and annoying her brother, I just love that. She used to do that before, but now she does it much more often.**

**Father:** When she starts dancing and jumping up and down on the bed, then I think yes, okay, you're really, really sick. How is it possible that you are doing that? There are just so many moments. I suppose that will happen as well, soon, you know that you start to remember how she was and how she lived. We have made photos. We went to a professional studio and we had a whole portfolio of photos made of her. Now, that is really fantastic.

### **Just Going On**

**Father:** Yes, see how she is. She will tell us . . . we'll just follow. I really have a deep admiration for her. What a character! Yes, you can learn from that. If you're feeling down yourself, well then, you just think of Dianne, how she does it all. Then you just have to think about stopping moaning yourself.

### **Keeping the Child Going**

**Father:** Yes, she does have a kind of picture of what can happen but she is a little bit . . . well, I have a feeling that she is really putting some things off . . . as if she doesn't really want to accept it totally yet. She hasn't been to school for a long time, and now she really likes going to school. And it provides a bit of distraction for her as well. And she does tend to push some things away, things going on now. She has been talking about her education . . . she isn't really there yet . . . she doesn't know that she should be talking about weeks . . . you know, she talks in terms of months. . . . Look, if it gets worse soon and she can't go to school . . . there might come a point . . . when we have to talk about the funeral. But not yet. It's too early for that.

### **Directing and Controlling the Outside World**

**Mother:** What I think is really important is that she can go to school. So it needs to be well organized there as well. But they know at her school that she wants to go to school, and that if anything happens, they can call us straight away.

*Note.* Quotes were edited for readability. Names are fictitious.

## **Figure 2. Illustrative Quotes of Stage 2: Making the Child's Life Enjoyable**

**Being there and enjoying life:** Thinking that their child's life would end in misery was unbearable to parents. Parents wanted to be present and felt they had no alternative other than to help their child to enjoy his or her life. That surpassed the regular parental aim of well-being. Enjoying life involves experiencing a fulfillment that is worth living for. Enjoyment was reached by the continuation of positively evaluated aspects of normal life (e.g., cooking together, playing with friends, special activities that increased the child's happiness). In turn, parents took pleasure in seeing their child enjoy life. This orientation to the child's joy and the parents' satisfaction when they succeeded was so great that the reasons why these efforts were made often disappeared into the background. When asked, parents indicated they knew what was happening but presently were able to live in a positive mood. As long as their child expressed happiness and that life was rewarding, parents tended to forget about the threat of loss and death.

**Cherishing the child's identity and wholeness:** Any active participation from the child made the parents especially happy. They felt touched by behavior that reflected their child's identity: "This is how he really is." Facilitating situations in which the child's identity flourished became rewarding. For instance, one father made arrangements so his son could rejoin in his sports team, and he had enjoyed seeing his son play like he always did, despite his fatigue. Focusing on the child's identity enabled parents to cherish the wholeness of their child's being, despite physical deterioration. Parents realized the experiences would become beloved memories once the child had passed away. However, that realization also made parents feel how immense the loss would be. Daily life was photographed, but special attention was paid to capturing the child's identity and wholeness. Some parents created images of physical or family wholeness. They arranged a professional photo shoot, removed the feeding tube in advance, and had the child photographed from his or her less-affected side with and without family.

**Just going on:** The disruption of stage 1 was replaced by a feeling of control related to the continuation of a relatively stable life. The strong focus on creating a good time directed the parents' activities. Parents emphasized feeling empowered by how their child coped with the situation. They were proud of how their child managed to continue life and seemed to enjoy it. The child's coping gave parents the energy to keep going. Parents restricted their perspective to the present and did not think about future stages. That happened spontaneously; life took precedence over loss.

Although parents enjoyed life, many stories revealed that the situation was fragile. Parents sometimes felt overwhelmed. Forewarnings of loss were a strong threat to their emotional stability. A sudden manifestation of a symptom made parents confront imminent

loss. The intrusion of feelings of loss triggered by situations in daily life was another threat. When parents saw their child having difficulty in climbing up the slide, parents realized it could be the last time they would go to the playground together. Such thoughts triggered emotions that could cause a temporary loss of control. Most parents tried to control their emotions by discussing sensitive themes rationally or by postponing grief to a later stage or after the child's death. However, the course chosen in stage 1 gave parents a firm footing. Decisions were mostly in line with earlier ones and were aimed at prolonging this stage and the child's well-being.

**Keeping the child going:** Parents expressed a strong need to keep their child going. That was not only considered a precondition to participate in and enjoy life, but also was necessary to prevent premature loss. Parents hypothesized that when their child gave up mentally, a downward spiral would be initiated that might hasten death. As a result, parents tried not to disrupt their child's psychological stability. In addition, physical deterioration was considered a threat to the child's ability to keep going. Therefore, parents strengthened and protected the child's physical condition by doing activities such as feeding him or her high-quality food, encouraging physical activity, or using alternative medicine to "keep him the way he is now."

Keeping the child going sometimes was a complicated task because parents' success depended on their child's ability to cope with the situation. One strategy was to preserve a future perspective or to create one if none existed. The perspective had to become real by being enacted for the child to be convinced. For example, parents enrolled their child in a new course at school. Parents sometimes wrestled with what they called the "double track": organizing a future perspective that might never come. For some parents, keeping the child going by enacting a future perspective also served as a way to keep their own future perspective alive. The parents of children who did not succeed in "keeping going" felt very powerless, wondering how to give meaning to the time left when the child lacked the power to participate.

Parents of children aged eight years or older described how their child avoided the EOL topic and talked about a much longer future than could reasonably be expected. Parents did not correct their child, but felt slightly uneasy. One mother said: "You have to ask yourself if he has understood everything he was told." Those thoughts appealed to their parental responsibility. Parents intended to guide their child in coping with the EOL and death; however, parents felt that discussing his or her real perspectives and death was beyond the child's capacity to cope and defied the parents' wish to keep their child going by enjoying life. In addition, some parents and older children had agreed to focus on the positive aspects of life. Parents feared that highlighting

the EOL might lead to a loss of the child's trust and affection, drawing them apart. Parents felt that initiating the discussion about EOL was like breaking the bond between their child and themselves; therefore, having EOL discussions was not considered a fruitful strategy during this stage.

**Directing and controlling the outside world:** Participation in social situations outside family life often made parents feel confronted by the dynamics of the outside world regarding EOL. Parents felt very frustrated when other people seemed to threaten their stability or their child's by showing grief or discussing EOL. A lot of energy was required to guide others, including some healthcare professionals, toward the same positive approach that parents had set to keep their child going. If parents did not succeed in guiding others not to cross the boundaries, they distanced themselves from those people.

### Managing the Change for the Worse

The third stage was marked by obvious decline in the child's condition, most strongly felt in the child's lack of energy (see Figure 3). Parents noticed that their child could no longer participate in daily life: "We hardly do anything anymore. We used to go everywhere with him, but now he's just too tired. He just sits on the sofa the whole day." The physical deterioration often was accompanied by the accumulation of disease-related symptoms marking the downward course of the disease.

**Discovering illness has taken over life:** In hindsight, parents often concluded they had adapted to their child's gradual deterioration or failed to notice it. They had been focused on arranging life positively around the symptoms. However, they could identify a moment when they realized their child was only just present or they witnessed an unexpected rapid deterioration. The child sometimes showed signs of giving up; at those moments, parents' perspectives changed. Parents had arrived in the stage they had feared; they were actually losing their child. Parents interviewed in stage 1 or 2 indicated that they hoped things would progress quickly when their child began to deteriorate. Although a few parents now showed some withdrawal and signs of waiting for death to come, the vast majority had adapted to their child's condition and focused on comfort and well-being. Their perspective changed to one of settling: "He is still with us."

**Being there during suffering:** When parents noticed how much their child was suffering, the need to "be there" was conceived as the most important manifestation of parenting. The only answer to the child's vulnerability and dependency was for parents to transform their boundless love into unconditionally caring for their child and being present. In being there, parents expressed that they did not leave the child alone in his or

Michael was a 14-year-old boy with acute myelogenous leukemia. His father and mother were interviewed one week before his death.

### Discovering Illness Has Taken Over Life

**Father:** [While Michael was taking the study medication, he went to the United States for a holiday before his death.] Every morning, he was talking about what we were going to do that day. And after an hour or two . . . it was over; his energy was all gone again. And then he just laid on the bed. And then it became clear that it would never be fine again and we realized that very many things were not going to be possible. He came back with pain in his bones. He was really in a lot of pain. In the United States, we didn't dare go to the hospital because we didn't want to leave him behind in the hospital, because then he wouldn't have come home again.

**Father:** As long as he stays like he is now, that he keeps calm, and that he goes through everything consciously . . . earlier this week we had visitors . . . sitting there, you know, making a lot of fun . . . and then I think to myself. That's really good for him, making jokes. And he joins in with all that, he can still laugh at so many things. And yes, at that point, I say to myself. It's fine. Hold on in there, wait. It can take its time.

### Being There During Suffering

**Father:** Recently, I've taken over a lot of his care. I want to be his main support, make sure that he keeps some trust in things, and I want to do everything I can do for him. And that's what I'm doing. If he wants something, then I help him. To make him as comfortable as possible in every sense of the word. This week, for instance, he wanted to let off some fireworks. So that's what we did. Then, with all his pain, he had to get into the wheelchair and he said to me: "You do that, because you know exactly how to hold me." So his trust in me is much, much more than it was. He's not like that with other people. That's what keeps me going. It is really the last thing you can do for him.

### Keeping Going

**Father:** It's like I just said, we just live from day to day, and there will come a day . . . at the moment we're living in a kind of tunnel. A dark tunnel, that's just how I experience it, but at a certain point in time . . . there will be a wall coming unexpectedly toward us, and it will crush us. That's how I see the future. That dark tunnel . . . the walls are keeping us upright . . . but there will come a time when that just stops. As long as you're caring for him, you can just keep going, and where the energy comes from . . . ? Don't ask me, but when you stop with the care tasks . . . that's when you're going to collapse.

### Sharing the Process of Death and Dying

**Father:** We have tried to talk about it, but he didn't want anything to do with it. He's not stupid. He's quite clever, and he knows why he's there. He knows he's going to die. We know that just from the answers he gives us. He gets angry if his brother and sister argue together, then he says clearly why they shouldn't argue. He says, I may only have five days left. He's just . . . scared. **And that's allowed.** It would be crazy if he wasn't. He's scared of death. He's just kind of letting it all happen, the visitors as well; he just takes it in his stride. But okay, we have said you just have to let everybody come and say goodbye who wants to.

### Preparing for the Funeral

**Mother:** [Michael's parents had made funeral preparations and chosen a mourning card the day they were interviewed.] I want something with a setting sun, with blue in it. Because he is always the sunshine in the house, and he loves blue. But that wasn't in the choices . . . and I think that's awful. [She cries.]

Note. Quotes were edited for readability. Names are fictitious.

## Figure 3. Illustrative Quotes of State 3: Managing the Change for the Worse

her suffering. Even parents who needed some distance or showed some avoidance to relieve the stress of their suffering from the threat of loss expressed a need to be there and to receive the rewarding response from their child. Although parents were unable to prevent what was happening, they felt they were more capable than anyone to offer their child the desired comfort, familiarity, and safety. This was a task for them alone, defining their unique position as parents.

Caring had a significant meaning: "There was nothing I would rather do than care for him." By caring, parents could preserve physical contact when the child did not want to be touched. Most parents slept side by side with their child. In this respect, "being there" provided a continuous presence desired by both child and parents.

Parents tried to continue normal daily life lightheartedly. The child's participation was limited, so parents compensated by shaping their child's life; the child lived through his or her parents. This aspect of being there also helped parents to manage their child's deterioration. Shaping their child's life meant parents could focus on positive reactions that often resulted in a glimpse of the child's identity. Being present was achieved through absolute love; however, it also was exhausting.

**Keeping going:** During this stage, parents kept going by being active and suppressing their emotions. Their days were filled with providing comfort and facilitating the child's well-being, which kept parents busy and helped them not to break down. Conversations were kept on the level of caring and comfort and were steered away from emotions triggered by thoughts of loss.

However, the limits of parents' abilities to be present became evident. The progressive course of the illness inevitably meant coping with the child's suffering and the actual loss. Some parents felt overwhelmed and exhausted by the process because they were no longer able to control their situation. Others felt as if they were outsiders or their child was not their own: "Sometimes you don't see him as your own child, but as a child of someone else. Like he's a nice child, but he belongs to the neighbors. . . . It feels like watching a film about him." Some parents described moments when they switched from parenting into a coaching role to safeguard their caring ability. Most families withdrew from the outside world except for a few close contacts.

**Sharing the process of death and dying:** Many parents experienced moments where their child withdrew from them by turning inward or not wanting to be touched. Parents explained that their child had enough problems of his or her own. Although parents understood their child's reaction, they felt powerless. Parents realized that, in the end, their child inevitably would have to go through the process of deterioration and dying alone. Their usual parenting role of accompanying the child in unknown and threatening situations failed, meaning the bond between parent and child was broken by death.



During this stage in particular, parents spoke about caring, comforting, and being there as a way to express and continue their bond with the child. Parents of children aged eight years or older strove to comfort their child on the question of dying alone. Some parents constructed an image of the continuation of the parent-child bond after death. Others created a substitute bond with a deceased relative. Being able to comfort the child by saying they will hand him or her over to a beloved person in the afterlife gave parents something to hold onto. Two confirmed Christian couples were consoled when their children felt safe going to Jesus. The importance of continuing bonds became visible in the confession of one mother. For her, holding hands was not enough: "In fact, I want to go with him after death."

Once parents and their child arrived at stage 3, discussion of death and facing the dying process inevitably came into the child's reality. Parents often thought discussing those themes was more threatening in stage 3 than in stage 1. When sincere feelings and comforting ideas about death and dying were shared during stage 1, parents found discussing those themes to be easier in stage 3.

**Preparing for the funeral:** Despite having a need to postpone the reality of loss, many parents made practical preparations for the funeral. Parents hoped to maintain a bond with their child, for instance, by placing the grave nearby. Others consciously decided on a cremation so they could take their child's remains with them if they moved. Parents carefully designed ways to highlight their child's personality during the ceremony, showing his or her identity to others. Many parents expressed a need to discuss funeral arrangements with their child to ensure his or her wishes would be fulfilled. In summary, preparations were more focused on the child's figurative presence than on the parents' loss.

## Being With the Dying Child

In contrast with the previous stages, stage 4 is based on retrospective stories (see Figure 4). Apart from losing communication, drawing a typical picture of the terminal stage was impossible. For many parents, the process of dying started abruptly, even though death had been expected.

**Losing reciprocity:** During the dying phase, parents lost communication, either naturally or because of the child's medication. For parents, that meant losing reciprocity in the parent-child relationship and, as such, losing part of their parenthood. Parents of children who received sedation often did not anticipate this loss of communication and felt overwhelmed by it. This was particularly harsh when parents' last contact had occurred when their child was crying or screaming.

**Being there and letting the child go:** During this stage, almost all parents felt ready to let their child go, supporting the child's passage to death. No farewells were communicated. Some parents had encouraged their child

Jonathan was a two-year-old boy with acute myelogenous leukemia. Jonathan's condition deteriorated very quickly. His mother was interviewed seven weeks after his death.

### Losing Reciprocity

Then he was given Dormicum® [midazolam]. That was a really horrible moment, because [the general practitioner on call] just gave the injection in his leg and I thought he was really nonchalant about it. And Jonathan started to cry because it hurt. And shortly after that he just lost consciousness, so we didn't have any time at all to comfort him. I found that . . . it felt like sort of as if you deserted him . . . and I still think that that was a really, really difficult moment. [She cries.] . . . Yes . . . it was only about one and a half minutes, but still.

### Being There and Letting the Child Go

He really was such a mummy's child. Yes . . . even on that Wednesday, when he really wasn't at all well, he didn't want anyone with him, just mum had to stay with him. He was lying there with his mouth open, it was horrible to see that. . . . And yes, just sitting there, next to him. Must have been about one o'clock when I lay down next to him, and held his hand. . . . And yes, I suppose kind of fell asleep, I think, well, of course I hadn't slept the whole night. And then [her husband] came up because there was someone on the telephone. And yes, we both saw that he was hardly breathing any more. So yes, we put the phone down quickly and grabbed Jonathan's hands, he took one more little breath, and then that was it.

### Fulfilling Wishes and Promises

[When the general practitioner did not react sufficiently to Jonathan's pain and restlessness, the mother called the oncologist on her own.] The oncologist then phoned the general practitioner and he came here immediately. And yeah, he really got a shock when he saw him lying there. But . . . he said, "He's in a coma, because the Dormicum only works for three hours." That was, of course, well, now it must be three and a half to four hours ago. He said, "Otherwise he would have woken up by now. So, then you know he's in a coma." He said, "If I give him any more Dormicum it will be fatal for him." But . . . he wasn't going to get better any more, so I just thought, okay, well, give it to him." But well, he just didn't want to. He said, "His breathing will stop on its own through the course of the day."

### Unbearable Aspects of the Dying Phase

I found . . . it was just absolutely awful, because he was breathing in a really scary way, you didn't even want to sit next to him . . . but yes, you had to. . . . The whole of his little body . . . it was completely gray, he was totally cold, the only thing that was still working was his heart, and he was breathing. I just thought he was suffering. And then it's okay for the general practitioner to say that he doesn't notice that, but I'm not sure. Now, he was from five o'clock in the morning until quarter past two in the afternoon, he was just, well, I can only describe it as if the motor had to break down . . . the heart had to stop working. And he had to work really hard to make that happen.

Note. Quotes were edited for readability. Names are fictitious.

## Figure 4. Illustrative Quotes of Stage 4: Being With the Dying Child

to go and felt satisfied about it. Afterward, knowing that they had provided support and comfort to their child as he or she died was very important to parents.

**Fulfilling wishes and promises:** Parents who had discussed the dying phase with their child in advance felt especially responsible for honoring the wishes and promises they had made. Of major importance was the promise to prevent suffering. In hindsight, parents positively evaluated the accomplishment of those sometimes unspoken promises.

**Unbearable aspects of the dying phase:** All parents hoped that their child would have a peaceful death without pain or suffering. In hindsight, almost all parents evaluated aspects of the dying process as severe suffering. The carefully built comforting situation became disrupted by symptoms parents felt unable to palliate, such as restlessness or gasping. Even when a professional caregiver reassured parents that their child was not aware of his or her situation, parents felt no better. Parents found being there and watching their child die to be a severe burden. Most parents could not give any positive meaning to their child's suffering.

## Discussion

The current study identified four EOL stages from the parents' perceptions: becoming aware of the inevitable death, making the child's life enjoyable, managing the change for the worse, and being with the dying child. The essence of parenting during those stages is captured by the notions of being meaningful to the child and preserving the parent-child relationship. The child's deterioration forced parents to face loss and to reframe their parenting role to maintain a meaningful relationship. Despite their own suffering, parents were able to hold on because of their ability to postpone grief, enjoy the child's expressions of happiness, look beyond the child's physical deterioration and keep the child's identity and wholeness in view, and value and take comfort from the rewards experienced while caring and being there in response to their child's needs.

The current study had limitations. The authors could not collect concurrent data from all parents during all stages. In addition, some parents were interviewed only after the EOL phase. The sample also consisted mainly of Dutch couples. However, studying an existential experience and having rich descriptions of all phases from both fathers and mothers increased the trustworthiness. Similar patterns were seen in all respondents. The recurrence of themes and the clarity of the patterns signified to the authors that their reconstruction had identified essential themes.

Parenting themes were clearly connected with the parents' experiences and management of current and anticipated loss. The four stages incorporated numerous aspects of actual loss: the loss of a shared future, normal life, the wholeness of the child's body, happiness, identity, and reciprocity. The current study confirmed the idea that whatever the individual construes as loss triggers grief, even if the loss has been anticipated (Fulton, Madden, & Minichiello, 1996; Parkes, 1971). The current authors agree with Fulton (2003), Fulton et al. (1996), and Gunnarson and Ohlen (2006) that this is actual grief and should not be conceptualized as anticipatory grief, as some researchers have (Fulton, 2003; Rando, 1986). The confrontation with

losses while being unable to give any positive meaning to the death of their child brings parents to the edge of an existential crisis. The knowledge that their life with the child will be finished by the child's death is too much to bear. The interviews demonstrated that parents shoulder their responsibilities as caregivers. In doing so, parents manage feelings of loss and postpone their grief to keep going, a precondition for parenting. The current analysis also revealed that parents were better able to cope by giving a significant meaning to their parenting and caring activities. For example, parents knew that they would have to adapt to how the illness developed but were capable of postponing threatening thoughts. The postponing helped parents to be with the child and created an atmosphere worth living in for their child and themselves. In addition, parents could facilitate their child's joy and enjoy it only if they limited their perspective to stage 2.

Parents particularly found meaning in being there and doing their utmost for their child. Being there is the parental response to the perceived needs of the child and can be characterized as the embodiment of not leaving the child alone in his or her suffering. The concept has been identified as a parental response to the perceived vulnerability of children treated for leukemia and as a parental need to give meaning to parenthood (Kars, Duijnste, Pool, van Delden, & Gryphonck, 2008). Protecting the child to safeguard his or her well-being and being the one from whom the child can derive power when coping with suffering matches the concept of being there found in the current study. In the EOL, being there appeared to help parents cope with the stressful process of losing their child. As in Kars et al. (2008), the current study found that being there strengthened the parent-child relationship and increased the parents' capabilities to give care. Although caregiving was demanding, most parents succeeded in prolonging the act of being there and saw caring for the child themselves as a rewarding task. The latter was reflected in earlier research (Saiki-Craighill, 2002; Vickers & Carlisle, 2000). From the perspective of the child, Woodgate (2006) indicated that adolescents appreciated their parents being there.

The interviews showed that many parents redefined their parental role over time. **Initially, meaningful strategies** such as facilitating an enjoyable life seemed to fail when either physical decline drastically progressed or the child psychologically gave up. Sometime during stage 3 or 4, most parents came to terms with the idea that parenting aimed at comforting the child and helping him or her accept death also can be meaningful and does not mean giving up on the child. That change in perspective facilitated the parents' abilities to care during the last stages. Many parents, however, were threatened by leaving their traditional parental role aimed at protecting the child's life. Parents feared the dying process and

the definite loss of their child. Therefore, parents clung to stages 2 and 3. The finding that the awareness of having reached stage 3 or 4 often was delayed stressed the influence of the parents' meaning giving and coping. In hindsight, parents often concluded that their child's condition gave legitimacy to an earlier acknowledgment that they had reached the next stage. That conclusion would have enabled them to better synchronize their care with the child's needs and to act more proactively, for instance, with respect to symptom treatment or facilities to make the child's life easier. This finding may explain why parents stress their need for information in retrospective studies (Freeman et al., 2000; Monterosso & Kristjanson, 2008; Rini & Loriz, 2007).

Like Kreicbergs et al. (2004), the current authors found that some parents talked about death and others did not. Parents experienced an inner conflict between creating a worthwhile life and supporting their child to cope with death. Few studies have explored talking about death. Avoiding the theme of death often is considered a way to protect the child from breaking down (De Trill & Kovalcik, 1997; Nitschke et al., 2000). The current study consolidated the parents' needs to continue their bond, both by keeping the child going and also by enjoying life. Continuing bonds is known from bereavement literature; an ongoing inner relationship with the deceased can facilitate adjustment (Marwit & Klass, 1996; Silverman & Nickman, 1996; Stroebe & Schut, 2005). The authors found that the parents' abilities to face loss and find meaningful ways of expressing their bond with the child were helpful in discussing death while providing comfort and seemed to overrule the influence of the child's age or coping style. A temporary mutual pretence where the parent and child both know but do not mention impending death can be fruitful in stage 2. However, parents may feel the need to avoid the topic of death, which hampers an awareness of the child's need for that discussion. The avoidance was caused by being unable to manage the existential threat of loss and the difficulty of guiding their child during the phase of decline, rather than unwillingness. This finding supports the notion of Grootenhuis and Last (2006), who concluded that parental guidance and communication about EOL issues can be inadequate.

## Implications for Nursing Practice

Nurses can learn from the current study that parenting at the EOL is influenced by parents' meaning giving in addition to rational considerations. The meaning giving found in the current study enabled parents to provide loving care and cope in response to the stress related to parenting at the EOL (e.g., feeling powerless, witnessing the child's deterioration, forewarnings of loss). Some aspects of meaning giving (e.g., supporting the child in enjoying life, pleasure in seeing expressions of the child's identity) can hamper parents' recognition of having reached the

next stage and their abilities to adapt their care to changes in the child's medical condition and needs. Although information can be helpful in making those transfers, nurses should facilitate the parents' change in attitude by helping them to develop new meaningful perspectives. Nurses can explain that letting the child go does not mean giving up. Many parents expressed the over-riding importance of hearing from professional caregivers that they had facilitated a peaceful death at home and decreased the risk of an uncontrolled death in the intensive care unit by deciding to finish their child's cancer-directed treatment. Many parents learned that aspect of meaning giving from healthcare providers.

Nurses should strive to preserve the parent-child relationship and facilitate the act of being there. Both notions are important to ensuring that parents will make the necessary change in perspective as the illness progresses. Nurses can help parents find strategies that are meaningful to them and still appropriate to the child's condition. For example, a child who does not want to be hugged may like being rubbed with a favorite lotion.

Parents appeared to be more open to discussing EOL themes in stage 1 than in later stages when they were focused on enjoying life or when illness progressed rapidly and their impending loss had become reality. Preparing parents for what to expect and discussing difficult themes and outcomes of care in advance can help them to live up to their intentions in the more difficult later stages.

Parents continuously made efforts to keep going and fulfill their parental role, which left them vulnerable in a crisis. The authors encountered signals of depersonalization, which must be taken seriously because they are considered a symptom of acute stress disorder (Bryant, 2003). Suggestions for future research include further exploration of the consequences of the parents' meaning giving and coping for the child's well-being, particularly the assessment and management of the child's symptoms and suffering.

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