Parenting and palliative care in paediatric oncology

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Contents

Chapter 1

General introduction

"It's just terrible to realize. That you're taking care of him and would do anything for him and that you realize that soon he won't be in your hands anymore."

The father of Cas (9 months)

It is widely accepted that the needs of ill children can best be met at home. Hence many parents of seriously ill children take care of their child at home, even when this care is complex, time-consuming and disrupts normal family life [1, 2]. This is even more so for children with cancer for whom all curative options are exhausted. They are increasingly cared for at home during the end-of-life (EOL) phase. While parents play a major role in the practical and emotional aspects of childcare, research into the parents' perspective is scarce. Indeed, most studies focus on clinical care and EOL decision-making. The parents' experiences of caring for their child with cancer during the palliative phase, what it means to parent a child while facing the child's death and to what extent they feel supported by professional caregivers have hardly been studied. This study explores the lived experience of parents of children with cancer, in particular in parents of children for whom all curative options have been exhausted and who are cared for at home. Also the provision of palliative care, by caregivers who are professionally involved in these cases, will be explored.

Before starting the study on parenting in the critical palliative phase of children with cancer, a preliminary study on parenting was conducted among parents of children with leukaemia who were treated with the intention of achieving a cure. This preliminary study helped us to develop a research approach that could be applied to parents whom we presume to be more vulnerable. It also provided insight into the stages that preceded the palliative phase and which most of the respondents included in our main study had gone through.

At the start of this study, research on paediatric palliative care in either hospital or home settings was scarce, thus preventing any chance of conducting a review. In this introduction the landscape in which this study took place is sketched. We will provide a brief overview of the characteristics of childhood cancer, the concept of palliative care, EOL care in paediatric oncology, parenting during the palliative phase, paediatric palliative home care, and the experiences of professionals in providing paediatric palliative care.

Childhood cancer: incidence, treatment, survival and the end-of-life

Over the past decades, as a result of improvements in treatment, childhood cancer has been transformed from a 'killer' to a curable disease. However, cancer is still the leading cause of non-accidental death in childhood [3].

Incidence

Cancer incidence rates in European children and adolescents for all cancers are 157 per million for ages 0-19 years [4]. Incidence rates in West Europe, including the Netherlands, are slightly lower than in Eastern Europe, but still give a cumulative risk of 1 in 514 of developing cancer during the first 15 years of life [4, 5]. Throughout childhood, the total cancer incidence is highest in the first five years of life and among adolescents aged 15-19 years, and is significantly higher in boys than in girls. Child cancer is generally diagnosed according to the International Classification of Childhood Cancer [6]. Overall in western industrialized countries, including the Netherlands, about a third of all childhood cancers are leukaemias, predominantly acute lymphoblastic leukaemia (ALL). Brain and spinal tumours are the second most common diagnostic group, accounting for about a quarter of registrations, followed by lymphomas 9-10%. Neuroblastoma, Wilms' tumour and soft tissue sarcomas each account for 6-7%. The remaining groups that only account for a small percentage are retinoblastoma, bone sarcomas, germ cell tumours and epithelial tumours [5].

Every year a growing number of children is diagnosed with cancer as the incidence of cancer in European children and adolescents increases at a rate of 1.0% to 2.0% each year [7].

Treatment

Most children receive treatment on nationally and internationally agreed protocols. In the Netherlands this is co-ordinated and monitored by the 'Stichting Kinderoncologie Nederland' (SKION) (The Dutch Foundation for Paediatric Oncology). Treatment depends on the type of tumour, its stage of development, as well as on the biological characteristics of the tumour. Treatment may consist of surgery, chemotherapy, radiotherapy or a combination of these treatments. Bone marrow transplantation can be applied to children diagnosed with leukaemia with a high risk of treatment failure or in case of relapse [8].

Survival

Improvements in treatment have substantially increased the number of children surviving from childhood cancer. Five year survival rates in Europe increased from 44% in the 1970s to 63% in the 1980s and range from 64% in Eastern Europe and 75% in the west in the 1990s. This is similar to that in the United States of America [4]. Survival rates vary by diagnosis and guide prognosis. They range from approximately 55% (neuroblastoma , acute non-lymphocytic leukaemia or osteosarcoma) through to 80% (Wilms' tumour or ALL). Children suffering from Hodgkin's disease, retinoblastoma or germ cell tumour may have even up to a 95% chance of survival [5].

End-of-life

Notwithstanding these significant improvements in survival, a quarter of all children diagnosed with cancer will still die of their disease even in countries with the highest survival rates. In the Netherlands approximately 100 children die annually of their disease according to recent figures from SKION.

Some children die suddenly as a consequence of complications of the disease or its treatment. However the approaching death can be expected for the majority of children and is preceded by a period of EOL care. While the highly protocol-driven academic research has made huge improvements in frontline treatment and cure, palliative care in children lags far behind. It has been recognized that paediatric palliative care is often inadequate and efforts have to be made to develop knowledge to substantiate EOL care for children [9-13].

Palliative care

Definition and model

Palliative care is a philosophy of care that evolved from the hospice movement to meet the gaps in care for seriously ill and dying patients [14]. Since the beginning, 30 years ago now, its definition has changed several times, reflecting changes in tasks and goals. Although no generally agreed definition exists, a broad consensus exists about its central goals and key aspects [15]. The definition of the World Health Organization (WHO) [16], which incorporates the agreed goals and key aspects, seems a good starting point. It is frequently used, too, in paediatric palliative care literature. The WHO defines palliative care as:
"An approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance the quality of life, and may also positively influence the course of the illness;
- is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to understand better, and manage, distressing clinical complications."

The definition propagates the more recent opinion that the principle of palliative care should be applied as early as possible in the course of a chronic, ultimately fatal, disease instead of only to patients who are not responsive to curative treatment [17] (Figure 1).

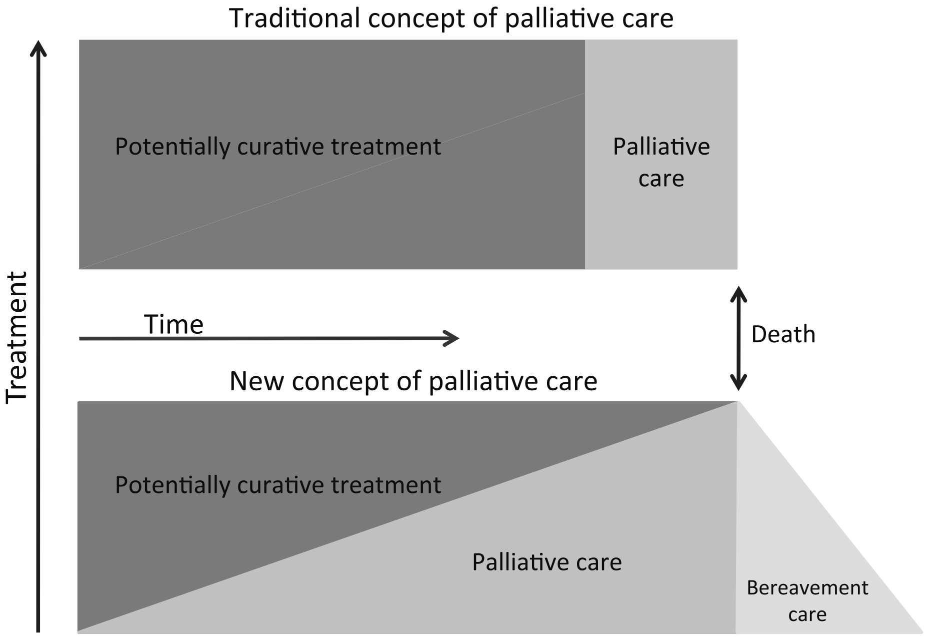

Figure 1 Old and new concept of palliative care (Lynn and Adamson 2003)

Definition of paediatric palliative care

According to the WHO, palliative care for children represents a special, albeit closely related field to adult palliative care. This is reflected in an additional definition for children and their families [18] :

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

In line with the WHO definition all children diagnosed with cancer are eligible for a palliative approach. The perspective of providing palliative care for children with life limiting and life threatening conditions from diagnosis is broadly supported in paediatrics [19-21]. Caregivers and researchers in paediatric oncology have embraced the so-called 'integrated care' model in which care directed at a cure and palliative care are combined. It is considered that it will facilitate access to palliative care [9, 22-25].

Clarifications of concepts

In the literature a plethora of terms referring to aspects of palliative care can be found, such as: 'EOL care', 'terminal care', 'hospice care', 'comfort care', 'supportive care' et cetera. However, the term 'palliative' appears to be a confusing term in clinical oncology, especially with respect to treatment during the palliative phase [26]. Therefore an explanation is given of the terms used in this thesis.

In clinical oncology all patients diagnosed with cancer are eligible for a palliative approach; however, the moment that there is no realistic hope for cure anymore is a landmark. For our convenience we refer to the 'palliative phase' as the time span between the moment that cure is not or no longer possible till the moment of death. With Nuss et al [27] we consider EOL care as an aspect of palliative care that is provided when all curative options have been exhausted and care is focused on preparing for an anticipated death. The terminal phase is the last part of the palliative phase during which it becomes clear that the child is in a progressive state of decline and that death is imminent. Consequently, terminal care is care for the dying child [23].

Once cure is deemed impossible, non-curative anti-cancer treatments can still be applied, for instance palliative chemotherapy, surgery or radiation. In clinical oncology these are called palliative cancer therapy. They can serve several goals such as the alleviation of symptoms, the increase of the quality of life and/or the increase of the length of survival by slowing down the progression of the tumour [26]. To facilitate a clear communication, in paediatric oncology literature a distinction is made between cancer-directed treatment and symptom-directed treatment. Both are aimed at the quality of life. However cancer-directed treatment also includes anti-cancer treatment to prolong life. Symptom-directed treatment focuses only on symptom treatment to relieve suffering. However, in symptom-directed treatment the tumour can also still be the target when this is helpful to alleviate the suffering.

End-of-life care in paediatric oncology

The child's suffering from symptoms, and EOL decision-making, are central themes in palliative care in paediatric oncology. We will discuss the suffering from symptoms, quality versus quantity of life, decision-making at the EOL and the parents' role in decision-making.

Suffering from symptoms

The child's suffering from symptoms is one of the major concerns at the EOL. Symptoms can be defined as 'physical or mental phenomena, circumstances or changes of condition arising from and accompanying a disorder and constituting evidence for it' [28]. Studies show a high prevalence of multiple debilitating symptoms in children with advanced cancer [29-32]. Symptom prevalence increases drastically during the last weeks before death [32].

From retrospective parent reports it is known that many children with incurable cancer suffer severely from symptoms. Although attention to physical problems, such as pain, dyspnoea, fatigue or vomiting has increased, many of these symptoms are still reported as remaining untreated or unsuccessfully treated [12, 33-35]. More recently it has been recognized that a high proportion of children had suffered from depression or anxiety during the last weeks of life [12, 35]. Teunissen et al. [12] demonstrated that psychological distress is often not recognized by healthcare professionals and therefore not treated effectively.

While agreement exists about the necessity for improving symptom treatment, this is mainly accomplished by the improvement of medicine and education aimed at adequate use of medicine. We however, have hardly any insight into how symptom treatment is dealt with in current practice at home and how both parents and caregivers fulfil their roles.

Quality versus quantity of life

In a well-documented publication Krueger has described the paradox of hope and suffering that characterizes paediatric oncology [36]. The enormous desire to cure, the difficult search for promising treatments and the positive treatment results gained over the past decades, have always legitimated some degree of suffering inflicted upon children being treated for cancer. Even when perspectives diminished and the chances for survival could be expected to be minimal, the hope of saving the child may make it worthwhile giving the treatment a try, despite its burden and side effects [36]. For parents, who are socialized in hope and curative goals, the transition from cure to palliative goals such as quality of life and quality of death is difficult [11, 37-40]. As a result of advances in medical treatment, cancer-directed treatment aimed at prolonging life has become a serious option during the palliative phase. This brings about difficult questions about how to weigh quality of life and quantity of life. Most parents try to reconcile dual primary goals: a primary cancer-directed goal of prolonging life and a primary comfort-related goal of lessening suffering [11, 25, 40]. For many parents, however, the quantity of life takes priority[40, 41]. Almost half of the children receive palliative chemotherapy during the EOL [10, 35]. Bluebond Langner et al [40] demonstrated in a cross-cultural study that nearly all parents agreed to chemotherapy during the palliative phase when this was suggested by the paediatric oncologist. When the paediatric oncologist discarded an additional chemotherapy treatment, however, many parents still sought life prolonging cancer-directed treatment options on their own. Whether the parents' search for cancer-directed treatment adds to the quality of life can be questioned [42]. Several retrospective studies show that approximately a quarter of children die due to therapeutic complications during the palliative phase [10, 35]. There are indications that bereaved parents retrospectively tend to be more reticent concerning palliative cancer-directed therapy than parents during the palliative phase [35, 43]. It seems that with strategies aimed at prolonging life, the ethical dilemma of hope and suffering has entered the palliative phase. It is one of the most difficult aspects for parents to decide upon. The grounds underlying their decision-making are still poorly understood. In paediatric palliative care research dilemmas concerning treatment at the EOL and the change in perspective from cure to quality of life are usually approached from a perspective of making a decision [39, 42, 44-47].

Decision-making in the palliative phase

In general, EOL decisions refer to the withdrawing or withholding of life sustaining treatment, the intensified alleviation of pain and other symptoms and the deliberate hastening of death by means of provision or administration of lethal drugs [48]. In paediatric oncology parents are faced with many choices that may also include enrolling their child onto a phase I/II clinical trial, do not resuscitate (DNR) orders and advanced care planning, including taking decisions about the place of death. Parents consider EOL decisions on behalf of their seriously ill child the most difficult they face [44]. Although the difficulty of making trade offs and decisions are generally acknowledged most research focuses on the outcomes of parental EOL decision-making [40,48,49] . Parental decision-making in the setting of incurable cancer is still a complex and poorly understood process [25].

Professional caregivers face the difficult task of guiding parents through the EOL course and help them to make decisions in the best interest of their child. The extent of their involvement can be diverse [50]. In general three predominant models of treatment decision-making are distinguished: paternalistic, shared and informed [51,52]. In paternalistic models decisions are predominantly made by the physician in the patient's best interest. This has been the dominant decision-making model for a long time, based on the assumption that each disease has one single best treatment and physicians are best placed to weigh different alternatives and to make the decision. During the 1980s and beyond, the credibility of the above assumptions began to be questioned. The notion of the best treatment appeared to be a myth. Different treatments could be equally effective while having different types of trade offs between benefits and risk. Reinforced by the rise of the concepts of informed consent and of patient autonomy, the paternalistic model shifted to become more centred on the patient. In the informed decision-making model the physician's role is limited to providing the patient with all the relevant information regarding the various treatments. This includes the amount of evidence, risks and benefits. The expectation here is that the patient will be the sole decision-maker and takes responsibility for it. This model also appeared to have some shortcomings in that the patient's deliberations and choices will be influenced by beliefs or preferences which may result in questionable decisions. Therefore the so-called shared decision-making model, sharing aspects of both models, is the most widely accepted. [52]. In shared decision-making there is a relationship between patient and clinician in which information is exchanged in both directions; both parties participating in the deliberation, and then agreeing about the final decision [53].

The role of parents in the decision-making process

In paediatric practice parents, traditionally, are intensively involved in decision-making. This has a formal reason: parents are the presumed decision-makers for their children because children are not or only partially, legally competent to make decisions for themselves [47,54]. Besides this, parents, in particular parents of chronically ill children and their interest groups have fought for years to convince professionals that as their primary caregivers they know the child and his/her needs best and must be taken seriously [41,55]. Parents consider themselves the ones who can best protect and act as advocate for their child [40].

From retrospective surveys it is known that parents desire honest and realistic information, an open communication [37,56] and seek strategies and goals that are consistent with their values and priorities [25]. On the other hand parents report that they are influenced by the healthcare team [50]. Decision-making in palliative care has a relational aspect. Parents, for instance, stress their need for caregivers they can trust and with whom they feel connected [57].

Whether professionals answer those needs can be questioned. Sirkia [58] showed professional caregivers mainly focus on physical care and rely on physical parameters for their treatment decisions. However, even with adults, physicians report that they provide an honest estimate of the likelihood of survival in only 37% of cases. 60-70% of discrepant survival estimates were overly optimistic [59,60]. In paediatric oncology research, Wolfe [11] demonstrated that the parents understanding that the child no longer had a realistic chance of being cured was delayed, lagging behind the explicit documentation of this fact by the primary oncologist by more than three months.

Parenting during the palliative phase

During the EOL children require more and more care. The role of parents as care providers at home is extensive, especially in the terminal palliative phase [61, 62]. From chronically ill children it is known that parents and mothers in particular, are deeply involved with the child and willing to make a tremendous effort in caring for their child. The parents provide by far the largest part of the care even when they receive much support from home care services [1, 63]. Research into caring for children at the EOL has focused on the parents' problems and needs. It shows that in hindsight, many parents felt satisfied having cared for the child themselves. [41, 62-65]. Parents stress the need for honest information to enhance their ability to provide adequate care [37, 56]. Inadequate symptom management [10, 12, 34], the child's distress [35] and the parents' own fear of the moment of death[64] appeared as problems.

Providing care, however, is only a part of the parenting role. According to the handbook of parenting, parenting means "performing the role of a father or mother by giving care, nurturing, and protection of the child through a complex process that involves relationships in both directions between members of two generations" [66]. A review on parenting in nursing research showed research concerning parenting is scarce, mainly focused on mothers and primarily on parenting children with physical or developmental disabilities [67]. Whereas giving care has received substantial attention; parenting is hardly addressed in paediatric oncology. Parents as caregivers remain parents and have to intertwine both roles. Little is known about how parents intertwine their roles as caregiver and as parent, how they give meaning to their parental role and how this influences their care-giving and decision-making. Also the relational aspect between the parent and the child has hardly been explored, except for one study that indicated relational aspects played a role in the decision whether or not to talk about death with the child [68]. For a better understanding of the parents' role in the palliative phase a better understanding of the meaning and essence of parenting is needed.

Paediatric palliative care at home

The place of EOL care and death

Recent population studies on the place of death show a substantial increase in home deaths among chronically ill children [69, 70]. Compared with other chronic conditions, children with cancer are more likely to die at home. On average 40% of the children with cancer die at home [69, 71, 72]. Large differences, however, are reported between countries and/or regions, ranging from 16% to 77% [35, 70, 73-78]. The Netherlands has a leading position with 63% of Dutch children with malignancies dying at home [70].

In paediatric oncology home death is considered a desirable outcome. Care providers assume that the needs of the dying child can best be met at home [19, 64]. Based on reports from bereaved parents, it is assumed that children themselves prefer to die at home [37, 41, 79] and, although this has not yet been systematically researched, many parents also prefer their child to be at home in the EOL phase [29, 41, 79, 80]. Some studies report positive aspects of home based EOL care, for example the lower levels of symptoms related to grief and psychological distress among families whose child died at home [81, 82]. Parents, who had decided to care for their terminally ill child at home (n=3), indicated that this decision was made instinctively or intuitively, rather than through a calculated weighing–up of options [79]. Some, however, had felt stimulated by the healthcare team or mentioned it was the physician's usual practice [63]. In retrospect, parents felt positive believing they had acted in line with their child's preference of being at home and having enabled him or her to continue normal life as much as possible [37, 41, 57, 63, 79, 80]. Furthermore parents had felt comfortable staying together as a family in their own environment. There were additional advantages in that they could control their own lives and their privacy and could safeguard the continuation of the lives of the dying child's siblings better [41, 63, 64, 79]. Some authors, however, have adopted a more nuanced view of the importance of place of death. It appeared, for instance, that when easy access to a hospice was offered, approximately 10% of the families choose it as an alternative location to care for their child [76, 83]. In a small qualitative study Papadatou [80] explored the motives of parents whose child had died in hospital. These parents (n=5) indicated they had felt more secure by the continuous support of the medical staff and mentioned medical factors had influenced their decision such as better pain control, or the need for complex technical care. It is also worth noticing that aggressive treatments are sometimes not abandoned until shortly before death. Hence there is little or no time for the child and his/her parents to decide on the place of death or to plan any EOL care in advance. Some of those children die on the intensive care unit due to complications [34, 35, 72].

Several studies identified factors related to home death. Studies from various countries demonstrate a positive correlation between the availability of comprehensive home care services and the number of children with life limiting conditions who actually died at home [10, 58, 74]. From qualitative reports we learn that the availability of immediate professional support increases the parents' self-confidence and makes them feel more safe and secure in caring for their child at home [79]. Planning the location of death in advance is also associated with more home deaths [84], as is the parents' understanding of prognosis, their awareness of imminent death and the sense that the child is aware of imminent death[72].

The parents' preference for a home death appeared to increase in the last month of life [74]. From the above it can be concluded that children are increasingly cared for at home. Parents and professionals agree with the notion that this satisfies the child's and the parents' preferences. This, however, is based mainly on retrospective studies among bereaved parents who have fulfilled this task. Until now the experiences of parents and what it means to them to reconcile parenting and care-giving tasks during their child's EOL and death, have hardly been described.

Paediatric palliative home care services

With the adoption of paediatric palliative care as a special discipline and the broad consensus among caregivers and opinion leaders that children can best be cared for at home during EOL, the facilities for professional palliative care support at home increased. In the past decade many institutions have developed palliative care services based on the local resources and policy of their governments. This has resulted in different approaches of paediatric palliative care within different organizational settings [35, 76, 85-87]. Most programmes are in hands of paediatric oncology centres. Others are coordinated and provided by community palliative care services or the local primary healthcare team.

In Western Europe, the United Kingdom has a rich tradition of palliative home care, including a well established model of paediatric palliative care for children with cancer based on paediatric oncology outreach nurse specialists working from a tertiary or shared care centre. These nurse specialists offer symptom management, psychological support and serve as the liaison between the paediatric oncology centre, the local hospitals and primary healthcare team. Social workers contribute to psycho-social support. Medical backup comes from paediatric oncologists, general paediatricians, general practitioners, and sometimes adult or paediatric palliative care consultants [74,88]. In other European countries similar services are developed, but on a much smaller scale. Examples are the 'Koester project' (Belgium), the 'Children's Palliative Care Centre Datteln' (Germany) and 'das Regenbogenteam '(Austria). They often serve as role models for the rest of their country. They have in common that specialist nurses, backed up by multidisciplinary teams, provide palliative support and care to children with life limiting and life threatening diseases including children with cancer. Children are visited at home and some teams also perform medical interventions at home, such as blood tests, chemotherapy, and blood transfusions [35].

Palliative home care services in the Netherlands

During the past decade in the Netherlands, health care services for terminally ill patients have been developed with financial support from the Dutch government. Based on the advice of the board of Centres for Palliative Care Development [89] the Dutch government took the position that, whereas death and dying are common events in human life, the provision of EOL care should be, as much as possible, a part of the patients' regular care system. The provision of EOL care should be part of the professional skills of the generalist professionals [90]. Patients cared for at home receive care from their general practitioner and home care organizations. In order to guarantee good quality palliative care Palliative Care Consultation teams were established, which inform, support and advise professional caregivers involved with patients in palliative care but without taking over responsibility [91]. These teams have no specific expertise in paediatrics.

Experiences of professionals

Today there is an overwhelming amount of literature and guidelines making recommendations and describing best practices for paediatric palliative care [9, 19, 20, 25]. However, far less is known about the experiences of the professionals who enact paediatric palliative care and who are presumed to make the translation from knowledge to practice. Most research is based on self-reports based on surveys of medical and nursing staff on oncology wards.

Professionals stress their need for education and role models, thus showing their awareness of their shortcomings in paediatric palliative care [92, 93]. Because of the infrequency of child death in most practices, paediatric care providers lack experience and expertise in dealing with death [94]. In a survey of Hilden [92] 92% of the paediatric oncologists practicing in the United Sates, the United Kingdom and Canada, reported that they learned by trial and error in practice. Only 10% had taken formal courses on paediatric palliative care. Although several approaches have been used to reduce the educational gap, education is still identified as a main challenge in paediatric palliative care [23]. While professionals feel competent to manage physical symptoms they speak of having difficulty managing psychological problems such as depression in children or the counselling of issues surrounding terminal illness [92, 95].

Because the death of a child is felt as unnatural and does not fit a system of health care focused on healing, palliative care can be emotionally demanding and stressful. Feelings of grief among carers are reported [95]. Nurses appeared to experience distress when curative efforts meant that they were unable to provide a comfortable death for a child [95, 96]. This aside, caring for children during EOL was often experienced as emotionally satisfying even though at the same time a sense of failure and guilt were reported accompanying the conclusion that despite the best treatment the child could not be cured. However, many oncologists struggled with what they called the parents' 'unrealistic expectations' and denial of the illness as terminal and the conflicts this brought about [92].

We identified a gap in knowledge concerning the perspective of professional carers involved in palliative care for children cared for at home. In addition, the interplay between professionals and parents at home is still uncharted territory.

Research objectives and method

Research into paediatric palliative care provides little insight into what it means to parent a child at home during the palliative phase. Furthermore the processes that underlie the parents' and the professionals' decision-making and care-giving are still unclear. Also, some methodological gaps were identified. Research in paediatric palliative care is almost always retrospective, consisting mainly of surveys and small qualitative studies. The samples are often limited to one setting and data are gathered predominantly from mothers whose child may have died many years before. In addition, studies on decision-making focus predominantly on isolated EOL decisions. We hypothesized that the perspective of bereaved parents may change over time due to processes of coping. We also preferred to include professionals who were currently providing palliative care. It was expected that interviewing parents and professionals about the current care-giving situation brings our findings as close as possible to their 'lived experience' instead of to reflections of what ought to be or what would be socially desirable. Consequently, we conducted a multi-centre study and collected our data during the palliative phase from both fathers and mothers, and professional caregivers involved in the cases under study. This study is referred to as the PRESENCE-study. PRESENCE being an acronym for the **P**a**R**ents' **E**xperiences and need**S** in **E**nd-of-life care for childre**N** with can**CE**r.

General objective and research approach

The general objective of the PRESENCE-study was to investigate, the parents' experiences, their struggle to give meaning to what they are going through, their needs and coping strategies when caring for a child (0-16 years) with incurable cancer throughout the palliative phase. Besides this we sought to know how palliative care is shaped by caregivers from various disciplines who are professionally involved in the care for the children included in this study and to what extent they meet the needs of the parents.

To our knowledge, this was the first study in paediatric oncology that explored the parents' perspective throughout the palliative phase. Our main question for the parents was: What does it mean to parent a child with incurable cancer at home throughout the palliative phase? The main focus of questioning the professional caregivers was: What is good palliative care given the situation you are currently involved in? However, we could not accurately estimate the degree to which parents were able to speak freely about their experiences and what concerned them most. Therefore, we originally adopted a relatively open approach and only focused our study as the research progressed, as is quite common in qualitative research [97]. The following research questions will be addressed in this dissertation:

As stated already in the introduction a preliminary study on parenting was conducted among parents of children with leukaemia (chapter 2):

1. What is the essence of parenting during the first year of treatment for parents who take care of their child diagnosed with leukaemia?

Based on our findings we elaborated on 3 questions from the parents' perspective (chapter 3,4 and 5):

2. What does it mean to parent and care for a child with incurable cancer and how do parents give meaning to their parental role throughout the palliative phase?

3. What processes do parents go through when cure is not obtainable, and how do those processes influence the choices parents make for their child's treatment and care?

4. What are, from the parents' perspective, the main factors that influence the parents' position between preserving their child and letting their child go at the end-of-life?

We focused the analysis of palliative care from the caregiver's perspective on the concrete aspect of care, namely symptom treatment (chapter 6):

5. How are symptoms treated amid the interplay between parents and professionals in the final EOL stages at home?

Method of the study

Methodological approach

The purpose of our study was to throw light upon the inside perspective of our respondents in order to understand how they feel, perceive and give meaning to their situation. Therefore we used qualitative interpretative methods such as phenomenology and grounded theory. The method used in the preliminary study corresponds with the method used in the PRESENCE study, as is described below. For more precise methodological details of the preliminary study we refer to the method section of chapter 2.

In phenomenological research, reference is made to the *lived experience* as the point of departure for understanding [98, 99]. We understand this *lived experience* to be the whole of the respondents' experiences, the interpretation they give to events and situations and the meaning they assign to them. Our interpretation of the meaning of the separate parts of our data was determined by the interpretation of the interview as a whole [99]. Based on those interpretations, our data were structured and condensed. This inductive thematic analysis [99, 100] was used in chapter three and chapter six and resulted in descriptions of experiences and meaning giving, in a phenomenological style.

However, our aim was not only to describe the EOL experience from the respondents' perspective but also to improve understanding by identifying commonalities, differences and relations in order to reconstruct processes that explain what was seen to take place in our respondents. This grounded theory approach according to Charmaz [101] results in theoretical statements, explaining how the experience and the behaviour that is part of it, comes about and what the internal source is. The reconstruction of the internal logic of the behaviour, thoughts, feelings and meaning allows an understanding beyond the mere cognitive comprehension of what is said or takes place. It is grounded in the data but goes beyond what is directly said by the respondents [99, 101]. This was the predominant approach of chapter two, four and five.

Data collection

Face to face interviews were the main data source. While interviews only give indirect access to events or behaviour, they are the most direct route to interpretations and meaning, and thus to the lived experience. Thoughts, feelings and certainly meaning can most clearly be revealed by the interviewee's own reconstruction and interpretation of the experiences. Interviews were held at the parent's home. This created the opportunity for some participant observation. Contact summary sheets were made of each interview and included the notes of these observations[102].

To minimize the parents' burden we developed a matrix approach. All parents were interviewed once. One or two successive interviews were conducted with one third of the parents in order to increase our insight into the course of the illness and how processes developed over time.

Interviewing in this study was focused on facilitating the articulation of the lived experience and on collecting information that enhances a truthful interpretation by an outsider. We intentionally used an open, unstructured interview strategy, supported by a topic list (Appendix 1). For the parents we started with broad opening questions. 'Will you tell me how your son/daughter has been doing from the moment he/she became ill?' followed by: 'Will you tell me how your son/daughter is doing at the moment?' This was done for two reasons. First, we wanted parents to take the lead in order to see which themes came up for discussion and what was of main importance for them. The topic list was used at the end of each interview to ensure all topics came up for discussion. Secondly we wanted the interviewer to adopt a similar tone as the interviewee in order to help the interviewee talk about delicate themes.

For ethical reasons, transferring interview information between the parents and caregivers had to be avoided. Hence the parents and caregivers were interviewed by two different interviewers and no interview information was shared between interviewers. As a consequence the professional caregivers were primarily asked to provide a sketch and their analysis of the case they were involved in. Their interviews were organized around the question of what they considered to be good palliative care given their analysis of the situation of this child and their parents. The professional interviews were also supported by an interview guide (Appendix 2). As should be the case in Grounded Theory, the topic list was adapted to the emerging concepts and insights. Interviews were tape recorded and transcribed verbatim.

Data analysis

Three intertwined strategies were used in order to conduct the interpretative analysis able to lead to both a description of the lived experience and the construction of the processes underlying it. These strategies were: 'taking perspective', 'thinking theoretically' and 'coding'. The integration of the results of these three strategies is the process on which both the phenomenological description and the explanation of the underlying processes were based.

The starting point of our analysis was always, "taking perspective". The research team tried to enter the perspective of the respondent and to understand the meaning of the events and the respondent's reaction to it from their perspective. Thinking theoretically meant formulating the interpretative concepts and identifying relations between these concepts. This involved bringing together knowledge we had from our experience, previous research and the study of the literature. In doing so, the analysis went beyond the individual case to look at what can be considered shared by persons belonging to the same category. Coding by means of labelling selected fragments was used to support the analysis. In line with Charmaz [101] we frequently used 'active' coding. Because of this the codes reflected the interpretation. To preserve the context which is fundamental to our interpretation, meaningful paragraphs were coded instead of line by line coding.

In our analysis, the three basic strategies were used simultaneously and sometimes consecutively in a spiral, going back to the same data and the same question but at a higher level of understanding and/or a higher level of abstraction and conceptualization. For this process we used the four phase method of Wester [103] consisting of: exploration, specification, reduction and integration.

Sample

The parents interviewed in this study were recruited from five Dutch university paediatric oncology centres. Parents of children (0-16 years) with all types of cancer were considered eligible from the moment they entered the palliative phase. This was defined as the moment the oncologist had informed them that the remaining treatment options were not curative. In most cases this took place during a Final Stage Conference. Parents who spoke Dutch and who cared for their child at home were enrolled, irrespective of whether their child received cancer-directed (including phase I/II study medication) or symptom-directed therapy and irrespective of whether the parents felt convinced that their child was going to die. Individual in-depth open interviews were held at the patients' home. Interviews ranged from between two days and one year before the child's death. Ten parents could only be interviewed after their child had died. In order to increase our insight into the parents' process a second interview with one or both parents took place in seven cases and in one case a third was conducted (Table 1). Professionals caring for the children included in the study were purposefully selected for a maximum variation of discipline and support experienced by the parents. Throughout the study selection was guided by the analysis.

Outline of the thesis

This study consists of three parts. In the first part, the preliminary study on parenting the child with leukaemia during the first year after diagnosis, we describe from the parents' perspective the essence of parenting in the light of a life threatening disease (chapter two). In the second part several aspects of parenting a child with cancer during the palliative phase were described. Chapter three contains a description of the essence of parenting a child with incurable cancer throughout the palliative phase. In chapter four the processes that underlie the parents' behaviour and care-giving during the palliative phase are explored. Special attention is given to the parents' coping with loss in relation to their need to stay in control. Chapter five presents an overview of the main factors that influence the parents' ability to let their child go at the EOL. The third part of this thesis describes, from both perspectives, the interaction between parents and professionals with respect to symptom treatment (chapter six). Chapter seven discusses the findings of this thesis and its implications for practice.

Table 1. Moment of interview in relation to time of death

Case	**Time before death (weeks)**								**Time after death (weeks)**				
	39-52	**27-39**	**14-26**	**5-13**	**3-4**	**2**	**1**		**1-2**	**3-4**	**5-6**	**7-8**	**9-10**
1				f+m									
2						f+m							
3			f	m									
4				f+m		f							
5							f+m						m
6		f+m											
7											f+m		
8			f+m	m									f+m
9											f+m		
10							f+m	**Death**					
11										m			
12			f+m										
13											m		
14						f+m				m			
15					f+m								f+m
16	f+m			m									
17				f+m					f+m				
18					f+m								
19				f+m						f+m			
20			f+m										
21				f+m									
22												f+m	
23													f+m

m: interview with mother; f: interview with father;
f+m: individual interview with father and individual interview with mother

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Chapter 2

Being there: parenting the child with acute lymphoblastic leukaemia

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Abstract

Aims and objectives. To gain insight into the lived experience of parenting a child with leukaemia during treatment.

Background. Diagnosis of leukaemia in children leads to an existential shock for parents and a reversal of normal family life. Today, in the Netherlands, after diagnosis, children stay at home most of the time. Therefore, their parents face considerable responsibilities for administering home-based treatment and for the support of their child during illness and treatment.

Methods. A grounded theory study was undertaken at a Dutch University Hospital and involved one-time individual in-depth interviews with 12 mothers and 11 fathers (n=23) of 12 children.

Findings. 'Being there', was identified as the core concept. It means: 'I'll be there for you; I will never let you down'. 'Being there' is described as a parental response to the perceived vulnerability of the child and the parental need to give meaning to parenthood. It serves two purposes: protection and preservation. Protection means guarding the child against the negative aspects of illness and treatment. Preservation refers to the way parents influence the child's perception of his/her life, thus contributing to his/her coping and willingness to undergo treatment, to maximise chances for survival. Six aspects were identified: a trusting relationship, presence, emotional support, advocacy, routines and rituals and effacing oneself.

Conclusions. The concept provides a theoretical frame for parenting the child with cancer.
It clarifies the actions and reactions of parents and increases insight into the underlying force that enables parents to provide continuing care despite their personal burden.

Relevance to clinical practice. The concept offers an essential insight into parenting the child with Acute Lymphoblastic Leukaemia and has relevance for nursing practice and education. Understanding of the concept will improve the ability to understand, communicate and work pro-actively in partnership with parents.

Introduction

Leukaemia is still a life-threatening illness despite recent advances in treatment [1, 2]. Current five year survival rates range from 60-80% [3]. This success rate is achieved through a long invasive and arduous treatment. Today, in the Netherlands, children diagnosed with leukaemia stay at home most of the time. Therefore, their parents play an important role in their treatment. In addition to the emotional distress, they have a heavy undertaking in managing both medical and parental care tasks. Research has described parental distress, coping and adjustment. More recent the focus has shifted to parental experiences. Little is written about parenting and in particular about parenting while actively involved in the child's treatment

Background

Having a child with cancer is an overwhelming life experience for both parents. It causes psychological distress, especially at time of diagnosis. Crisis reactions, such as shock, disbelief, despair, sorrow and anger are described [4-8]. Parents, on being confronted with the possible loss of their child, experience an existential shock [5, 8-10]. Most parents emphasise this as the beginning of a reversal in the normal and expected flow of family life; it changes their view of life and death, as well as their goals, expectations, hopes and dreams with respect to their child and family life [4, 5, 9, 11]. Guided by the hospital staff, survival of their child becomes the main focus of parental care [12]. Parents realise that treatment is indispensable [8, 9]. The treatment protocol for Acute Lymphoblastic Leukaemia (ALL) includes chemotherapy and procedures, such as various punctures [2, 13]. Two years of invasive and very arduous treatment follow, including a restrictive infection prevention regime [14]. As a result of the treatment interventions, therapeutic conditions and management of the illness, parents have to face their child's distress and emotional reactions [4, 15]. Despite medications to manage pain and anxiety, parents still experience procedures and treatment interventions as a major stressor [8, 16-19].

In the Netherlands, children are usually discharged after the initial 8-10 days of hospitalisation for diagnosis and treatment initiation. Hospitalisation is restricted to the time required for treatment or management of complications. This implies a heavy task for parents who have to reconcile treatment and parenting goals. Parents are confronted with unexpected stressful events and uncertainty associated with unpredictable outcomes [4]. Adjusting to the illness requires considerable coping efforts [10, 20, 21]. Taking care of the child with leukaemia is physically and emotionally demanding. Little attention has been, as yet, paid to the caring efforts of parents. The present study seeks insight into the lived experience of parents who take care of their child with leukaemia.

Aim

The aim of this study was to explore the lived experience of parenting the child with leukaemia during the first year after diagnosis.

Methodology

A qualitative design that employed grounded theory was used. This method facilitates description of phenomenon and the development of theory about the processes underlying experience and meaning [22, 23]. The underlying theoretical perspective is that people give meaning to their situation in interaction with others. This is the tenet of Symbolic Interaction in which grounded theory is rooted [24].

Sample

Parents were eligible for selection if their child was care-dependent (≤12 years), within the first year of treatment for ALL and able to converse in Dutch. Initial selection focused on maximum variation [22] on factors related to illness (phase of treatment, prognosis) and family demographics (child age, family size). Data collection and analysis alternated. This allowed preliminary analysis to guide purposeful selection of respondents who were of importance with respect to our emerging theory about parenting the child with leukaemia.

In all cases, nursing staff asked parents if the researcher could contact them. Of the 13 families approached, one couple refused because of the high degree of stress they had already experienced; one father refused because of his heavy workload.

Table 1. Characteristics of the children (N=12) [a]

Identification number	Age	Sex	Prognosis
1	4	f	>75%
2	2	m	50%
3	12	m	>75%
4	3	f	>75%
5	7	m	>75%
6	2	m	>75%
7	10	f	>75%
8	2	m	50%
9	6	m	>75%
10	2	m	50%
11	3	m	50%
12	5	m	>75%

[a] to prevent identification the sequence of the children does not correspondent with the sequence of the parents in table 2

A purposive sample of 23 parents (12 mothers and 11 fathers) of 12 children recruited from a paediatric oncology unit of a Dutch university hospital, participated in this study. The children, aged 2 - 12 years, differed in stages of illness and treatment, with a range from 10 days up to 12 months after diagnosis (Table 1). Parents, aged 29 – 42 years, were all Dutch. Their level of education showed diversity (Table 2). All families consisted of father, mother and the child with leukaemia. In eight families there were one or two siblings.

Table 2. Characteristics of the respondents (N=23)

Identifcation number	Sex	Age[a]	Interview after diagnosis[b]	Living arrangement[c]	Education[d]	Cultural Background
1	f	41	18 d	F,M,2S	middle	Dutch
2	m	41	18 d		middle	Dutch
3	f	40	10 m	F,M,2S,D	high	Dutch
4	m	39	10 m		high	Dutch
5	f	29	24 d	F,M,S,D	low	Dutch
6	m	32	24 d		middle	Dutch
7	f	27	20 d	F,M,S,D	middle	Dutch
8	m	36	20 d		low	Dutch
9	f	33	3 m	F,M,S,D	high	Dutch
10	m	32	3 m		high	Dutch
11	m	42	6m	F,M,2S	high	Dutch
12	f	42	6m		middle	Dutch
13	f	39	3 m	F,M,2D	high	Dutch
14	m	41	4 m	F,M,2S	middle	Dutch
15	f	39	4 m		middle	Dutch
16	f	42	12 m	F,M,S	high	Dutch
17	m	40	12 m		high	Dutch
18	f	41	3 m	F,M,S,2D	middle	Dutch
19	m	42	3 m		middle	Dutch
20	f	38	1 m	F,M,2S	high	Dutch
21	m	40	1 m		high	Dutch
22	f	36	10 m	F,M,S	middle	Dutch
23	m	37	10 m		middle	Dutch

[a] male (m), female (f)
[b] period between diagnosis and interview in days (d) or months (m)
[c] father (F), mother (M), son (S), daugther (D)
[d] low: primary school, lower secondary general, lower vocational
middle: higher secondary general aducation, intermediate vocational education
high: higher vocational eduacation, university

Data collection

Individual one-time in-depth interviews were conducted. Interviews took one to two hours and were held in the home of the respondents. All spouses left the room during the interview of their partner.

To ensure sufficient depth, parents were encouraged to tell their story. The interviews started with an open-ended question: ‘What has it been like for you since the moment the first symptoms appeared?’ With this question, parents needed little encouragement to talk about their experiences, emotions and motives. A topic list, compiled on the basis of literature, knowledge of nursing experts and preliminary studies of the research group was used as a check afterwards to ensure al topics came under discussion. Topics included parenting, family life, illness process, including discharge and coming home, caring activities, parental goals, crisis management and risk control. Data collection was completed in 2001.

The interviews were tape recorded and transcribed verbatim. Peer debriefing prevented from ‘going native’ [25] and preserved full engagement in subsequent interviews. Validity of data collection was enhanced by peer review of interview style. We paid attention to gaining the trust of the interviewee to raise the quality of the data. The interviewer showed understanding by being familiar with the factual content and empathising with the emotional undertones [26].

Data analysis

Data analysis was conducted in accordance with methods that optimised validity and rigor [27]. During the analysis, two complementary intertwined strategies, namely coding and thinking theoretically [28], were used and incorporated in the tried and tested method described by [29]. This method consists of four phases: exploration, specification, reduction and integration. It guided the constant comparative analysis and included open, axial and selective coding [28, 30]. Coding was supported by the software program WinMAX [31]. A research team of four members, including the interviewer, was involved in the entire process from data analysis through theory generation. The first researcher coded the interviews. The team members individually read the transcripts and the coding results. During joint meetings, they worked toward consensus about the interpretation considering possible meanings. The first researcher checked these interpretations in confrontation with existing data and new material. This approach increased the depth and the reliability of the analysis and constituted researcher triangulation. For instance, questions about (dis)similarities in caring intentions and activities were posed and explored in subsequent data collection. By using memos and explicating provisional conclusions and interpretations, the transparency of the analytical process and verifiability of the research were enhanced. Within the domain of our sample, saturation was reached.

Ethical considerations

The study was approved by the medical ethics committee of the university hospital in which the study took place. Written informed consent was obtained from both parents. All identifying details were removed from transcripts.

Findings

The study revealed ‘being there’ as the core-concept. First the concept is described. Then the purposes served by ‘being there’, the way parents express ‘being there’, the reinforcing power and the less constructive aspects of ‘being there’ are examined.

Being there as a response and a parental need

‘Being there’, as it is used by parents, must be understood as: ‘I’ll be there for you’ and ’whatever happens, you can count on me, I will never let you down’. All parents emphasise this meaning. The concept emerged as a fundamental aspect of parenthood. For most parents, ‘being there’ is the heart of their parenthood and the core of their existence.

‘Being there’ is the parental response to the perceived vulnerability of the child. Parents told us how at diagnosis they could only imagine their child would die. After becoming informed about treatment, it took time to interiorise hope. We consider this ‘in between’ phase as an existential crisis. ‘Being there’ is triggered by this existential crisis at diagnosis and the parental perception of the child suffering from illness and treatment. The perceived vulnerability, the awareness of the threatening and possibly traumatic events the child with leukaemia has to go through and the prospect of possible loss of their beloved child enlarges this parental awareness of how fragile his life is:

> *The fact that you have a seriously ill child makes you want to be with him, you’re afraid to lose him.* (R9)

‘Being there’ is also a deeply rooted parental need; a feeling of ‘not being able to act otherwise’. By ‘being there’, parents meet the perceived needs of their child and by fulfilling their own caring needs they give meaning to their parenthood.

Parents told us the child appeals to their care and support. This changes their relationship. In spite of the usual weighing up of the child needs and interests against their own to maintain a justifiable equilibrium, parents place themselves in service of their child:

> *I was with her during the first bone marrow puncture. Someone asked me: ‘Were you with her then?’ and I answered: ‘Of course I was.’ I mean, if I wasn’t there then who else would be? I mean, it’s so unpleasant, there’s no way that I could just wait for her on the ward. At a time like that, you want to be there for her, you want to stay calm for her. And you’re able to do just that. The child comes first and me? ... Well that comes later.* (R18)

Caring and supporting the child and experiencing the child's positive reactions feed the bond between both. By 'being there', parents materialise their involvement with their child in everyday life, and in doing so, they exercise a meaningful parenthood.

The power of practising 'being there' resides in the fact that when nothing is left to be done or seems to help, they can still 'be there'. Some of the parents speculated that in the eventuality of the child facing death, 'being there' would be the most important and meaningful thing they had to offer.

Purposes of 'being there'

'Being there' serves two purposes: protection and preservation.

Protection

Protection means guarding the child against the negative influence and consequences of illness and treatment to improve his/her well-being. Additional purposes associated with protection are: creating feelings of safety and comfort, relieving suffering and preventing (the threat of) harm inflicted by others.

Parents describe how, especially during diagnosis and initial treatment, their unprepared child is exposed to threatening situations such as the confrontation with strangers and technical equipment, the need for immediate medical intervention and parents who are frightened and tense. What matters to the parents first is that they can offer their vulnerable child comfort and safety.

Although parents experience professionals as being attentive to the relief of the child's burden, there is still the inevitable pain and suffering related to hospitalisation, complications of medication, punctures and other invasive treatments. Most parents emphasise that they feel an overwhelming drive to relieve the burden and suffering of their child. Moreover, their child, in his own way, 'asks' them to 'be there'. They see that when they, as parents, behave according to the concept 'being there' their child derives a certain power and stability from them and develops the ability to manage unpleasant situations.

'Being there' is also important in preventing harm that other persons can inflict. Parents realise that, unlike themselves, professional care-givers do not always place the child first. They often have other priorities. Sometimes, they even make mistakes. Parents describe threatening or harmful consequences and emphasise the importance of being alert and being able to direct others to safeguard the child's interests:

> *The first time he got a spinal tap and a bone marrow tap on the ward. They didn't anaesthetize him but instead of this gave him Dormicum®. I can understand that because they wanted to treat him as soon as possible. But soon you find out there are plenty other reasons why things proceed the way they do. And often it has nothing to do with him. It's just a logistic problem or a lack of communication. The moment you realise that you can't accept it anymore.* (R10)

In two cases, the child had difficulties with this parental protectiveness. This was partly ascribed to behavioural changes as a side effect of medication (dexamethasone) and partly to the developmental stage of the child (early adolescence). It made their parents feel very frustrated and powerless.

Preservation

Preservation refers to the way parents influence the child's perception of his/her life so the child can better cope with it, thus trying to increase his/her willingness to undergo the treatment to maximise his/her chances for survival.

The restrictive treatment regime and the infection prevention instructions frustrate the child's daily living pattern and well being. Parents notice their child has difficulties coping with illness-related unpredictable and uncertain events.

They also realise their child has difficulties understanding the connection between treatment and recovery. Consequently, he/she does not perceive the importance of struggling and persevering now to survive in the future. Parents describe moments or phases when the burden is too heavy for the child. At best this results in a temporary refusal to cooperate, at worst in violent (sometimes physically and prolonged) protest. Losing cooperation is considered a threat for the cure. Parents feel that by 'being there' the process the child has to go through develops into a joint process. That they are doing it together enhances his/her willingness to endure treatment.

Furthermore, they influence the child's perception of his/her life and the manner in which their child experiences the illness and treatment. They defuse threatening situations, explicate and regulate unexpected events and compensate his burden. Parents guide their child and make his life easier, in such ways as, for example, arranging visits with school friends as soon as the danger of infection is diminished and the child feels well enough to enjoy it.

Such parental actions enable the child to cope better with the entire process and in turn the parents feel that, by 'being there', they contribute to their child's chances of survival. A father spoke about the spinal tap his son had to undergo:

> *It is hard to see your child wrestling because they are holding him so tight. It was so difficult. The medication didn't take away his fear. He fought to get away, to be released. It makes you feel sad. You know it has to be done and as his parent you try to calm him down, to take away his panic. His cooperation is necessary for them to do the puncture, but it was awful. You feel powerless and at the same time you hope that by being there you can give him the power and strength to help him get through this. After all you just want to see him get better…* (R 17)

Ways to express 'being there'

Parental life contains numerous expressions of 'being there'. Based on our data six aspects were distinguished: trusting relationship, presence, emotional support, advocacy, routines and effacing oneself. The individual parent uses a mix of all these.

A trusting relationship

'Being there' takes form in a trusting relationship between child and parent. Parents are well aware of this, actively building, deepening and strengthening the existing trusting relation. Parents build this relationship by being honest and clear (tuned into the child's level of understanding), trying not to harm their child's trust. They show a certain amount of power, so the child can lean on and derive his power from them.

Tensions can arise when parental involvement in treatment implies carrying out interventions that are unpleasant in the child's opinion. Unpleasant interventions force the parent to abandon the role as comforter. The tension between 'being there' and carrying out unpleasant interventions can be so great that parents look for the opportunity to delegate them to professionals to safeguard the trusting relationship with their child.

Presence

Parents manage their activities so that at least one of them can be near the child, both literally and figuratively. This means they room in during hospitalisations and at least one of them is present with the child at home. Parents want to be available in case their child needs them. In addition to presence and availability, physical contact is a powerful manner of expressing 'being there'. Taking the child on their lap or holding hands allows the child to feel calm and safe.

Both presence and a trusting relationship were mentioned:

> *It's Agnes' (the mother's) work. She has built an enormous trusting relationship with him. Going to the hospital, giving medication, doing all those awful things… The fact he still goes to the hospital with pleasure, is still able to make the best of it, is for a great deal due to us, to the work of Agnes, because we always stay with him, we have always been with him. Until now, he never woke up without us. He never had to go to the hospital without us. He can always feel safe because he is with us, his parents. That's what makes him feel supported, helps him to cope with it.* (R11)

Emotional Support

'Being there' is optimised by emotional support. To provide emotional support, insight is needed into the experiences, needs and coping strategies of the child. For parents, it is crystal clear that they are the experts. They know their child best; are aware of the background of his feeling and thinking. Because they know how the child usually copes with stress and burden, parents are convinced they can best interpret the child's needs and know how to support the child:

> *Nurses often get irritated because he talks the whole day. We know it is just his way to keep him on his feet. For us it is a sign of his difficulty coping with every day life in hospital. We understand he needs to talk and we are more patient with him.* (R16)

Advocacy
Their child is unique and the object of their never failing care. Preservation and well being of the child comes first. During treatment, parents develop their parental role and become more experienced and conscious of the differences between themselves and the professionals concerning the interest in and goals for the child. Particularly, when they notice that the child's suffering is unnecessary or the treatment has shortcomings do they become advocates for the interests of the child (see also quote R10 under purposes of 'being there').

Routines and rituals
'Being there' is also expressed by managing daily living in such a way that the child experiences it as familiar. Daily habits and rituals are continued whenever possible, new comforting rituals are introduced. New rituals focus mainly on the transformation of burdensome interventions or experiences into a manner that the child can handle. This is one of the reasons parents can become furious when a new laboratory assistant takes blood without using the comforting rituals.

Effacing oneself
'Being there' implies that parents efface themselves. Parents told us that they tried to ignore their own fears, worries and needs when it was necessary to support their child. At crucial moments, they suppressed their own emotions to act for the benefit of their child. They wanted to be the strong person the child can rely on, even during crises, so that they could still manage to take in information, make decisions and perform the necessary caring activities:

> *You want to be there for him, to not allow your emotions to influence your ability to do the necessary things for him. He's just so small; he doesn't understand it when he sees me crying.* (R10)

Differences between fathers and mothers

Although both father and mother expressed their need to 'be there' some differences were seen. Mothers focus on involvement in the life of their child- a feeling of empathy and staying together is important. Fathers tend to advocate and support the child in a more practical way; they want to 'have done' something. Fathers also seem better able to leave 'being there' to mothers, than the other way around. They feel fine when their spouse is with the ill child in hospital and they facilitate her 'being there' by maintaining family life at home. Mothers prefer to 'be there' themselves.

The reinforcing power of 'being there'

'Being there' takes time and is physically and emotionally energy consuming. Most parents mentioned the tension between managing family life complicated by the illness of their child and their need to 'be there'. Although they feel it is beyond their strength, they still try to 'be there'. Three factors explain their perseverance. First, 'being there' reinforces itself. By 'being there', parents experience their unique significance as parents. Most parents described the relationship with their child as having deepened. They became closer which in turn supported the parents' feelings of well being. Second, the life-threatening character of leukaemia makes distancing almost impossible. Knowing that death is not beyond the horizon but in front of them reinforces the need to maximise their parental role. Parents realised they might not have the chance to do it over again. In the third place, 'being there' offers parents the opportunity to find an optimal fit between the limitations caused by the illness and the wish to support the child during the unique and irreversible process of paediatric growth and development. Although their child is ill, they choose to actively contribute to his growing up like his peers:

> *I went to school when his class played at the schoolyard. Four-year-olds play outside the school every day. I tried to be there with him, so he could play with his schoolmates just like other children. It structured his day, he became tired in a healthy way and it contributed to his development.* (R12)

Less constructive aspects of 'being there'

'Being there' is highly demanding, parents running the risk of becoming burned out. 'Being there' implies that parents are more exposed to the emotional and physical reactions of the child. Hence, their workload increases. Parents prefer not to delegate care because in their opinion this negatively influences the care situation for their child. No one can provide care in the same secure way and so totally harmonised with the perceived needs of their child as they do.

Another risk is that the intense relationship with the child becomes symbiotic, thereby frustrating the normal development of the child including the process of distancing that adolescents have to go through. One case portrayed how the initial empathetic and trusting relationship changed in identification. In identification, the parent is no longer able to separate the experiences and needs of the child from his/her own experiences. One respondent spoke consistently from a shared perspective: 'We looked forward to the implantable venous access, but it is not as helpful as we hoped.'

Discussion

This study provides 'being there' as a new framing concept with respect to parenting the child with ALL. It describes the parental protectiveness aimed at well being and their support in helping the child cope with treatment aimed at survival.

The literature about parenting the child with cancer provides support for several aspects of 'being there' and our interpretation of the concept.

Protection is seen at diagnosis where parents reshape their parental role [5]. Focus is on the child's' physical and emotional needs [7]. Parents enhance their involvement and control by choosing tasks that give them the feeling of having a positive contribution to his/her situation [17, 32]. This may be compared to paediatric intensive care settings where parents have to leave the most consequential part of the care to professionals. In reaction to this, they try to hold on to parenthood, by developing a comforting and protective parental role [33, 34].

Studies confirm that although parenting is physically and emotionally demanding, parents do not withdraw from their caring tasks [11, 17, 35, 36]; they dislike being separated from their child during hospitalisation [17, 36] and want to be strong for their child [4]. This can result in feelings of exhausting [10]. The fact that parents still try to care supports our idea that 'being there' is a parental need. This was also observed by Wilson et al. [37] and described as the absolute involvement of mothers of ventilator-dependent children, by putting themselves in the service of their child. In her study of care-giving demands, Svavarsdottir [38] found that parents consider giving emotional support as the most important, even though it is the most time-consuming and difficult task. Svavarsdottir [38] did not explicate emotional care, however in line with her findings; we suggest the parental emotional support is related to enhanced parental receptiveness for the child's attempts to cope with illness. We suggest that the concept of 'being there' provides a theoretical frame in which these separate facts can all be labelled as expressions of the need to 'be there'.

ALL is seen as a major stressor for parents [39, 40]. Adjustment asks considerable coping efforts [20]. In our analysis, 'being there' is the parental response to the perceived vulnerability and suffering of the child and thus not considered as a coping strategy of the parent. It motivates to care and gives meaning to parenthood. Coping can be explained as 'the efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person, to reduce stress' [41]. The need 'to be there' as well as actually 'being there' can even cause or enlarge feelings of distress.

'Being there' throws new light on parental experiences and thereby on the literature concerning negotiation of care and conflicts between parents and health care providers. Parents' criticism concerns a lack of the team's attention to the child's distress [19] together with a lack of understanding of the parenting situation [6]. Moore & Beckwitt [18] stated that, besides differences in information and interests, the origin of conflicts can be attributed to dissonant worldviews concerning the child's interests. This divergent view often leads to a breaking point, after which parents become the advocate for their child [18]. We suggest that the need to 'be there' influences parental evaluation of professional care. The parental need to 'be there' directed at protection and preservation guides the parents in acting towards and dealing with health-care providers. Parents are convinced that they know their child best and professional staff should make more use of this parental knowledge to develop a partnership which serves the child's health and well being [37, 42-45].

The knowledge of the need to 'be there' has implications for nurses. Nurses should organise and manage their care-giving in a way that enables and encourages parents to 'be there'. At the same time and in partnership with parents, they need to be alert for the less constructive parts of 'being there': an overly protective relationship or 'burning out'. Owing to duties and obligations and to other roles in family or work, parents can have limitations. If nurses take over caring activities they should incorporate the modalities of 'being there' noticeable in their caring activities to be supportive to the parents.

Study limitations

Our sample consists of couples only and therefore does not reflect all types of parents in wider society. The relative older age of the parents reflects the mean age of Dutch women who give birth to their first child (29 years) [46] and the age-specific incidence rates of ALL (increased risk between 2 and 7 years) [47]. This can have impact on the concept because older parents may benefit from greater life skills compared with young parents. As our study intended to describe the first year after diagnosis, we have no insight into alterations that may have occurred in the later experiences of parents.

Conclusion

This study explored the lived experience of parenting the child with leukaemia. The concept 'being there' is described as a parental response to the perceived vulnerability of the child and a parental need to give meaning to parenthood. 'Being there' means 'I'll be there for you'. It is the driving force behind parental care and supports the never-ceasing involvement of parents with their child. It triggers and considerably enlarges their care- giving capabilities.

The concept provides a theoretical frame for the aspects of parenting found in this study as well as in earlier studies of parenting a seriously ill child. With respect to parenting the child with ALL, coping is a reaction of parents to reduce their own stress. 'Being there' is a reaction to the vulnerability of the child to increase the child's well being and his ability to cope with illness and treatment. The concept 'being there' contributes to a better understanding of parents and their interactions with their child with ALL as well as with professional care givers.

Because of the limitations of the sample, further study of the concept 'being there' is recommended, especially with respect to diversity in sample characteristics such as family arrangement (single parents), cultural background and situations where the life threatening aspect is less prominent. In line with the sense of some parents that 'being there' is the only thing they can offer in situations where the child will not survive, more insight into 'being there' during the palliative phase is indicated.

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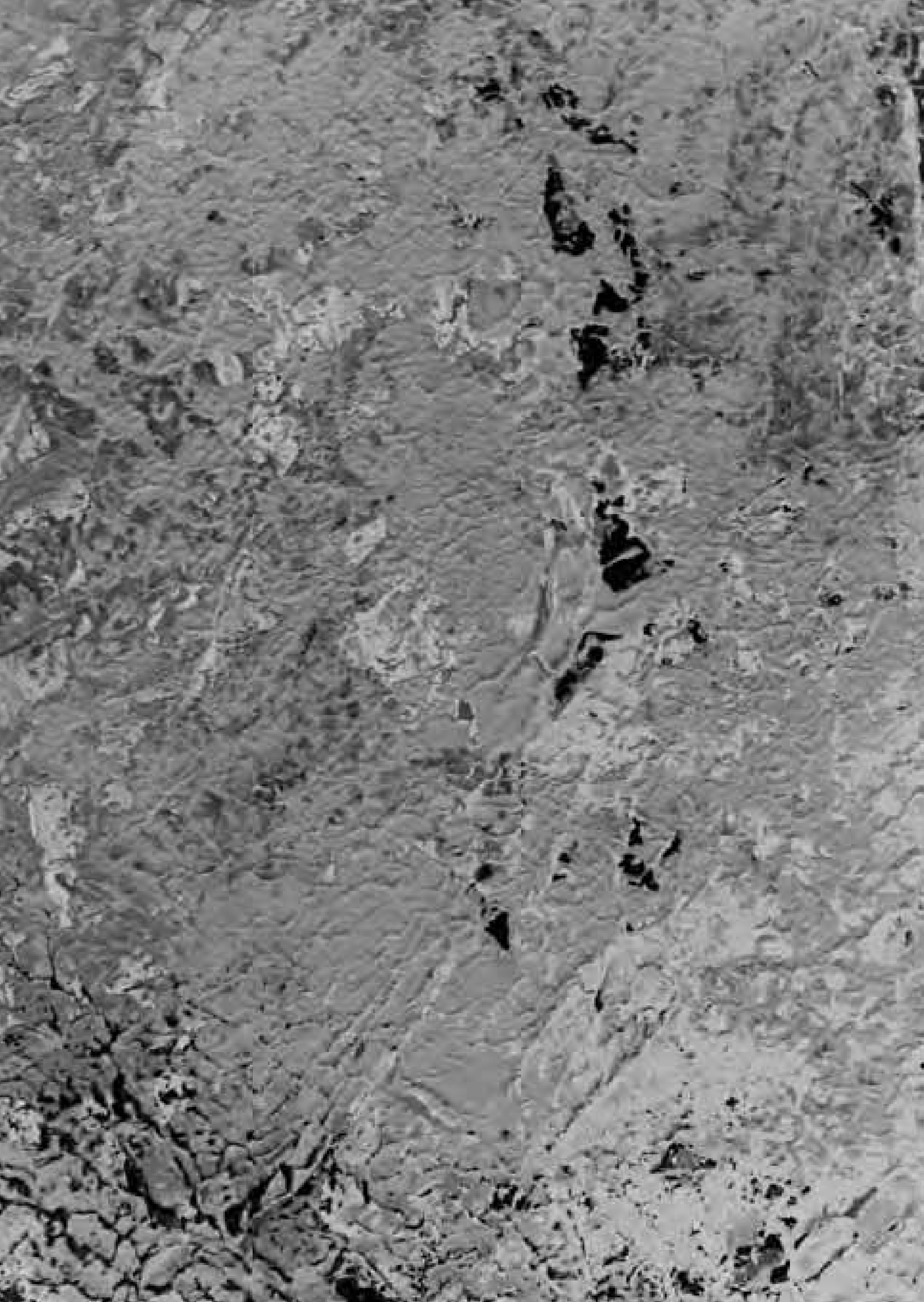

Chapter 3

Being a parent of a child with cancer throughout the end-of-life course

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Abstract

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 paediatric oncology centres

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

Methods. 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 care-giving 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 the child's situation and redefine their role accordingly, such as by providing information and alternative perceptions that fit to the child's changed needs while preserving the parent-child relationship. Attention to signals indicating stress disorders is needed.

Introduction

Death can be anticipated for most children with progressive cancer. Parents often aware of their imminent loss [1] 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 [2, 3]. In most western countries, EOL care increasingly comprises cancer-directed therapy to prolong life or phase I/II studies [3, 4]. 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 [5, 6]. In the Netherlands 63% of children who die from cancer pass away at home [7]. 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 homecare. As a consequence, all children and their parents transfer from the multidisciplinary team of the paediatric oncology ward (with among others nurses as their primary caregivers) to the general practitioner. Once 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: transmural 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 [8, 9]. Previous research has focused on their problems and needs. Parents report EOL decisions to be the most difficult treatment-related decisions they face during their child's cancer experience [10, 11]. However, parents stress their need to have their views taken into account when decisions are made [12, 13]. In addition, parents need honest information and open communication to provide adequate care [14, 15]. Finally, parents find having access to care providers they can trust and with whom they feel a bond to be helpful [16]. Parents felt positive as a result of nursing their child themselves [17, 18]. However, several problems have been reported, including inadequate symptom management [19-21], the child's distress [22] and the parents' own fears of the moment of death [17].

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 [22-24]. The few prospective EOL studies revealed that parenting at EOL is not guided solely by objective medical arguments or by clearly defined child-centred goals such as improving the child's quality of life or relieving suffering. Kars et al [25] 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 of palliative cancer-directed treatment [11, 22, 26]. Parenting at the EOL increasingly is believed to be influenced by existential issues and meaning giving [11, 15, 25]. Parents may fare better in this experience by finding meaning in what they are going through [3]. Therefore, a better understanding of how parents give meaning in these circumstances is important to improving paediatric 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 End-of life phase.

Methods

The authors conducted an interpretative qualitative study using an inductive thematic analysis [27]. Analytical techniques that are common in phenomenological research were used to gain insight in the parents' main experiences and meaning giving during EOL [28]. The aim was to improve the understanding of the EOL experience from the parents' perspective [29].

Sample

Parents were recruited from five university paediatric oncology centres, which together cover 80% of all Dutch paediatric 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/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 it 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' home. 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.

Table 1. Participant Characteristics (N=42)

Characteristics	N	%
Gender		
Male	20	48
Female	22	52
Age		
<30	2	5
30-40	27	64
≥40	13	31
Marital status		
Married/cohabiting	39	93
Divorced/not cohabiting	3	7
Education		
low*	13	31
middle**	17	40
high***	12	29
Age child at first interview		
0-1	2	9
1-5	9	41
5-12	6	27
12-16	4	18
16	1	5
Type of cancer		
Leukaemia or lymphoma	9	41
Central nervous system tumours	5	23
Neuroblastoma	2	9
Renal tumours	1	5
Hepatic tumours	2	9
Bone tumour/Soft tissue sarcomas	3	14
Time first interview before death		
10-12 months	2	
7-9 months	2	
4 - 6 months	6	
1-3 months	10	
3-4 weeks	4	
1-2 weeks	4	
1-7 days	4	
Time first interview after death		
4 weeks	1	
5 weeks	1	
6 weeks	4	
7 weeks	2	
10 weeks	2	

*low: primary school, lower secondary general, lower vocational;
**middle: higher secondary general education, intermediate vocational education;
***high: higher vocational education, university

The study was approved by the medical ethics committee of the University Medical Centre Utrecht. Written informed consent was obtained from all participating parents.

Data analysis

Data analysis conducted according to the Giorgi method [28, 30], 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 [27]. The team worked towards a consensus in interpretation – comparing meaning units within and between cases. MK 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 NVivo7 was used to increase insight into the content, the meaning and the 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' perspective. 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 paediatric 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.

Stage 1 Becoming aware of the inevitable death

Inevitability of death

This 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 the 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 and, as such, offer them 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 towards 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 counselling 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 for new anchor points.

Having done everything to save their child

The most pressing concern was to explore remaining medical options. Participants related how 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 bears the promise of prolonging their child's life and, therefore, 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 the child's well-being during the EOL phase. Irrespective of whether parents decided to focus on cancer-directed treatment to prolong life or to 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 fulfil 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 who 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, picking up and 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 had 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

Roy was a seven-year-old boy with renal tumour. His mother was interviewed two weeks after the oncologist 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 tumour. 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	*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.*
Relying on yourselves/being left alone	*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 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	*And that was just so, so difficult for me. I can't just stand by and watch. I just can't do that. So I went to a homeopath and I went to an uhhm…what do you call it? …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…I mean…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.*
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 cd's 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 the 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 that horrible tumour, those nasty cancer cells have come back again.' He's still taking medication to protect him. I am so scared that at if we stop giving him the medication that Roy… well you know at that moment will realise 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 realise. 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?*

Note. Quotes were slightly edited to increase readability. Names are fictitious.

Figure 1. Illustrative quotes of stage 1: Becoming aware of the inevitable death

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 and her 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 how to behave so the child would appreciate participation. A kind of balance developed, which appeared to be the start of the second stage.

Stage 2 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.

Being there: enjoying life
Thinking that their child's life would end in misery was unbearable to parents. Parents wanted to be there for the child 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 fulfilment 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 behaviour 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 that 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, the 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, keeping future stages out of sight. This 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 did give parents a firm footing. Decisions were mostly in line with earlier ones and were aimed at prolonging this stage and/or 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 lacks 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

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	*And she keeps saying 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. (F)*
Being there: enjoying life	*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. (M)*
	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…(starts to cry) but that she does know I am there. (M)
Cherishing the child's identity and wholeness	*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.* *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 (F)*
Just going on	*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 Diane how she does it all. Then you just have to think about stopping moaning yourself. (F)*
Keeping the child going	*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. You know, sort of 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… yes… 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… well… there might come a point… you know. When we have to talk about the funeral. But not yet. It's too early for that (F).*
Directing and controlling the outside world	*What I think is really important is that she can go to school. So it needs to be well organised 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. (M)*

Note. Quotes were slightly edited to increase readability. Names are fictitious.

Figure 2. Illustrative quotes of stage 2: Making the child's life enjoyable

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 the 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.

Stage 3 Managing the change for the worse

The third stage was marked by the 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 1or 2 indicated 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 the child was affected and saw his/her 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 her suffering. It is a response to the parents' perception of the child's appeal, but also to their own need to be of meaning to the child. Even parents who needed some distance or showed some avoidance to relieve the stress of their suffering from the threat of loss expressed their 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.

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

Discovering illness has taken over from life	Whilst Michael was taking the study medication, he went to the United States for a holiday three weeks 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 realised 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. (F)* Regarding the approaching end of life: *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. (F)*
Being there: presence during suffering	*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. (F)*
Keeping going	*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 towards 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 gonna collapse. (F)*
Sharing the process of death and dying	*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… I don't know, 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. (F)*
Preparing the funeral	Parents have 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… (cries). (M)*

Note. Quotes were slightly edited to increase readability. Names are fictitious.

Figure 3. Illustrative quotes of stage 3: Managing the change for the worse

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 light heartedly. The child's participation was limited, so the 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 the 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 was also 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 there' 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 neighbours.... 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 inwards 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 on to. 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 for a cremation so that they could take the 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.

Stage 4 Being with the dying child

In contrast with the previous stages, stage 4 is based on retrospective stories. 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 (see Figure 4).

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

Fulfilling wishes and promises
Parents who had discussed the dying phase with their child in advance felt especially responsible for honouring the wishes and promises they had made. Of major importance was the promise to prevent suffering. In hindsight, parents positively evaluated the accomplishment of these 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. Most parents felt there was no control. 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 present and watching die to be a severe burden. Most parents could not give any positive meaning to their child's suffering.

Jonathan was a two-year-old boy with acute myelogenous leukaemia. Jonathan's condition deteriorated very quickly on Wednesday and he died on Thursday afternoon. His mother was interviewed seven weeks after his death.

Losing reciprocity	*Then he was given Dormicum®. That was a really horrible moment, because he (the General Practitioner (GP) 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. (cries)… yes…it was only about 1 1/2 minutes, but still.*
Being there 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 Kevin (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.*
Being the child's advocate: alleviation of suffering, fulfilling wishes and promises	When the GP in her perception did not react sufficiently to Jonathan's pain and restlessness the mother phoned the oncologist, on her own initiative. *The oncologist then phoned the GP 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 3 ½ 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".*
The unbearable aspects of the dying phase	*I found that….well 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 grey, 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 GP 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 slightly edited to increase readability .Names are fictitious.

Figure 4. Illustrative citations of stage 4: Being with the dying child

Discussion

The current study identified four EOL stages from the parents' perception: 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 from caring and being there in response to their child's needs.

The current study has 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 'thick descriptions' of all phases from both fathers and mothers increased the trustworthiness. Similar patterns were seen in all the 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 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 what the individual construes as loss triggers grief, even if the loss has been anticipated [31, 32]. The current authors agree with Fulton et al. [31, 33] and Gunnarson and Ohlen [34] that this is actual grief and should not be conceptualized as anticipatory grief, as some authors have [35]. The confrontation with losses while being unable to give any positive meaning to the loss 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 in order 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 limit their perspective to living in 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 leukaemia and as a parental need to give meaning to parenthood [36]. 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. [36], the current study found that 'being there' strengthened the parent-child relationship and increased the parents' capabilities to give care. Although care-giving 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 [6, 18]. From the perspective of the child, Woodgate [37] 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 to surrender to 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 stage 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 acknowledgement 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 pro-actively, 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 [14, 15, 38].

Like [23] 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 [39, 40]. The current study consolidated the parents' need 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 [41-43].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 the 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 [44], who concluded 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, facilitating the parents' change in attitude by helping them to develop new meaningful perspectives is also needed. Nurses can explain that letting the child go does not equal giving up. Many parents expressed the over-riding importance of hearing from professional caregivers that they facilitated a peaceful death at home and decreased the risk of an uncontrolled death in the intensive care unit by deciding to finish cancer-directed treatment. Many parents learned that aspect of meaning giving from healthcare providers.

Nurses should strive to preserve the parent-child relationship and to facilitate being there. Both 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 favourite 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 fulfil their parental role, which left them vulnerable in a crisis. The authors encountered signals of depersonalisation, which must be taken seriously, because they are considered a symptom of acute stress disorder [45].

Suggestions for further 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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Chapter 4

Parental experience at the end-of-life in children with cancer: 'preservation' and 'letting go' in relation to loss

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Astract

Purpose. For children with incurable cancer death usually is anticipated and preceded by a phase of palliative care. Despite recognition that parents have difficulty adapting to a palliative perspective there is little insight into this process. This study explored, from a parental perspective, the process parents go through when cure is no longer a possibility.

Participants and Methods. A multi-centre study using qualitative research was undertaken during the EOL-phase. One-time and repeated open interviews were conducted with 44 parents of 23 children with incurable cancer.

Results. Feelings of loss play a prominent role during the EOL-phase. Dealing with loss is a process of stepwise relinquishing that becomes manifest in an internal struggle between preservation and letting go. Preservation means that parents try to maintain the child's status quo. Letting go means parents give up their resistance to loss in service of their child's well-being. Although the relative measure of each changes over time, parents have great difficulty making the transition because it implies a change in source of control. A timely completion of this transition positively influences the child's well-being as well as the evaluation of enacted parenthood.

Conclusion. For parents the essence of the palliative process is not to accept death but to deal with the loss of their child. Although the need to avoid loss and gain control by means of preservation is fully understandable the study indicated that parents who made the transition to letting go had an increased receptiveness of their child's real situation and needs.

Introduction

Although many children with cancer can be cured, approximately 25% will die of their disease [1]. These deaths are usually anticipated and preceded by a period of palliative care focused on the End of Life (EOL) [2]. Palliative care is an approach which improves the quality of life of the patient and his family facing life threatening illness, through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems from diagnosis to the end of life and bereavement [3]. During treatment parents are socialized in hope and curative goals [4]. Within the context of palliation the transition to EOL-care requires a transition in thought from 'cure' to 'quality of life' [5, 6]. In paediatric oncology this change in perspective is usually seen from a decision perspective [7, 8]. Parents report end-of-life decisions to be the most difficult treatment decisions they face during their child's cancer experience [9]. Research shows that the timing of the decision on entirely symptom-directed treatment varies largely across parents [8, 10, 11].

Although the difficulty of making trade-offs and decisions are generally acknowledged most research focuses on the outcomes of parental decision-making especially with respect to medical decisions [12, 13]. It is unclear how parental perception and decision-making comes about and changes over time. Overall the process parents go through during the EOL experience is quite unclear. Research into the parental perspective is scarce, often limited to a single institution and retrospective [14]. Usually data are gathered from parents whose child died many years before. This multi-centre study is designed to investigate the 'lived experience' of parents who are informed treatment has failed. The study objective is to identify processes parents go through when cure is not obtainable, and to explore the influence of parental processes on the choices they make with respect to their child's treatment and care.

Methods

We used a Grounded Theory approach in order to develop theory that interprets the data [15, 16].

Sample

Parents were recruited from 5 Dutch paediatric oncology university centres which together cover 80% of the Dutch paediatric oncology patients. Parents of children (0-16 years) with all types of cancer were considered eligible the moment the oncologist informed them that curative treatment had failed. Parents who spoke Dutch and cared for their child at home were enrolled, irrespective of whether their child received cancer-directed or symptom-directed therapy or participated in a phase I/II study. The oncologist introduced the study and asked permission for the researcher to contact them. Available data indicate that parents were not asked to participate when the course of disease was very progressive (oncologists reported the child died within 1 week) or when communication was complex due to relational or cultural problems. In three cases parents refused participation. They expected it to be too burdensome or the palliative undertone of the study did not fit with their perception. 44 parents (23 mothers and 21 fathers) of 23 children (aged 6 months to 18 years) participated. For characteristics see Table 1.

Table 1. Characteristics of the Respondents (N=44)

Characteristics	N	%
Gender parents interviewed		
Male	21	48
Female	23	52
Age parent		
<30	2	9
30-40	27	61
≥40	15	34
Marital status		
Married/cohabiting	39	89
Divorced/not cohabiting	5	11
Cultural background		
Dutch	42	95
Other	2	5
Education		
low*	13	30
middle**	19	43
high***	12	27
Age child at first interview		
0-1	2	9
1-5	9	39
5-12	6	26
12-16	4	17
≥16	2	9
Type of cancer		
Leukaemia or lymphoma	9	39
Central nervous system tumours	5	22
Neuroblastoma	2	9
Renal tumours	1	4
Hepatic tumours	2	9
Bone tumour/Soft tissue sarcomas	3	13
Germ cell tumours	1	4
Time first interview before death		
6-12 months	4	
1-6 months	18	
1-4 weeks	8	
1-7 days	4	
After death	10	

*low: primary school, lower secondary general, lower vocational;

**middle: higher secondary general education, intermediate vocational education;

***high: higher vocational education, university

Data collection

Individual in-depth open interviews were held at home. In seven cases second interviews with one or both parents took place and in one case also a third one, resulting in 57 interviews at different moments during the EOL-process. Interviews were conducted between 2005 and 2007, lasted one to two hours, and ranged between two days and one year before death (Table 1). Ten parents were not able to talk with us during the process. They could only be interviewed after the death of their child. A topic list, compiled on the basis of literature, knowledge of experts and preliminary studies of the research group, was used as a check at the end of the interview to ensure all topics came up for discussion. Topics included parental care and goals, parent-child relationship, loss and parting, coping, professional care and family life. Interviews were tape recorded and transcribed verbatim. The study was approved by the medical ethics committee of the University Medical Centre of Utrecht. Written informed consent was obtained from both parents.

Data analysis

Data analysis was conducted in accordance with methods that optimized validity and rigor [17]. During the analysis, two complementary intertwined strategies, namely coding and thinking theoretically were used [18]. A research team of four members, including both interviewers (MK, MdK), was involved in the entire process from data analysis through theory generation. They individually read transcripts and coding results. Peer review with respect to interview style enhanced validity. During joint meetings they worked towards consensus about the interpretation considering possible meanings thus guiding the constant comparative analysis. MK checked these interpretations against existing data and new material. As such we continuously verified the correspondence between our interpretations and the original interviews. This method constituted researcher triangulation and increased the depth and the reliability of the analysis. Coding was supported by the software program NVivo7 [19] and included initial and focused coding. The attention to meaning was enhanced by 'active coding' as is described by Charmaz [16], thus facilitating interpretative theory that fits the experience of our respondents. By using memos and explicating provisional interpretations and conclusions the transparency of the analytical process and verifiability of the research were enhanced.

It was considered unethical to ask parents to reflect on the interviews and our interpretations while still being in the process of losing their child. Moreover due to changes in the parents' perspective member checks would possibly rather decrease than improve validity [20, 21]. We can account for our findings because we adapted the focus of our interviews to increase our understanding of how, when and why theoretical categories vary. Also parents interviewed after the child's death were invited to reflect on their process and as such provided validation for the existence and the essence of the internal struggle and transition. Initial theory and conclusions were discussed with Dutch experts from various disciplines who worked in the area of paediatric oncology.

This study revealed a central organizing construct, i.e. preservation versus letting go. These two concepts were intrinsically linked to a third concept: loss. Our data showed parents made a transition that could be explained by the relation between these concepts. Theoretical saturation [16, 18] was reached with respect to aforementioned concepts and the transition.

Results

‘Letting go’ and ‘preservation’ in relation to loss

From the ‘treatment failed’ announcement till the moment their child passes away, parents experience an internal struggle between the wish for ‘preservation’ and the willingness to ‘let the child go’. It was expressed in every interview regardless of the child’s condition or illness stage. During the palliative process parents alternate between ‘letting go’ and ‘preservation’. At the same time, the balance shifts over the course of illness towards ‘letting the child go’. The individual course and the variation between parents are strongly related to their ability to manage feelings of loss. Loss was encountered in all interviews.

Parental experience of loss

During the curative phase parents and medical staff worked side by side for the survival of the child. The ‘treatment failed’ message confronts parents with the inescapability of the loss of their child. The dominating feeling is that they cannot let him go; life is meaningless without him/her.

During the interviews the tragedy of the (imminent) loss was often expressed more intensely non-verbally than verbally. Parents broke down as soon as feelings of loss were addressed. They emphasized their special attachment to this child and how they cherished and enjoyed all those expressions which in their opinion reflect his/her identity. Till far into the dying phase, even if their child could hardly move or express anything, parents saw and encouraged these expressions as signs of his/her personal identity. For parents this makes caring worthwhile, reinforces their caring efforts and encourages them to provide ongoing care even when the child cannot give much in return.

Feelings of loss are also triggered by anticipated loss. The mother of Anco (3, ANLL):

> *...sometimes, when you see him playing, you suddenly realize that soon that will be gone. And then you really realize it...yes, then you can just lay me out.*

Parents expressed pride in their child’s development and competences. Most of them sensed in advance what the loss of their child would mean to them in future: they will not feel the pride and pleasure of seeing their child grown and self-reliant, never again be a complete family and they will be unable to see themselves reflected in the look and performance of this child. They lose a part of their parenthood as is expressed by the mother of Tom (12, rhabdomyosarcoma)

> *This is such a strong child; he could have accomplished so much. He’s a fighter, in that respect he takes after me.*

Knowing this all will end, together with the awareness of the excruciating pain his/her absence will cause in their future life, brings about unbearable feelings of loss.

In the lived experience of parents, loss occurs in stages is divided in separated parts and characterized by moments of decision-making. For instance, when the child leaves his food untouched, the parents, who are already cooking his favourite dishes, have to decide what to do: press to have the child eat a bit or accept this as the next step in the downward course: a new piece of loss. Parents consider these to be moments of decision which make them feel that they are influencing the course of loss. Thus dealing with loss for the parents is a process of stepwise relinquishing. Steps in relinquishing are often forced by the child's physical deterioration and his/her loss of desire to live. Due to the opportunity to intervene, to withhold or to withdraw interventions the tension between 'preservation' and 'letting go' becomes manifest and forces parents to deal with it.

Preservation and letting go

Preservation

Many parents are inclined to fight the downward process to the greatest extent possible. They need to do this to avoid the reality of loss. Preservation means that parents try to preserve their life with their child. We use 'preservation' because it captures the essence: the prevention of the loss of the child by maintaining, in fact improving, the existing situation and especially of what is still there of their child.

Striving for preservation becomes manifest in two ways. First, parents look for interventions to postpone loss by sustaining life. For instance, through efforts to gain a chance for cure or to extend life. With respect to this parents mentioned cancer-directed life-prolonging treatment, interventions aimed at improvement of the child's physical and mental condition (blood transfusion, complementary medicine), or measures to minimize the risk of physical complications such as preventing the child from catching a cold.

The mother of Pepijn, (2, AML) spoke about the reason he got palliative treatment to suppress the cancer process:

> *Well, because it was supposed to make him feel better…that we would have him the way he was. That we, so to say, would have a little of our old Pepijn back.*

Second, parents try to postpone loss by refraining from doing things that might accelerate the downward course. They try for instance to avoid or delay those interventions which in their opinion could initiate or accelerate loss. It became clear that some parents tend to wait when pain increases, hoping it will pass in order not have to take the step of increasing medication, especially morphine. Parents who are entirely directed toward preservation (preservative parents) for instance prefer not to discuss the end of life with their child because they fear that in doing so their child will lose his/her desire to live.

The need for preservation can be strong and preservative parents are prepared to compromise the child's well-being. With respect to preservation the goal is 'as long as possible, as well as possible' with an emphasis on long.

The father of Leonie (3, neuroblastoma) spoke about a radioactive iodine-131 treatment (MIBG). The child will be isolated for 4 days. Contact is possible only via a camera. Face-to-face contact is strictly limited.

> *You know that your child is going to die soon and then you have to stay away from her for 4 days. My feeling was no, absolutely not. But, if you do nothing, then she could be gone in a week or two. [...] and suppose that she's with us two months longer because of the therapy, what's four days out of two months? [...] And last week we went to the amusement park, and there she was so healthy and energetic and happy, almost like our Leonie the way she would be normally, then we felt we couldn't just let this go. Doing nothing was not an option for us.*

Letting go

Almost all parents knew the moment would come when their child would pass away and referred to this as: '*then you have to let him go*'. In earlier phases of the palliative process parents used the term 'letting go' to refer to the absence of interventions aimed at 'preservation'. Awareness of (approaching) death seems to be a precondition to be able to 'let the child go'. For parents 'letting go' means they recognize the inevitability of death and give up their resistance to loss.

Letting go becomes manifest in the parental willingness to subordinate their need to avoid loss to the child's well-being and comfort. Well-being and comfort take precedence over prolonging life. This means that interventions aimed at prolonging life are considered worthwhile only if they contribute to the well-being and comfort of the child. Parents who are open to 'let the child go' are able to give up preservative ambitions when the interventions hamper quality of life. The mother of Cas, who later on took the initiative to terminate palliative chemotherapy because she noticed a decrease in his usual signals of happiness (1, medulloblastoma):

> *My biggest fear is that he will suffer. [...] if there's a day that he's really not feeling well then I say if it's going to start now, then let it be over very quickly, just go to sleep now. Yes, I think: "We owe it to him. You're a parent and you love your child and you choose the best for your child and not for yourself."*

The shifting balance between 'preservation' and 'letting go'

We found that 'preservation' and 'letting go' coexist. This happens because the struggle against loss takes place on several fronts. Parents are able to 'let go' in one respect and (continue) to 'preserve' in another. For instance, they can accept that no chemotherapy will be given to prolong life, and in the mean time optimize the child's condition with special food or alternative medicine. Each parent vacillates between 'preservation' and 'letting go'. Because most parents develop a readiness to 'let the child go' the measure of each changes over time. This transition from preservation to letting go is not a linear process. The domination of either 'preservation' or 'letting go' has consequences for both the child and the parent.

'Letting go' and 'preservation' in relation to control

Feelings of loss threaten parental strength and in reaction, parents seek control. Parents who adopt a 'preservative' versus a 'letting go' perspective use different kinds of control. This contrast became most clear when highly 'preservative' and highly 'letting go' parents were compared.

Both experience the flow of the unpredictable illness process. 'Preservative' parents try to stop this flow. This can be compared with a chain of locks to regulate differences in level in a river. These parents try to preserve the existing situation by keeping the gates closed. When the water leakage becomes unstoppable they descend to the next basin and try to preserve the new situation. They experience control by maintaining the status quo. They do this by restricting their world to the part they are in and by directing others in accordance with their view; however it costs energy to maintain their view. As a consequence the outside world, including professionals, can become a threat to their stability. Highly preservative parents showed the greatest tendency to withdraw from their social and health system.

'Letting go' parents also seek control. In contrast to 'preservative' parents they find ways to adapt to the downward process and integrate the reality of approaching death in daily life. They experience control in exerting parenthood aimed at the best interest of the child and the creation of parent-child togetherness. These parents, when necessary, communicate with the child about the end of life even if this temporarily enlarges the burden of the child. Just like the mother of Rolf (10, medulloblastoma) did, knowing he has only two weeks left from the moment treatment failed.

> *And then we were talking together and suddenly he said: "Mama, how old do you think I'll get? Will I live to be 18?" And of course we hadn't discussed that yet, because I find it so difficult to tell everything at once. Also because he didn't want to discuss it directly. He knew he couldn't be treated any more, but that it could be over so quickly, that wasn't clear to him at all. And then I said: "(…) I find it very difficult to tell you this…it's something that makes us so sad, because it's very, very hard for you to hear. That is, that the doctors in the hospital have said…" Yes, then I still expressed it in months. I said: "Maybe three, maybe two but maybe just one month…it could be over as soon as that."*

At the same time they behave in such a way as to empower the child to cope with his situation or are able to create an atmosphere of togetherness to cope with the powerlessness they all feel as a family unit. Parents for instance prepare their child for death by giving a description of what can be expected during and after death with a strong focus on preventing anxiety. In terms of the ‘chain of locks’ metaphor they are gatekeepers more tuned to the flow and leakage.

Many parents emphasized needs that contribute to their control. In line with the dominant perspective of their transition this can be in quite different ways as is illustrated in Table 2.

The need for control is immense and seems a precondition to fulfilling parental tasks. Parents who lost their control surrendered their actorship. Such parents often piggyback on the directions of their partner, remain on the sidelines during discussions between the stronger parent and the medical staff and express difficulty in caring for and ‘being there’ for their child. The mother of Anco (3, AML):

> *I wish I could take really good care of him. That I could deal with it better and therefore take care of him more easily...but sometimes I really think: I’m going to go away and come back when it’s all over.*

Table 2. Difference in control with respect to disclosure of expected lifetime

Attitude	Situation	Quote
Preservation	The father of Jordi when still behaving in a very preservative manner forced the oncologist not to tell him and his son how long his son still had. He wanted his son to enjoy life. For him feelings of joy served as a counterbalance against feelings of loss. The disclosure of life expectancy not only threatened his own ability to keep the approaching death out of sight but in his view also harmed his son’s ability to enjoy life and as such would hasten his son’s death. This was what he as a father feared most because he felt unable to parent a son who had lost his desire to live.	Look ... the moment is going to come, the moment that he’s not doing well or that it’s come to the point that he’s doing very poorly. You feel it.. all kinds of things are going to happen, but until that moment you have to let people.. let them hope. And not a time frame that you have a specific amount of time to live. Then you kind of give up. (...) They way he is now is the way I want to keep him. So I protect him as much as I can. Because I don’t know what certain information would do to him. (...) Also, the moment you give up hope and accept the situation that you’re in at that moment, that’s not a good one, then I think the end would come very quickly.
Letting go	The father of Rolf who behaved in a ‘letting go manner almost from the moment treatment failed, expressed a strong need to know the life expectancy during the final stage conference to be able to manage his emotions and reframe his parental role	And at the end of the conference I asked once again, doctor... you say a few weeks, but to me a few weeks is two weeks, but also ten weeks. Which is it more likely to be? (...) Well, he says, think closer to two weeks. And at that moment I was very calm because I had an answer, because I knew how to plan emotionally (...) The time to say goodbye has begun. And saying these goodbyes, if you know ahead of time that you have two weeks or ten weeks, then you start to fill in that time differently.

The transition from ‘preservation’ to ‘letting go’ requires a switch in source of control. It is part of the parental dilemma.

Moving from a preservative perspective and give up control to increase the ability to be near their child out of the preparedness to ‘let him go’ is difficult to recognize and threatening to do.

Parents fear their own disintegration and the risk of hastening death. Some parents manage this transition on their own due to personal strength, their philosophy of life or earlier experiences with loss. For most parents movements towards ‘letting go’ could only be made with the aid of guidance that helps them to understand and justify the necessity of this transition, and supports them in dealing with their feelings of loss.

‘Letting go’ and ‘preservation’ in relation to the child’s condition and situation

Although over time most parents become more able to ‘let the child go’, it became clear this was not a natural and fluent process. For many parents in our study it appeared to be difficult to stay attuned to changes in the child’s condition and needs. We identified parents who lagged behind and parents who got ahead of their child’s situation. ‘Preservative’ parents more often lagged behind.

Sometimes the difference between parental perception and the real situation resulted in unnecessary suffering for the child or inadequate care. In hindsight some parents felt they had (at times) lost sight of reality and therefore had inadequately assessed and managed their child’s symptoms, suffering or needs. Interviews also showed discrepancies between the child’s signals as described by the parents and their perception of these. Although parents noticed signals, they seemed not always able to analyse and react to these signals in line with their child’s real situation.

Tim (7, Wilms’ tumour) knew his cancer could not be cured. To safeguard his happiness his parents decided not to tell him this implies he will die, although his father was convinced Tim felt it. His mother wrestled with the issue:

> *Then he asks: “Mom, do you want to be cremated or to be buried?” and that at 7:30 in the morning. I say: “well, Tim, will you give me a chance to wake up first?” He says: “Well, I want to be buried, because, well, cremated...then you don’t exist any more.” And a few days later: “Mom, they say that if you’re in a coffin that you become a plant.” I think, what’s going on here? And I don’t take the conversation any further. Because I don’t think these are the signals that the social worker and the psychologist mean.*

The dominant attitude strongly influences parental perception and therefore has direct consequences for care and communication with the child. We can elucidate this with respect to the parental perception of suffering. For parents the child’s pain, anxiety, treatment burden and dying process are connected with suffering. Whether they are interpreted as suffering depends in part on the dominance of ‘preservation’ or ‘letting go’. Highly ‘preservative’ parents did not mention the suffering of the child spontaneously. When asked about aspects of pain or treatment burden they acknowledged their child's situation but would not label it as suffering. Even when bad moments became bad hours these are experienced as inevitable with respect to the parental 'preservative' goals or outweighed by the good moments parents enjoy so much. Parents for whom 'letting go' prevailed; more often interpreted similar burden as suffering.

Especially just before and during the terminal phase some 'letting go' parents were ahead of their child's reality. From their perspective they would welcome death, but the moment of death was not yet there. This causes a waiting situation which is experienced as very hard, especially when parents see the child suffering from his/her illness or perceive aspects of the dying process as suffering. For some parents feelings of senselessness dominated, sometimes reinforced by the loss of communication with their child. Some of them felt they would have preferred to actively hasten death in order to terminate their child's and their own suffering.

Discussion

In this study, we found that feelings of loss do not start after death but already force themselves upon parents during the EOL phase. Parental difficulty in dealing with them results in ambiguity: knowing death is inevitable can coexist with the avoidance of loss. Dealing with loss is a process of stepwise relinquishing that becomes manifest in an internal struggle between preservation and letting go. For most parents the balance between the two changes over time, showing a transition to letting go. Parents can have great difficulty making this transition because it implies a change in source of control. A timely completion of this transition is of importance for the child's well-being at the EOL and for a positive evaluation of enacted parenthood once the child has passed away.

The study has limitations. Our sample consists mainly of Dutch couples. As such, the sample does not reflect all types of parents in wider society. Theoretical sampling could only be used to a limited extent because a limited number of subjects met the inclusion criteria [22]. Nevertheless, our sample showed wide variation with respect to the central concepts, including sufficient representatives of the extremes. Although findings cannot directly be applied to other settings; we are confident our analysis captures parental processes in similar situations.

An important observation is that feelings of loss already play a prominent role during the EOL phase. Feelings of loss are commonly acknowledged from the perspective of bereavement and grief after the death of a child. The heart of this harrowing type of bereavement is the loss of an unique relationship that is felt to be vital for the self [23-25]. We found that management of (anticipated) feelings of loss is a daunting task for parents at the EOL. In paediatric EOL literature the concept of (anticipated) loss is hardly touched upon.

It is clear from these data that parental ambiguity is not a momentary state or exclusively related to important treatment decisions. In the lived experience of parents ambiguity is constantly present and directs everyday life and child care. Although we did not find literature concerning the parental process as a whole we found support for several aspects of our findings. Monterosso & Kristjanson [26] who also interviewed during the EOL experience, pointed out that parents behaved in an ambivalent manner due to hope while feeling their child would not get better, thus supporting our observation of ambiguity. Especially in the literature on decision-making we found exponents of preservation and letting go. Research into the parental response to the unlikelihood of cure shows most parents decide on cancer-directed therapy, grasping every chance for life extension or even for cure [8, 11, 27]. Some parents negotiate treatment to the end, never reaching the moment they choose for entirely symptom-directed therapy [8, 10, 11]. This fits into a preservative attitude. However, the aforementioned and other studies [11, 28, 29] also indicate there are parents who are able to resign themselves to symptom-directed treatment, even at an early stage. This can be explained as indicative for a letting go attitude. Arguments underlying parental EOL decision-making reflect a similar duality [8] and include arguments aimed at the child's well-being. This supports our conclusion that the need to avoid loss is immense but that not all parents fight loss at any price. Some parents seem able to subordinate their feelings of loss to child-focused goals. Considering the internal struggle we observed, this suggests the process can be guided. It is worth studying the influences on the parental transition.

With respect to the difficulties parents have to gear to the child's real situation several studies confirm our observation that parents can lag behind. For instance reports on a delay in recognizing that treatment has failed [28, 30] and a delay between intellectual and emotional awareness of death [29]. These delays are often explained by a lack of clear information due to professionals' inexperience in discussing the child's death [28, 29, 31, 32] along with a lack of knowledge about how to integrate palliative care [26]. Although we agree, based on our findings we hypothesize it also has to do with the parents' difficulty in dealing with loss and the perspective parents may adopt to retain control. Our study showed being informed does not automatically result in a parental 'letting go' perspective.

This study showed that the dominant perspective of parents largely influences the child's situation. With respect to the EOL, professionals stress the importance of respecting individual preferences of both parent and child, although the role of children seems to be small [8, 33-35]. Within the context of decision-making it is legally and customarily accepted that parents will make decisions in the 'best interest' of their child [36]. We observed that for parents, as participants in the process that will lead to the definite loss of their child, this was not always the case. This can have negative consequences for the child [37].

For parents the shift to letting go is a precondition to taking the child's perspective. The transition increases parental receptiveness to their child's real situation and needs. It facilitates their ability to 'be there' and guide their child when life is nearing its end and death is in view. 'Being there' has been identified as an essential and rewarding aspect of parenting during treatment [38]. Because parents are the closest and most continuous actors in the child's care and guidance and because of the interest parents attach to their actorship [39] we think in line with Vickers and Carlisle [40] that actorship should be supported. Within the EOL context and with the interest of both, the child and the parent, in mind we suggest the professional focus should shift from a decision-making perspective to guiding the process of relinquishing thus supporting the transition from 'preservation' to 'letting go'. Hurwitz et al [32] state that in order to improve palliation, once the end of life is communicated, subsequent communication should focus on establishing goals of care. We suggest that the guidance of the process of relinquishing is a precondition to enable parents to set child-focused goals. By doing so, both parents and professionals, are forced to take better account of the child's perspective and psycho-social difficulties. Both are gaps in the care for children at the end of life [35, 41].

Guiding the process of relinquishing is a very delicate task. When forced, parents can react in an increasingly 'preservative' manner or break down. Professionals have the complex task of guiding parents towards 'letting go' and helping them to stay attuned to the illness process and at the same time support them in order to safeguard their actorship. Therefore a proactive policy and close involvement is needed. Beyond expertise about the medical aspects of the illness course there is a need for expertise to help parents find meaningful answers to the difficulties of parenting a child in the downward phase. Palliative thinking requires a reorientation in parenting. Professionals can support parents' awareness that this special situation requires relinquishment, an attitude parents may never have thought of as positive. Therefore it must be clearly distinguished from detachment. The attachment of parents to the child enables them to find meaning in parenting and retain their ability to give care even in the situation that the child cannot give much in return. Professionals can support parents by providing encouragement and a justification for their transition to a 'letting go' attitude.

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Chapter 5

Factors influencing parental readiness to let their child with cancer go at the end-of-life

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Abstract

Background. One in four cases of childhood cancer is incurable. In these cases death can usually be anticipated and therefore preceded by a phase of palliative care. For parents, preparing to let their child die is an extraordinarily painful process. Most struggle to preserve their child. This study identified, from a parental perspective, the main factors that influence the transition from preserving life to letting go.

Procedure. A multi-centre, qualitative research, study was undertaken during the end-of-life (EOL) phase, comprising single or repeated interviews with 44 parents of 23 children with incurable cancer.

Results. We discovered that uncertainty, fragmentation and anxiety underpin the preserving life perspective. A perspective of letting go could be supported by a variety of factors. These included: certainty that the child cannot be cured, postponed grief, the perception of suffering, the ability to disentangle needs and the ability to parent meaningfully. Hope, creating a peaceful parent-child relationship, and the attitude of professionals, could support movements in either direction. Of these, certainty, and in most cases postponed grief, were pre-conditions for the transition towards letting go. Strategies such as not challenging the parents' suppression of grief, creating certainty about the child's condition and supporting parents in efforts to redefine their parental role, supported progress towards accepting a letting go perspective.

Conclusions. Parents' internal struggle between a preserving frame of mind and one of letting go is influenced by a combination of factors. However, professionals can influence some of these factors in order to facilitate this transition.

Introduction

Death can be anticipated for most of the 25% of children with cancer who die of their disease [1]. Increased attention is being given to paediatric palliative care, spurred by publications demonstrating that children experience substantial suffering during the end-of-life (EOL) phase, and that communication with parents is often deficient [2, 3]. Research demonstrates that professionals' attitude and knowledge with respect to communication, symptom control and the integration of palliative care into the treatment of children with a life-threatening illness have improved [4-6]. Paediatric care models have been developed and are applied increasingly often [7-9]. However, there are indications that palliative goals remain difficult to set and that children suffer more than is necessary [5, 10-12].

The role of parents has also been studied. It has become apparent that parents have difficulty foregoing treatment even if there is no improvement in symptoms and complaints [13-15]. Parents also have difficulty shifting to palliative goals such as the quality of life and a good death [2, 4, 16, 17]. Traditionally, improvements in achieving this change in perspective are sought in decision-making [18, 19]. The assumption is that clear and honest information enables parents to weigh the best interests of the child while making decisions during the EOL process. However, some children cared for at home received less adequate palliative care due to parental difficulty facing loss.

This article is part of a larger study into the lived experiences of parents from the moment they were informed their child could not be cured. Earlier we described that the degree to which the parents were able to face the impending loss of the child was the factor that most influenced their decision-making [20]. From a parental perspective the essence of the EOL-phase is better characterized as coping with loss, than as the acceptance of death. For parents, dealing with loss was a process of giving things up, step by step. We identified this as an internal struggle between the wish for preservation and the willingness to let the child go. Preservation means that parents prevent the loss of their child by trying to maintain, in fact to improve, the existing situation and in particular to preserve what is still there of their child. They attempt to prolong their life with their child. Letting go means parents recognize the inevitability of death and subordinate their need to avoid loss to the child's well being and comfort. This is not the same as giving up.

Parents were able to adopt a letting go perspective in one respect and to continue to preserve in another. Almost all parents vacillated between preservation and letting go. Over time the degree of each perspective changed. Parents increasingly adopted a letting go perspective (Figure 1). A timely transition to letting go is of importance both for the child's well being at the EOL and also for a positive evaluation of their performance as parents once the child had passed away. The objective of this study is to identify, from a parental perspective, the main factors that influence the parents' position between preservation and letting go.

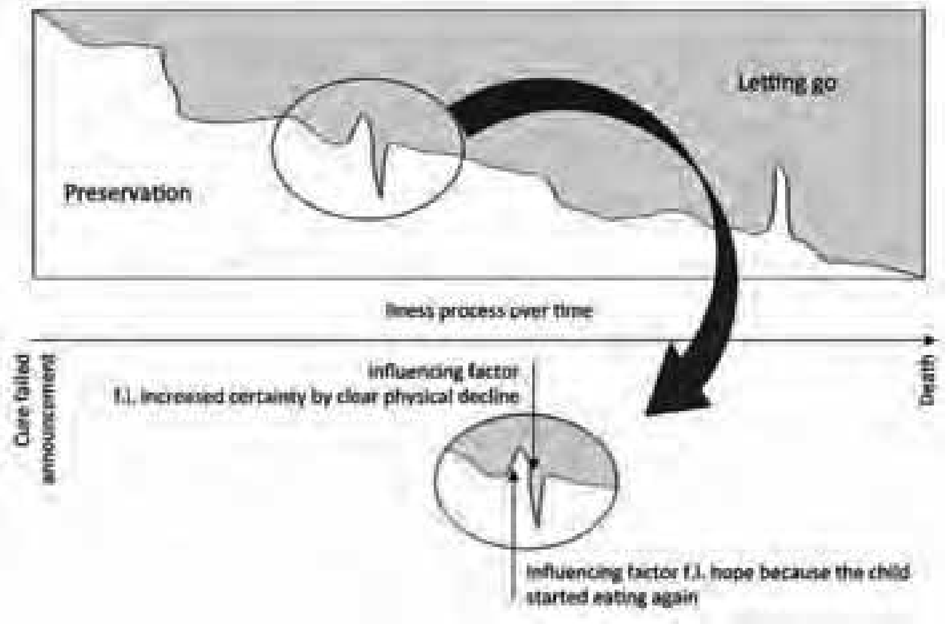

Figure1. Hypothetical representation of the influencing factors during the transition from 'preservation' to 'letting go'.

Methods

A grounded theory approach was used in order to develop theory that interprets the data [21, 22].

Sample

Parents were recruited from five Dutch paediatric oncology university centres which together cover 80% of the patients. Parents of children (0-16 years) with all types of cancer were considered eligible from the moment the oncologist had informed them that remaining treatment options were not curative. Parents who spoke Dutch and cared for their child at home were enrolled, irrespective of whether their child received cancer-directed (including phase I/II study medication) or symptom-directed therapy. The oncologist introduced the study and asked permission for the researcher to contact the parents. Available data indicated that parents were not asked to participate when the disease was rapidly progressing (oncologists reported the child died within 1 week) or when communication was complex due to relational or cultural problems. In three cases parents refused participation. They expected their burden would be too great or the palliative implications of the study did not fit their interpretation of the situation. Forty-four parents (23 mothers and 21 fathers) of 23 children, aged 6 months to 16 years, participated. One case of an 18 year-old was included as a contrasting case to see what happened when parents had, at least formally, less influence. For characteristics see Table 1.

Table 1. Characteristics of the respondents N=44)

Characteristics	N	%
Gender parents interviewed		
Male	21	48
Female	23	52
Age parent		
<30	2	9
30-40	27	61
≥40	15	34
Marital status		
Married/cohabiting	39	89
Divorced/not cohabiting	5	11
Cultural background		
Dutch	42	95
Other	2	5
Education		
low*	13	30
middle**	19	43
high***	12	27
Age child at first interview		
0-1	2	9
1-5	9	39
5-12	6	26
12-16	4	17
≥16	2	9
Type of cancer		
Leukaemia or lymphoma	9	39
Central nervous system tumours	5	22
Neuroblastoma	2	9
Renal tumours	1	4
Hepatic tumours	2	9
Bone tumour/Soft tissue sarcomas	3	13
Germ cell tumours	1	4
Time first interview before death		
10-12 months	2	
7-9 months	2	
4 - 6 months	8	
1-3 months	10	
3-4 weeks	4	
1-2 weeks	4	
1-7 days	4	
Time first interview after death		
4 weeks	1	
5 weeks	1	
6 weeks	4	
7 weeks	2	
10 weeks	2	

*low: primary school, lower secondary general, lower vocational;
**middle: higher secondary general education, intermediate vocational education;
***high: higher vocational education, university

Data collection

Individual open interviews were held at home. In seven cases we conducted second interviews (n=12) and in one case also a third. Interviews were conducted between 2005 and 2007, lasted 1-2 hr, and ranged between 2 days and 1 year before death. Ten parents were not able to talk with us during the process. They could only be interviewed after the death of their child. We included them even though their position with regard to loss was different. Their experiences provided thick description and contributed to a broader understanding of the issue and also to the validation of our findings. This resulted in 57 interviews at different moments during or soon after the EOL process.

Parents were informed that professionals lacked the perspective of what it meant as a parent to care for their incurable child and that we wanted to learn from them in order to improve professional care. We used a broad opening question: 'Will you tell me how your son/daughter has been doing from the moment he/she became ill?' followed by: 'Will you tell me how your son/daughter is doing at the moment?' For parents of deceased children we first took time to share their current experiences about having lost their child, which often occurred spontaneously. Then we referred to our goal to learn and to understand better the parents' experiences at the EOL-phase. We started with the same opening question. Some parents needed a more specific question such as: 'Will you tell me how things went after you were told that (name child) could not be cured?'

A list of topics compiled on the basis of literature, knowledge of experts and preliminary studies of the research group, was used as a check at the end of each interview to ensure all topics came up for discussion. Topics included parental care and goals, the parent-child relationship, parting and loss, coping, professional care and family life. 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.

Data analysis

During the analysis, two complementary and intertwined strategies, namely coding and thinking theoretically, were used [23, 24]. A research team of four members, including both interviewers (MK, RKV), was involved in the entire process from data-analysis through theory generation. They read transcripts and coding results individually. The style of the interviews was subject to peer review in order to enhance their validity. The team attempted to achieve a consensus on the interpretation by considering several possible meanings. This guided the constant comparative analysis. MK checked these interpretations against existing data and new material. This method constituted researcher triangulation and increased the depth and the reliability of the analysis.

Coding was supported by the software program NVivo7 [25] and included initial and focused coding. The attention to meaning was enhanced by 'active coding' as is described by Charmaz [22] thus facilitating interpretative theory that fits the experience of our respondents. The analysis was made more transparent, and the research more verifiable, by using memos to record and explain provisional interpretations and conclusions. The initial theory and conclusions were discussed with paediatric oncology specialists. Theoretical saturation was reached on a conceptual level. Given the complexity and number of variables saturation was not reached in detail.

Results

Modulating factors leading towards preservation (for illustrations see Table 2)

Uncertainty

All interviews encountered uncertainty, about the course of the illness, the effect of interventions or about the time left. Uncertainty can be defined as the parents' intrinsic belief that the predicted fatal outcome is not yet certain. Most parents actively sustained uncertainty. All parents, those who fostered uncertainty as well as those who tried to weigh the outcomes realistically, felt that decisions 'made the uncertain, certain'. For instance, the decision to install a bed in the living room marked the diminishing of the child's world. This feeling of definitively influencing the course of events

Table 2. Factors supporting preservation

Influencing factor	Illustrative quotes*
Uncertainty	The father of Gijs (14 yrs, solid tumour, receiving cancer-directed treatment) who was informed the scan showed that one spot had increased rapidly: *Yes, you know that that one is growing fast. And the other three or four were luckily not growing right then. (...) And you see that he's slowly deteriorating. But how long is that slowly going to last? It's very possible that they can get it under control now, that this one will also grow much more slowly… you just don't know. (...) So often you hear that people who basically have been given up are still around three, maybe even ten years later.* (R23)
Fragmentation	Tom (12 yrs, soft tissue sarcoma) attended school until one week before his death, despite his physical deterioration. His mother reflected two weeks after his death on the terminal stage: *Yes … well OK... it could have been a flu, but in that last week that he went to school he also got bruises on his legs, so I think that then.. well OK, we called it a flu, but I think he was already dying then. His body had had it. So, afterward now, I think that he was actually already dying from the moment that he started not feeling well and was given those antibiotics. (I: Did you think that then, or do you think that now?) No, I think that now. Yes, that's a big difference, isn't it.* (R31)
Anxiety	The father of Eileen (9 yrs, bone tumour) bargained for a very difficult and hazardous experimental operation. Medical staff had advised against it because she might not survive the treatment and chances for a cure were zero. (I: Are there things that you're very frightened of or dreading?) *Yes, just the moment of destruction, that Eileen deteriorates…yes, you have your love for your child and her love back. Yes, that, that is ripped apart.* *See, you already sometimes see it in her eyes, at least when she's in pain, then you can see everything in her eyes. Then you see the suffering and the sorrow in her eyes… and yes, if she gets worse, it will be very hard to read even more in her eyes. Look, if then on the other hand you have the possibility of trying this operation… that's also going to be a very hard row to hoe, but the possibility that she will recover, yes, then that's … (…)* *If you do nothing, then you know what's going to happen. You still have that image in your mind of the big swelling on her hip (image from before the chemotherapy) and well... you know what is coming. So yes, you grasp any possibility of making it smaller and with a possibility, hopefully... to remove it. Because at some moment to have to read the despair in her eyes... that seems to me… very, very hard.* (R 25)

I, Interviewer. * Quotes have been slightly edited to increase readability. Names are fictitious.

by closing off alternative courses was much more strongly expressed in relation to choices that in the opinion of parents result in moving towards letting go. Parents referred to this as not getting a second chance. As a consequence, a choice for letting go sometimes brought on secondary uncertainty: thoughts about what would have happened if they had decided differently. When decisions lead towards preservation parents emphasized they could always change their minds later on if things prove to be irreversible. There was an intense need not to lose any chance. This was reinforced by the parents' anticipation of regret afterwards. One comment was: *'during the funeral you do not want to think he could have made it if we had tried this treatment'*. Parents could not bear the thought of being the authors of the loss of their child. To safeguard themselves parents grasped every opportunity, even creating chances where there were none. They could only reconcile themselves with moving towards letting go if they were sure everything possible had been done. Until then parents took decisions that entailed the least risk of loss of what they cherish most. The management of uncertainty led toward preservation. Some parents felt supported by discussing difficult situations in advance. They were able to rely on theoretical decisions aimed at the well being of their child that had been discussed beforehand in moments prior to the loss being felt.

Fragmentation

When feelings of loss gained the upper hand parents broke down. To prevent this, parents developed protective mechanisms. One way to keep themselves going was by fragmentation. Fragmentation meant parents pushed back signals of the approaching death by focusing on details. This allowed parents to avoid reading the signs and created room for ambiguity, sometimes in such a tenacious manner that at the start of the interview it seemed there was no awareness of the approaching death of their child.

Parents for instance subdivided the child's complaints into isolated symptoms, thus loosening the connection with the overall process of dying. Isolated problems could be treated more easily. Pain could be controlled, fever managed, and tightness of the chest relieved. That they together represent a pulmonary infection caused by a tumour was kept out of sight. By fragmenting the signs parents could maintain the status quo. It supported preservation.

Anxiety

Most parents feared the dying process and the child's deterioration. Parents anticipated the confrontation with the child's suffering, terror and despair related to deterioration and dying. Parents tried to avoid or delay these threats. Anxiety was a strong modulator and resulted in a movement towards preservation.

Modulating factors leading towards letting go (for illustrations see Table 3)

Certainty

Certainty can be defined as the parents' conviction that the malignant process is unstoppable or certain aspects of the child's life are irreversibly lost. This covered major treatment decisions as well as small decisions of daily life.

Parents of children who lacked objective proof of a malignant progression or unambiguous signals of physical deterioration experienced the situation as unreal and often tended to continue their struggle for survival. The accumulation of physical symptoms on the other hand confirmed the messages that the illness was irreversible. It provided the certainty the child could not be saved, 'it is really true'. This acknowledgement of approaching death was fundamental for parents if they were to begin to reassess their struggle. It facilitated their moving towards letting go. Visualizing the malignant process corrected the distortion of reality that often took place in the parents' minds. Although parents feared bad news in general, they preferred concrete and reliable information. This did not imply they automatically gave up their search for a cure or wanted their child to be fully informed.

Hope relieved the distress caused by feelings of loss that increase because of certainty.

For most parents, consciously accepting the knowledge that there was no longer any effective treatment was the result of a process. Parents gathered information about options and weighed these against expected results. In seeking possible options some parents solely relied on the information of their primary oncologist; others searched for every possible option using internet and international contacts. Some parents managed to complete the final steps of this process by anticipating the consequences of the treatment and consequently decided against it.

Other parents needed to first try and actually observe the failure of the treatment in order to change their policy. Anticipation of specific criteria to judge such failure helped them to do so.

Certainty was an indispensable prerequisite to enable parents to move towards letting go. It was not a strong modulator in itself. The position of parents between preserving and letting go stabilized when signals, such as symptoms of the child's deterioration, stabilized. Parents even moved towards preservation, influenced by other modulating factors such as hope.

Anticipation helped parents to become convinced that death was unavoidable. Parents being told in advance that the treatment the child would undergo was the last one available were able to surrender more easily. Another strategy was the creation of certainty. One father had great difficulty believing curative treatment had failed. The oncologist not only visualized the treatment results by showing a graph of a tumour marker but also proposed a cut-off to influence the father's view of reality. They agreed to give one more round of chemotherapy, during which the tumour marker should fall to at least 6000 to justify continuing chemotherapy. It did not and the father considered this as the moment his hope for cure had disappeared.

Table 3. Factors supporting 'letting go'

Influencing factor	Illustrative quotes*
Certainty	One father had great difficulty giving up curative treatment. The oncologist attempted to construct certainty: *Then we arranged with the doctor that they would give him one more chemo and that then the tumour marker would have to go down from 9000 to at least 6000 in order to go on, to show that there was a purpose to continuing chemo. Well, it didn't. So then we were told definitively that there was no more chance for a cure.* (R5)
Postponing grief	*As soon as it becomes certain and you see that he's getting worse or is in pain, then more emotions take hold of me. But that sorrow separates you. And during that separation then you just continue in your daily routine. (R15)* *Don't feel anything… Enjoy every moment. I knew it (crying...) and I could tell everyone, I could take care of him, arrange the funeral... but I didn't feel it.* (R41)
Perception of suffering	The father of Rolf (10yrs, brain tumour) spoke about his experiences with morphine: *Now and then he was awake, but then he was.. well.. he couldn't make himself understood. And that was very frustrating for him. And for us it was so emotional, because... (father crying) of course you desperately want the things that he asks ... or which you think you can still help him with or be with him for.. if you can't understand him.. that makes you so helpless. It is a terrible feeling not to be able to do anything about that. But ok, it was a big comfort.. that we knew that he wasn't.. he musn't suffer any pain. So because of the morphine the pain was well controlled.* (R18)
The ability to disentangle needs or interests	The mother of Dianne (10yrs, AML) asked medical staff for life-prolonging chemotherapy: *They said if you do that it can cause new complications. Then we said: "We don't want it". We can't do that to her. No matter how much we want to keep her with us... or how much you want that for as long as possible, that isn't right for Dianne. It does mean that you are letting her die. That is of course very hard. That's also a struggle... because of course it's not what you want, but I'm very happy that she is now the way she is now and that she is able to go to school. Now she has a cute hairdo… Her appearance is very important to her at the moment. So, such things, then I think that another course of chemo... then you are short-changing her.* (R35)
Ability to parent meaningfully	*And then at the last moment... yes, that's terrible for us as parents... and for us as Christians... to [let him go] that last bit.. well you have to let him go then, don't you. And so that he has no fear of … that he's alone at that moment. So I said to him... when the time comes...we'll keep hold of your hand, Papa and I will be with you... until Jesus comes and takes your hand, so you won't be alone for a moment. And that was a great comfort to him, that that's the way it would happen.* (R17)
Feeling burdened	Father of Juul (1yr, ALL) two weeks before her death: *Yes, as far as I'm concerned it can happen now, today rather than tomorrow (...) We've had enough. We really need to begin a new chapter, to be able to get back to our own pursuits, be able to decide what we ourselves want and no longer the illness that now is directing our entire lives.* (R3)

AML, Acute myeloid Leukaemia; ALL, Acute Lymphoblastic Leukaemia.
* Illustrative quotes have been slightly edited to increase readability. Names are fictitious.

Postponing grief

Parents postponed grief in order to be able to care for their child and to continue family life. Parents who could modulate the intensity of their emotions were able to take decisions and to deal with situations through which loss came closer. The ability to postpone grief facilitated many parents' progress towards letting go. Parents who obviously made the transition to a letting go perspective were able to allow some grief.

Perception of suffering

Once parents had begun to let go they started to interpret former, existing or expected symptoms such as pain, dyspnoea, anxiety or the burden of treatment as suffering and used this to legitimize their letting go attitude. The perception of suffering supports movements towards letting go. However, a moderate letting go perspective seemed necessary to begin to perceive the child's symptoms or burden as suffering in the first place. The perception of suffering in itself was not a strong modulator. This was confirmed by our observation that some parents who acknowledged their child's suffering remained passive with respect to symptom management or still had difficulty with fully letting go. Randy (14, AML) who was expected to die within days, suffered from severe pain. His father fought for a Patient-Controlled Analgesia Unit so his son could control his pain better himself. But when he noticed his son used it frequently he incessantly warned him not to use it so often that it would mean they would lose communication.

Parents who behaved in a preserving manner did not mention the suffering of the child spontaneously during interviews. When asked about current aspects of pain or burden they acknowledged its existence but they would not label it as suffering. Even when bad moments became bad hours, these were experienced as inevitable with respect to preserving goals or outweighed by the good moments that parents enjoyed so much. However, all parents acknowledged suffering when their child screamed or cried out from intense pain.

The ability to disentangle needs or interests

Some parents managed to disentangle their own needs and interests from those of their child. They emphasized that their ability to guide their child depended on their own ability to distance themselves from their own needs. Others became aware of the difference in needs by coincidence. While talking to the oncologist without their child present they realized how they could talk about their own dilemmas without being afraid to harm their child or risking diminishing the child's desire to live. This opened up the possibility of discussing and weighing differences in needs. Parents who distinguished their own from their child's needs were more open to letting go. At the same time this movement towards letting go could reinforce the ability to disentangle needs.

Ability to parent meaningfully

All parents found meaning in their parental role by creating a worthwhile life the child could enjoy. In doing so, the parents tried to do justice to the unique identity of their child. Some parents found meaningful ways to guide their child, who had to live with the reality of death. This created a togetherness that helped them to move towards letting go. Spiritual beliefs could be supportive. Some parents, in line with their Christian tradition, comforted the child by sketching a positive image of heaven where Jesus will take care of him/her. Other parents emphasized their spiritual bond will continue after death.

Burden of care

Of the parents interviewed after their child's death many felt satisfied about their complete involvement in care-giving. Some, however, stressed feeling relieved that the process of deterioration and dying had not lasted any longer because otherwise they possibly would not have been able to prolong this involvement to the end. Among the parents interviewed during the process, we found indications that the burden of care was excessive. Reasons were diverse.

Some of them felt as if they had lost the battle for survival and experienced a sense of pointlessness. Others felt their efforts to act in the service of their child were considerable when compared to that which the child could give in return. This occurred for example when the child was him or herself too young to contribute to a meaningful life or when a child had difficulty in doing so. Their parents felt that their children lived increasingly through their efforts as his or her parents. This could exhaust parents. Also some parents felt a clear ambition to give new attention to their own life and to family life. We saw it occur most often after an intense struggle for life characterized by a long and intense treatment phase or a long-lasting EOL phase. In a way these parents were waiting for death to come. They expressed they could live with the idea that life comes to an end and hoped this would occur spontaneously within not too long a time. Their feelings of loss were overruled by feelings of the burden they bore. This took away their need for preservation. On the other hand they also had difficulties 'letting go' because actions aimed at the quality of life of their child also became a burden. They tended to give up. Most of them felt guilty about this and emphasized they wanted to carry on to the end. Although some of them requested interventions to hasten death, none of these parents used their care-giving burden as a straight argument in taking a decision because in their opinion to give up could not be part of the parental responsibility. Nevertheless they gave no resistance when professionals suggested interventions that brought death closer.

Modulating factors leading in both directions (for illustrations see Table 4)

Hope

All parents hoped that the future would bring a more positive outcome than that which could be expected. Hope constituted a delay in their confrontation with loss. It thus provided an escape from the threat of feelings of loss. Hope made the certain, uncertain. By keeping hope alive for a desired outcome, some parents even created their own reality and thus experienced, irrationally, an increased chance of cure or stabilization.

But with increasing symptoms and signals of deterioration the focus of hope changed over the course of the illness. It ran from hope for cure, to hope for stabilization, to hope for a slow course of deterioration, to hope for maintenance of communication, to hope for a short terminal phase, no suffering and a peaceful death. With the last three, hope contributed to the willingness to let the child go; the first four fed preservation.

Hope was a strong modulator. Even parents who adopted a total letting go attitude experienced an awakening of hope for a cure until far into the phase of deterioration, for instance by a promising blood count. Palliative cancer-directed therapy, including participation in experimental studies, fed parents' hope for a cure or merely a prolongation of life. It sustained uncertainty. The treatment made a future still possible: 'after all he/she is still being treated.' Life-prolonging and experimental treatments therefore inhibited the transformation of hope. As a consequence they fed preservation. Tensions or even a break with professionals were seen when professionals took away hope in a direct manner without at the same time strengthening, step by step, the degree of certainty and a corresponding decrease of uncertainty.

Table 4. Factors supporting preservation and letting go

Influencing factor	Illustrative quotes*
Hope	Father of Albert (2 yrs, brain tumour): *You know he's not doing well. But you still keep hoping. He did much better after they put the drain in. We also gave him herbal tea. We really believed in it and so we thought that maybe things weren't so bad after all. As for the rest, I just pushed it away for the present. Just don't think about the inevitable. (I: And when did the inevitable make itself felt?) Well, the fact was that he had little seizures. Those were scary. They kept getting worse. And then you know: this is going the wrong way. Well, your hope..., you always keep hoping that it's not so bad, that it'll be very gradual. The hope for a cure of course is gone. So it's a question of time. And then you hope that there's still a lot of that time .(14)*
Maintenance of a peaceful parent-child relationship	One mother feared the acceleration of the EOL process when her son (13 yrs, AML) refused to take his protective medicines. At first she begged him to continue: *After two days I gave that up. Then I thought this is no time to argue. Because soon he'll be gone and then we'll have parted fighting. (24)*
Professionals: Framing	*And then the oncologist said: 'There's not really anything more we can do for him now.' Then it was up to us. We could just leave it at that. There was one more very difficult course of treatment. But while they were obliged to tell us about it, they absolutely advised against it, because he was so weak. They told us he would probably not survive the treatment, and then he would probably die in the ICU. Of course you don't want that. And we could also choose medication which possibly would slow down the leukaemia. And he wouldn't get sicker from that. So that's what we chose.* (R21)
Professionals: Guiding	*And Marion (nurse practitioner) was there too. She put things on the agenda that we should think about, or Tom should think about. (I: Can you give an example of that?) Well, for instance, she talked about the moment that... well, that another course of chemotherapy wouldn't help any more and that you have to decide whether or not to stop. So, how do you deal with that... there is a real last phase and how do you want to spend that time?* (R32)

I, Interviewer; AML, Acute Myeloid Leukaemia.
* Quotes have been slightly edited to increase readability. Names are fictitious.

Maintaining a peaceful parent-child relationship

Parents needed to maintain a peaceful relationship with their child. Parents, especially of older children, had to deal with the way the child him or herself coped with the knowledge that his/her life will end. Most parents gave the impression that their child's and their own perspective could meet. As such they tended to follow the child's preferences which could result in movements towards preservation as well as letting go.

Professionals

Professionals significantly influenced the parental position between preserving and letting go. We detected in the parents' stories at least two strategies which had an effect. These we called, framing and guiding.

Framing referred to the parental experience in which professionals defined the child's situation in the context of the illness, available options for treatment, care arrangements, parenthood and the transition from curative to palliative thinking. Movements towards letting go could be achieved better when, by framing, medical staff legitimized a letting go perspective as appropriate given the situation.

Guiding referred to the parental experience of professionals coaching and supporting them during their transit through the unexplored territory of the EOL trajectory.

Discussion

We have identified factors that influence the parents' transition from a preserving to a letting go perspective. Uncertainty, fragmentation and anxiety support preservation. Certainty, postponed grief, the perception of suffering, the ability to disentangle needs, the ability to parent meaningfully, and the burden of care promote letting go. Hope, a good parent-child relationship and the attitude of professionals can support movements in both directions.

Although factors are described separately, in reality they are intertwined. Moreover, the degree of their influence changes over time and parents' sensitivity to some factors changes throughout their transition. This is best understood when one considers the relationship between the factors and the core process of the transition: the parents' suffering from loss (Figure 2).

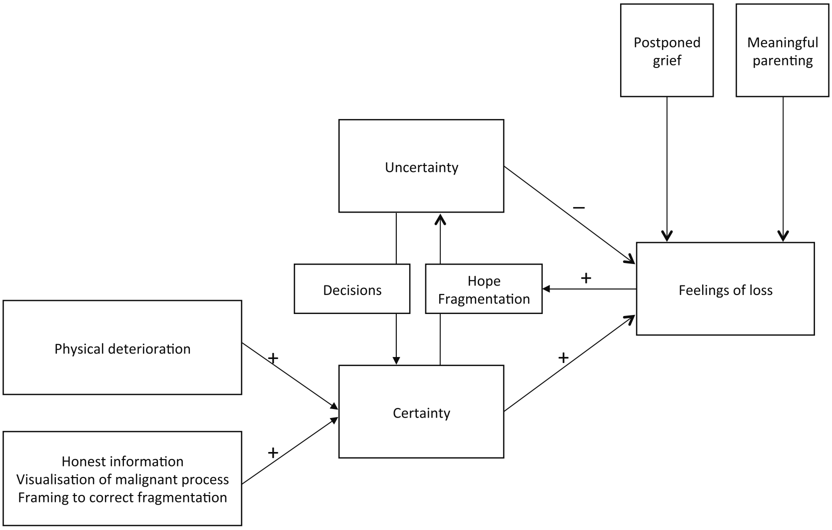

Figure 2. Synthesis of factors in relation to loss; + increase; –decrease.

Our study reveals that certainty, that is the conviction that death is inevitable, is of great importance in moving towards letting go. Certainty arises from the child's physical deterioration and can be supported by providing honest information, by visualizing the illness process and by framing. Irreversible decisions also make the uncertain certain. Feelings of loss are increased in the process of becoming certain. Parents foster uncertainty in order to find relief. They make the certain uncertain by creating hope or make the certain avoidable or ambiguous by fragmentation. By postponing grief, feelings of loss are suppressed. The increase of certainty forces parents to develop a manner of parenting that takes loss into account. We found that feelings of loss can be assuaged, temporarily or otherwise, by the parents' knowledge that they are doing the best for their child. Parents felt strengthened when they were able to disentangle their own needs from their child's or when they could create togetherness. The latter is influenced by their ability to find meaningful answers, within their role as parents, to the child's experience of impending death.

In conclusion, to be able to let the child go parents have to cope with feelings of loss and find meaning in occupying a letting go perspective. Parents are helped making the transition when they feel validated by professionals. A letting go attitude can only come about in close connection with the perceived reality and requires an integration of all modulating factors. Professionals can intentionally influence some factors in support of a transition towards letting go.

The study has limitations. Our sample consists mainly of Dutch couples. Theoretical sampling could only be used to a limited extent because only a limited number of subjects met the inclusion criteria [26]. Nevertheless, the richness of the data, with respect to the factors identified, makes us confident that our analysis captures similar parental processes in other palliative settings.

In paediatric oncology a moderate amount of anticipated grief is associated with better parental coping with bereavement and coming to terms with imminent death [27, 28]. From the perspective of anticipatory grief caregivers must recognize, normalize and legitimize the parents' experience and feelings[28, 29]. Sharing their problems with others was found to positively influence parental grief after losing the child to cancer [27].

However, in our study, parents had to cope with feelings of loss in order to be able to focus on the child's needs instead of their own. Although some parents were able to experience the emotional onslaught caused by feelings of loss, most parents separated emotion and reason by consciously postponing grief. They were for instance able to discuss problems and at the same time actively avoided feeling the accompanying emotions. This means of protecting oneself from suffering and overwhelming emotions, in order to do what needs to be done, is recognized as "enduring" [30-32]. We found many parents needed some distance from their grief to move towards letting go. In contrast to Rando's view that anticipatory grief supports the parent's ability to let the child go [28] our findings show the importance of making a distinction between the parents' cognitive acknowledgment of threats and losses and their ability to surrender themselves to the accompanying emotions. The challenge for professionals is to carefully balance designing comforting strategies that will not impede enduring behaviour against staying open to the expression of emotions while preventing parents becoming overwhelmed, in psychology known as containment.

This study confirms that hope can be seen as a response to a threat [33, 34] and it is essential too, to be able to live with death in view [6]. Like Verhaeghe et al. [35], we conclude that because the outcome is not yet determined, uncertainty provides rationale for hope. Parents are inclined to construct their own uncertainty to retain some hope. This supports the finding that prognostic disclosure did not disrupt parental hope even if the likelihood of a cure was low [36]. A clear communication about prognosis and the child's real situation are needed to reframe the focus of hope.

In hindsight, parents stress the need for information to provide adequate care tuned to the child's real condition [17, 37-39]. Our study shows more ambiguity: parents appreciated valid information but most of them sought information that sustained hope. While certainty is necessary to move towards letting go the existential character of the loss of a child complicates the achievement of certainty. An important finding is that certainty can be created, for instance by anticipating negative outcomes and by coming to agreement about reasonable cut-off points. Discussing difficult decisions in advance when related feelings of loss are not yet present can also be helpful. When a decision has to be made, the earlier discussions can function as a frame of reference.

The parents' anxiety was identified as a strong preserving modulator and is rarely addressed in research thus far.

The transition to letting go was also supported by the ability to disentangle needs and to develop meaningful ways of parenting even during the process of deterioration and dying. This enables parents to adapt their regular parental role to specific EOL goals such as the quality of life and a good death. This is in line with both, constructing a positive meaning to loss as identified in the dual process model of adaptive coping with bereavement [40] and meaning based coping as is found by Folkman [41]. Professionals can support this reconstruction of meaning and reframing of parenthood.

For some parents the burden of care-giving almost exceeded their forces. This resulted in a tendency to give up. We consider this as a critical situation because it threatened their ability to continue care-giving to the end.

A striking observation is that, in itself, the child's suffering is not a strong modulator. The degree of influence is determined by the parental perception of the suffering. This, in turn, is partly dependent on their actual readiness to let the child go and also to the influence of the child's coping. As such one should not take for granted the reliability of the parents' account of their child's suffering, especially in cases where the parents have great difficulty managing loss. This underlines the need for professionals to assess the child's situation themselves in order to be able to take an objective view of symptoms and suffering. Discussing the signals associated with suffering can support the development of a more realistic perspective. This in turn can empower parents to support a life that is worthwhile living, while dealing with the difficulty of the downwards course and the inevitability of death.

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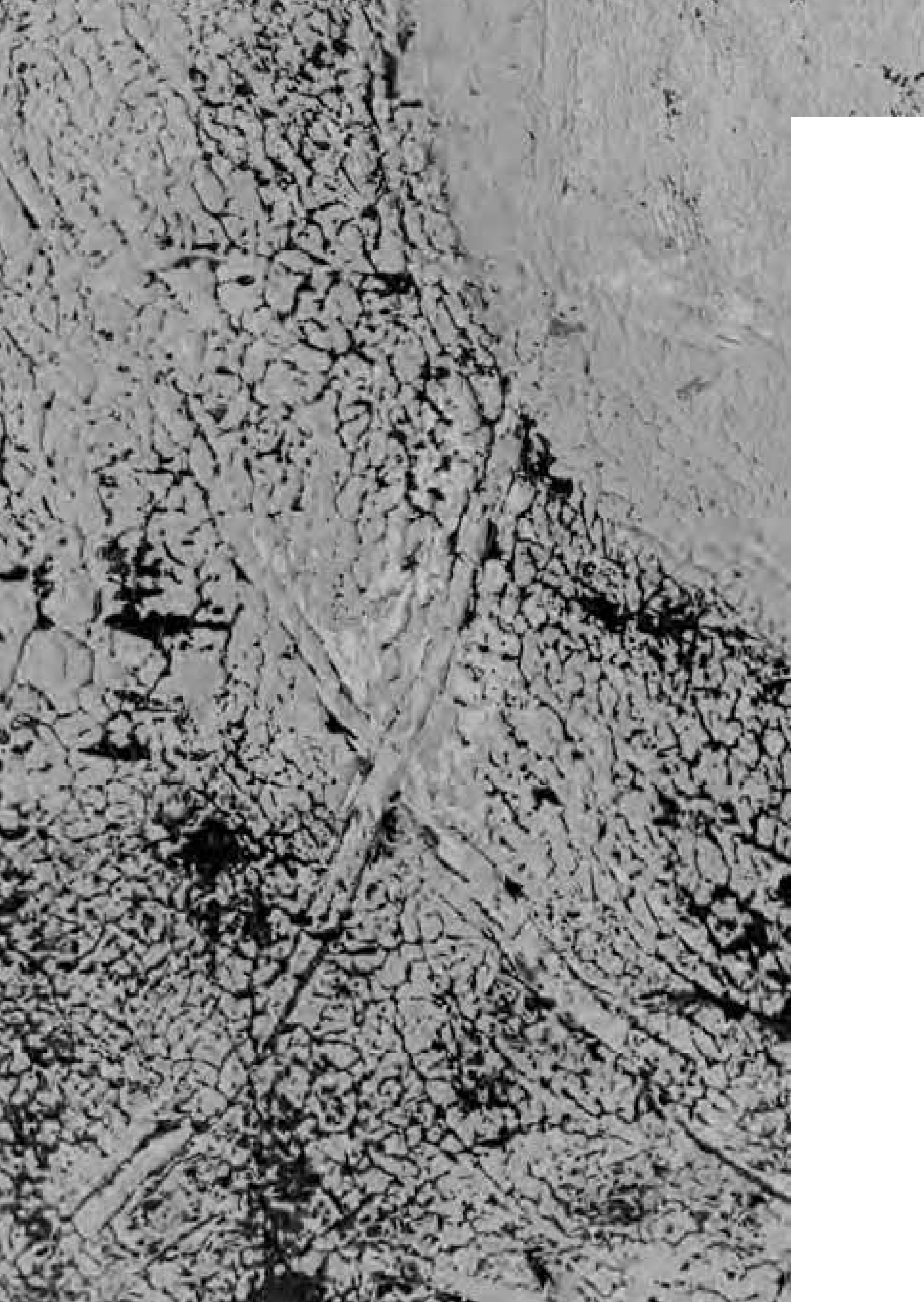

Chapter 6

Call me if you need me: the roles of parents and professionals in early identification, assessment and treatment at home of symptoms of terminal cancer among children

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Submitted

Abstract

Context. A child's suffering from symptoms is a major concern at the end of life (EOL). Symptom treatment among children with incurable cancer is still insufficient, while today many children do die at home. We do not fully understand how symptom treatment actually takes place amidst the interplay between parents and professionals in these last EOL stages at home.

Objectives. To gather insight into the roles of both parents and professionals, how they interact and what are its consequences for, symptom treatment at the EOL.

Methods. A multi-centre study, using qualitative interpretative methods, was undertaken during the EOL phase. One-time or repeated face-to-face in-depth interviews were conducted with 44 parents and 39 professional caregivers of 23 children with incurable cancer.

Results. During the stages of deterioration and dying, the early identification, assessment and treatment of symptoms among children cared for at home depends on the responsibilities taken both by the parents and the professionals, their intentions, and their skills, knowledge and expertise. We found professionals often adopted a 'reactive' attitude, thus shifting responsibility towards the parents. Parents in turn experienced symptom treatment as being a hastening factor in the child's death and therefore showed reluctance to begin treatments that have consequences they perceive as losses. This often resulted in symptoms not being properly treated. Parents felt supported by professionals who took full responsibility for the child's symptom treatment. These professionals also took the parents' perceptions into account seriously undertook a careful dialogue aimed at the child's best interests.

Conclusion. An early and accurate assessment and adequate symptom treatment requires an understanding of the parent's perspective and a dialogue aimed at lessening the child's suffering, just as much as professional knowledge and technical skills.

Introduction

Many children with incurable cancer suffer substantially from symptoms during the palliative phase [1-3]. Studies report a high prevalence of multiple debilitating symptoms in children with advanced cancer [4-7] .During the final weeks symptoms become far more prevalent [5]. Although attention to paediatric palliative care has increased and improvements are made [2, 8, 9], many symptoms are still reported as being untreated, undertreated or unsuccessfully treated [2-4, 7]. Retrospective studies show that bereaved parents consider the child's symptom burden as severe suffering, especially when symptoms are not addressed or are not adequately controlled [2, 3, 7, 10]. The World Health Organization defines palliative care as an approach that *"improves the quality of life (QOL) of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"* [11]. It must therefore be concluded that the goal of lessening suffering has not been fully achieved. This is often attributed to the limited knowledge of paediatric palliative care among professional caregivers [8, 12]. The parents of children with cancer are closely involved in monitoring the well-being of their child as well as in care-giving. Their role in the treatment of symptoms has, however, hardly been studied.

Currently about 40% of the children with malignancies die at home in western countries [13, 14]. The Netherlands is a leader in this with 63% of deaths occurring at home [14]. Since in western countries paediatric EOL care is increasingly provided at home [14] it can be expected that parents are increasingly involved in symptom treatment during EOL. In our study into the parents' and professionals' experiences during the palliative phase at home, symptom treatment often appeared to be problematic. It regularly resulted in the child enduring prolonged suffering or unnecessary burdens. This motivated us to search for an answer to the question of how symptom treatment takes place amid the interplay between parents and professionals in the final stages of EOL at home.

Methods

The aim of this study was to identify and describe from parents and professionals own perspectives, the processes that underlie the interaction between both parties with respect to the treatment of symptoms during the final EOL stages. Therefore, a qualitative interpretative design was used [15-17].

Sample

Parents from five Dutch paediatric oncology university centres, and their current key health professionals were recruited. In this prospective qualitative study none of the children was treated with curative intention, thus palliative care aimed at the child's QOL was paramount. Parents of children with any type of cancer were eligible once the oncologist had informed them that curative treatment had failed. Parents who spoke Dutch and cared for their child at home were enrolled, irrespective of whether their child received cancer-directed (including phase I/II study medication) and/or symptom-directed palliative therapy. Professionals caring for the children included in the study were purposefully selected to achieve a maximum variation with respect to discipline and the support experienced by the parents and secondly guided by the analysis.

Table 1. Characteristics parents (N=44)

Characteristics	N	%
Gender		
Male	21	48
Female	23	52
Age		
<30	2	9
30-40	27	61
≥40	15	34
Marital status		
Married/cohabiting	39	89
Divorced/not cohabiting	3	11
Education		
low*	13	30
middle**	19	43
high***	12	27
Age child at first interview		
0-1	2	9
1-5	9	39
5-12	6	26
12-16	4	17
≥16	2	9
Type of cancer		
Leukaemia or lymphoma	9	39
Central nervous system tumours	5	22
Neuroblastoma	2	9
Renal tumours	1	4
Hepatic tumours	2	9
Bone tumour/Soft tissue sarcomas	3	13
Germ cell tumours	1	4

*low: primary school, lower secondary general, lower vocational;
**middle: higher secondary general education, intermediate vocational education;
***high: higher vocational education, university

The data available indicated that parents were not asked to participate when the course of the disease was very progressive or when communication was complex due to relational or cultural problems. In three cases parents refused participation. They either regarded the burden as being too high or that the palliative undertone of the study did not fit their interpretation of their child's situation. All the professionals approached participated, except for one general practitioner (GP) whose participation, on his request, was restricted to filling in a questionnaire. The sample consisted of 44 parents (23 mothers and 21 fathers) of 23 children, aged from six months to 18 years. The majority of the children suffered from leukaemia or a tumour of the central nervous system. For characteristics see Table 1. 39 professionals from various disciplines were included: paediatric oncologists (9), general practitioners (12), home care nurses or equivalent (8), nurse specialists (2), paediatricians (2), and allied health disciplines (6) (Table 2).

Table 2. Characteristics professional caregivers (N=39)

Characteristics	N*	%
Gender		
Male	19	49
Female	20	51
Age		
<30	1	3
30-40	9	24
40-50	17	45
≥50	11	29
Discipline		
Paediatric oncologist	9	23
General practitioner	12	31
Paediatrician	2	5
Home care nurse	7	18
Nurse specialist	2	5
Practice nurse	1	2.5
Social worker	3	8
Psychologist	1	2.5
Remedial educationalist	1	2.5
Assistant remedial educationalist	1	2.5
Experience		
0-5 y	4	10
5-10 y	15	40
≥ 10 y	19	50

* Because of missing information of one professional not all columns total N

Data collection

During the palliative phase or soon after the child's death, 57 individual, in-depth, open interviews were held with the parents at home (Table 3). Besides one-time interviews (n=44), second interviews with one or both parents individually were held in seven cases (n=12) and in one case also a third interview took place. Interviews were scheduled from 2005 to 2007, lasted one to two hours and were held between two days and one year before death. Ten parents of six children were contacted before death but could only be interviewed after their child's death.

From the parents' perspective the palliative phase can be divided in four stages [18]. The current article focuses on stages three and four. During the first stage parents are informed that their child's condition is incurable. During the second stage symptoms can be controlled in such a way that the child participates to some extent in normal life. The third stage is one of deterioration, which is marked by a progressive decline in the child's condition mostly accompanied by an accumulation of symptoms. The fourth and terminal stage is dominated by symptoms related to the disease and dying. 39 parent interviews among 18 children covered the stages of deterioration and dying.

In total 43 interviews with 39 professionals concerning 20 children were scheduled at their offices. Three additional interviews with parents and two with professionals were conducted by telephone in order to seek additional information or to resolve ambiguities.

For both parents and professionals an interview guide was compiled on the basis of literature, knowledge of experts and previous studies of the research group. The interview guide consisted of open questions inviting parents to discuss their experiences and concerns. The interview guide for professionals invited them to outline the current care situation, the goals set for palliative care in this particular case and their views on the degree to which they succeeded or failed in achieving them. Both guides were adapted to growing insights and the need to explore them further.

For ethical reasons, the parents' and the professionals' interviews were conducted by two different interviewers. Interviews were tape recorded and transcribed verbatim.

The study was approved by the medical ethics committee of the University Medical Centre of Utrecht. Written informed consent was obtained from all participating parents.

Data analysis

Data analysis was conducted iteratively with data-collection and in accordance with methods that optimized validity and rigor [19]. Two complementary strategies, coding and thinking theoretically, were used in the analysis [20]. A research team of three members, including the main interviewers (MK, MKV), was involved in the entire process from data analysis through to the final results. Each member read transcripts and coding results of each case. Peer review with respect to interview style enhanced validity. The team sought to achieve a consensus regarding the variety of aspects that were related to symptom treatment, thus guiding the constant comparative analysis. MK and MKV checked all the insights against existing data and new material. Through this researcher triangulation the depth and the reliability of the analysis was increased.

The coding was supported by the software program NVivo7 [21] and included both initial and focused coding [16].

The transparency of the analytical process and verifiability of the research were enhanced by using memos and explicating provisional interpretations and conclusions.

A group of professional experts discussed and confirmed the initial conclusions. This group included people working in paediatric oncology, home care and palliative care plus a parent from the Dutch Childhood Cancer Parent Organization.

Table 3. Moment of interview in relation to time of death

Case	Time before death (weeks)								Time after death (weeks)				
	39-52	27-39	14-26	5-13	3-4	2	1		1-2	3-4	5-6	7-8	9-10
1				f+m				Death					
2						f+m							
3			f	m									
4				f+m		f							
5							f+m						m
6		f+m											
7											f+m		
8			f+m	m									f+m
9											f+m		
10							f+m						
11										m			
12			f+m										
13											m		
14						f+m				m			
15					f+m								f+m
16	f+m			m									
17				f+m					f+m				
18					f+m								
19				f+m						f+m			
20			f+m										
21				f+m									
22												f+m	
23													f+m

m: interview with mother; f: interview with father;
f+m: individual interview with father and individual interview with mother

Findings

Parents and professionals frequently spoke about their difficulties concerning symptom treatment and situations they questioned or evaluated as inadequate. Most examples given occurred during the final stages of the palliative phase where the physical deterioration was self evident. For examples see Table 4.

Symptom treatment at home arose through the interplay between the parent and the professional caregiver. The professionals' attention to symptom treatment was diverse, ranging from doing everything possible to achieve the best symptom control, through to almost total ignorance of the matter. The parental approach concerning symptom treatment was largely determined by their ability to cope with the loss of their child. Deeper analysis however revealed that the roles of the parents and the professionals with respect to symptom treatment at home could be divided into three domains.

These were 'responsibility', 'intentions' and 'knowledge, expertise and skills'. Beside these, two contextual aspects were identified that also influenced symptom treatment at home. First we describe the contextual areas. Second, we present the three domains. Each domain starts with a description of the role of the professionals followed by that of the parents and the interplay between both.

Context

The change of primary professional caregiver

During the palliative phase all children and their parents were formally transferred from the paediatric oncology ward (POW), with a multidisciplinary team as their primary carers, to the general practitioner (GP) and/or homecare nurses as their primary carers.

> *Of course they said "You can always call if there's a problem". But basically they kind of indicated that you have to do it with your GP. The oncologist can't come here to intervene at night or on the weekend. (Mother R41)*

For most children the transfer to the GP was initiated by the oncologist when life-prolonging cancer-directed treatment shifted towards treatment directed entirely towards the symptoms. When indicated the paediatric oncology ward continued symptom-directed treatment that could not be provided at home. In some cases these services were partly delegated to the general hospital near the child's home. Hence for symptom treatment during the last stages the parents had to deal with various medical professionals with different roles. Of these only the general practitioner and the home care nurse were available to provide services at home. For nursing care, parents could call on professional home care nurses and nurses from technical homecare services. In a few cases parents could also fall back on specialist nurses from the paediatric oncology centre, whose support was mainly provided by telephone. The involvement of nurses varied largely across the cases. It appeared that when the child had no need for complex, physical or technical care, nursing care was often never started. This was reinforced by the fact that most parents had become quite skilled during the treatment stage, preferred to care for the child themselves and wanted to preserve their privacy and control. Nurses were only involved in half of the cases.

Table 4. Examples of inadequate symptom treatment.

Father Alex (7yrs)	*He's had a great deal of pain... He also has...well I think that he's spent nights sitting downstairs, and only ow, ow, ow... then he sat with his hands on his stomach, he had pain then... then he walked around the room... then I would just put a DVD on...You can't do anything, you just sit there with him.*
General practitioner Job (2yrs)	*Actually I never quite caught up to the situation (..) I just thought, well, we'll see how it goes. Yes. Didn't expect that it would all go so quickly. A week after he was sent home he passed away, well, you just don't expect that. (...) Nevertheless, he still had a great deal of pain.*
Mother Peter (2yrs)	*Sunday afternoon I got him out of bed and then he just went to sleep in my lap. And that was the moment that things turned around 100%.* *Tuesday he had to go to the hospital for blood and platelets. But, well, that Monday he had already slept nearly the whole day. You just couldn't keep him awake. And that Tuesday at the hospital...well, the paediatrician was really shocked when he saw him, compared to the week before, that he had deteriorated so quickly. He said, I don't know if I would still have given him blood if I had foreseen this. But it was already ordered so they went ahead and gave it all to him. And he said at that time, it's not going to be too much longer. Yes, that's what we thought ourselves.. you see that yourself of course.. And then he did get the blood and platelets. But, well, they didn't do him any good. And he was hardly passing any urine any more. Suddenly he was retaining a lot of fluid, although he had had diuretics. And then they called the oncologist and he said "stop the morphine for a while", because the morphine was accumulating in his body since he wasn't urinating. They thought that that was making him so groggy. So then we lowered the morphine quite a bit. But Wednesday morning .. he had been so restless that whole night, and we had hardly got any sleep either. Then I called the GP. And he came by that morning and in consultation with the paediatrician they decided to raise the morphine again, so that he would rest quietly. (Peter died the following night)*
General practitioner Erik (10 months)	*Job had tube feeding and regurgitated a lot. We didn't pay enough attention to that. The parents called me about it several times. We gave them advice about the use of the Zofran® and also about positioning. And to prevent him from aspirating. So we gave advice about avoiding throwing up. But I didn't lower the amount of the feeding itself. (...) That's really strange, because there is an agreement with the other GPs here in the area that when adult patients come home to die we only take on their care if they are no longer getting tube feeding. I seem to have forgotten about that. It might have made a difference to the quality of his life to do it differently.*

Note. Quotes were slightly edited to increase readability. Names are fictitious.

Preparation for symptom treatment

Providing specific information on symptom management during EOL was often not the oncologists' main concern, although they acknowledged its importance. They assumed parents had learned from the treatment stage and were well prepared to recognize symptoms. Moreover, most parents had shown to be capable of contacting them when necessary. For the oncologists, a far more pressing concern was to help parents to cope with having reached the EOL stage and to encourage them to care for the child at home, which, in the oncologists' opinion, was the best EOL option for both parents and child.

For the parents there was no doubt they wanted to care for their child at home. However many parents expressed uncertainty about the task they faced: "*I've never seen someone dying before*". In anticipation of the EOL, parents spoke about their fear of witnessing the child's deterioration and their wish to prevent suffering, especially pain. The parents' uncertainty was well recognized by the oncologists. In response, oncologists tried to empower the parents to care for the child at home by providing information in a reassuring manner and encouraging them to make the best of the time left. Parents told how the oncologist had comforted them by explaining that symptoms nowadays can be well controlled, the child would not have to suffer from pain and, when necessary, he/she would not even have to be aware of the process of dying. Hence the oncologists focused on solving present problems, leaving further guidance on symptom management and the preparation for the dying phase to the general practitioner who now took charge.

Most parents had only a limited idea about how the EOL would come about and the kind of decisions that would have to be made. Parents who had asked for information about the terminal stage were mainly informed about how the malignancy would progress and what would most likely lead to their child's death. In hindsight, parents said that there was a focus on pain and problems specific to tumours such as seizures or bleeding. Parents did not feel prepared for symptoms related to the process of deterioration or dying. They were not prepared for symptoms such as restlessness, delirium, anxiety, gasping, or faecal vomiting. Nor were they prepared for how difficult it might be to treat some of these symptoms.

Responsibility

The professionals' role

Whether symptoms were recognized, assessed and treated depended largely on the responsibility taken by the individual professional. Taking responsibility meant the professional not only mentioned being responsible, but also expressed feeling responsible and showed involvement through concrete actions.

Shifting responsibilities

Sooner or later during the palliative phase, oncologists, depending on their policy concerning life-prolonging treatment, indicated "nothing could be done anymore". Most oncologists explained that future policy could take any direction. They felt parents, and their child, should make decisions about symptom management that suited their situation. The oncologists' main task became providing choices and trying to incorporate the parents' perspective in such a way as parents felt comfortable with the decisions made.

> *And what I asked is what it was they wanted to do? Do you still want to come in for check-ups? Yes, I also literally asked if we should still do blood tests... Mother didn't want us drawing blood. Father did. He also wanted to know the tumour marker, because he thought it would give him some control over the course of the illness. So I said then:"we'll do the tumour marker."* (Oncologist R38)

Yet at the same time they handed over the case to the GP. Most GPs indicated they had no, or only limited, contact with the family during the treatment stage. Their involvement now had to start largely from scratch. Meanwhile the responsibility for the child's well-being shifted to the parents as did the responsibility for the identification and management of symptoms. Professionals from the POW, who recognized the transfer to the GP was a critical moment, emphasized parents "could always call them if they needed them".

Call me if you need me: a reactive strategy concerning symptom treatment

Most GPs found the request for paediatric palliative care impressive. The fact that the child would die in the near future stimulated their sense of responsibility. They showed a willingness to take responsibility even though they estimated it could become time-consuming. However, not being familiar with the course of the illness and not knowing what to expect, many GPs struggled to organize their involvement in a manageable way. Hence the majority relied on their regular strategy: symptom treatment on request. Consequently, the parents remained primarily responsible for the early or later identification of symptoms and had to take the initiative in asking for help when necessary.

Besides this reactive "call me if you need me" strategy, most professionals showed their special involvement by offering an above average availability, for instance by disclosing their private phone number. Most GPs did not question the parents' competence to call them when it was necessary and did not make specific agreements about when to call.

> *The paediatrician prescribed paracetamol and diclofenac because he was starting to get pain. When I was there the last time on the Thursday before his passing away, he was given paracetamol with diclofenac. They found that sufficient at that moment. They also had Tramadol®. But they gave him that Saturday for the first time. I heard that that Sunday morning after he died. I knew that they had the medication and that it had been arranged with the paediatrician, but I didn't get involved any further. They did it all themselves, the dosage and frequency, even starting Tramadol®... that is, by themselves, but in consultation with the paediatrician.* (GP R8).

A few GPs in this study took their responsibility differently. They regularly visited the family in addition to being available on request. They stayed in touch and developed a relationship with the parents that they considered to be beneficial to decision-making about symptom treatment or the withdrawal of treatment. One example would be the GP (R3) who took the initiative to visit the child before discharge:

> *"...in order to get acquainted with the parents, and so that I wouldn't be thrown in cold (...) And a week later they were discharged. So then I paid them a house call once or twice a week. Now we've built up a kind of rapport. (GP R3)*

Parental attitude reinforces reactive care giving

From the parents' stories we learned that in order to safeguard their ability to care and to create a worthwhile time at the EOL, they postponed their grief, focused on the positive aspects of life and kept the approaching death out of sight by living one day at a time (Kars 2011). Consequently parents behaved stronger and more active than they actually felt. This was often not recognized by professionals who visited the child at home. Some GPs or nurses told us of their intention to take responsibility but how the parents' attitude made them shift towards leaving the initiative to the parents. They, for example, had encountered parents who appeared to be very powerful, almost aggressive or parents who behaved as if everything was under control, not showing a need for immediate support and even more striking, not sharing and thus not showing their grief. For example, one GP was confused when he visited the family to initiate EOL care only to find they were leaving for a short holiday: "*The oncologist spoke about a very progressive course and they were leaving for a holiday*" (GP R42). This kind of experience reinforced the reactive '*call me if you need me*' approach.

The parents' role and the interaction with professionals

The parents' stories about the transferral of the role of the primary caregiver and the shift in responsibility were congruent with the professionals. At home parents felt they were the primary caregivers, and as such primarily responsible for the child's symptom treatment.

> *Her platelets are very low, and that's a bit problematic at the moment... I can see that she's getting paler, I'm thinking, gee, when should we go in to give her blood.* (Mother R35).

In addition parents now felt that the dialogue with 'their' oncologist had been replaced by contacts with a diversity of professional givers. This reinforced their feeling of being responsible. To resolve problems with symptoms parents had to decide for themselves whom to call and when. Some parents appreciated being responsible because they could direct things according to their own perspective. Most parents, however, felt they lacked support. Although parents felt responsible, often encountered feelings or coping strategies which made it difficult to carry out this responsibility. Three of them are discussed below.

The parents' difficulties in taking action

The parents' need to live one day at a time (Kars 2011) limited their ability to anticipate events although this was required in order to prevent or treat symptoms. For many parents anticipating on future symptoms did not fit in with their concentration on the present. A pro-active attitude of the professional anticipating future complaints could already be too much for them to bear.

In several cases parents avoided professionals who in their opinion were not tuned to their perspective. In one case parents discontinued contact with a professional, who in their opinion, focused too much on the dying process, while they as parents, tried to enjoy their life with the child. Some professionals did not unintentionally run ahead when communicating with the parents. They were able to act pro-actively in service of the child's symptom treatment without frustrating the parents' focus. They, for instance, explained that to be prepared for sudden complications in the future, they would feel more comfortable if some medication was available by reassuring: "*you don't need to use it, just store it in the fridge*" (Nurse R30). By anticipating the child's increasing need for symptom treatment, without forcing the parents to think accordingly, professionals prevented unnecessary suffering caused by a delay in the availability of material and medication, which was often seen in this study.

The parents need to control the loss of their child

Where professionals thought in terms of relieving suffering, parents also evaluated what would be the consequences of symptom treatment in terms of loss. Most parents were very sensitive to signs reflecting the child's health status. They could provide a detailed report of their child's physical condition and spoke freely about his/her psychological and social situation. But from the parents' stories we learned that although parents noticed new symptoms or the worsening of symptoms, this did not necessarily result in contacting a professional or in adapting treatment. Symptoms were noticed but their meaning was questioned at the same time. Parents expressed uncertainty about the origin of symptoms, or how to assess them, or about the seriousness of the child's suffering. They doubted whether there was an immediate need to treat them. This could result in a 'waiting' attitude during which the parents felt unable to take the initiative. Parents tended to remain passive, to wait to see if the problem proved to be temporary, even when they were well informed about treatment options (for example see Box 1). By doing so they gained some control over the course of the loss of their child. In many interviews we found that although parents did not want their child to suffer, they also avoided hastening a process that, in their perception, entailed loss. The parents took action as long as symptom treatment lightened the child's burden without the risk of sacrificing the length of life, the characteristics reflecting the child's identity and his or her ability to communicate.

The parents' difficulty in taking control of the child's death

According to many parents taking responsibility for adequate symptom treatment felt like contributing to their child's death. Allowing the administration of morphine, or a decision to treat a symptom by withdrawal instead of fighting it, for example by diminishing tube feeding instead of using anti-emetics, was experienced as allowing death to come and was often considered as hastening death.

> *So he did get it, that morphine pump. Yes, for yourself that gives the feeling of, well, that's the beginning of the end. You want to postpone the end, so you're not eager to get it. (Father R15)*

Our interviews revealed that symptom treatment required the parents not only to be able to face the loss of their child but also to come to terms with actual losses as a consequence of symptom treatment. Most parents developed this ability during their involvement in EOL care, although not spontaneously. This ability required cognitive coping strategies to allow the parent to feel comfortable about acting in favour of the child's comfort and well-being instead of sustaining life. The father of Kay (R18) had made this shift:

> *We have a patient-controlled morphine pump, and that was a great invention, it helps a lot. Because you could always give a little more if he said 'it still hurts" (…) But because of that of course he slept more and more. And in fact it was already clear to us then that we… well…to tell it like it is, that it was our job to pump in morphine until he died. That's what it comes down to emotionally.*

Box 1 Jelle (4 yrs, leukaemia)

> The mother of Jelle spoke about his headache, which had taken serious proportions: it had kept them awake for several nights and he wanted her sitting next to him all day, keeping his head in her hands to relieve the pain. "*And now he is getting pain in his arms too, so we do not know what is going on now*". She wondered whether this pain was caused by his cold. When asked she showed she was informed about the pain protocol. "*Yes, I have analgesics (paracetamol); I've given it to him (...) well, in the evening he was alright… and then I didn't give him any more. Until he had pain again. And now I've started to really give it every four hours, to keep enough in him. So I hope that helps.*
> *I: Did they talk to you about ways to deal with the pain in the future?*
> *R: Yes, in the beginning, well...if this isn't enough any more then he gets morphine, of whatever they give him, from the Home Care. (...)*
> *So we sort of know what will happen. Yes... I don't want to yet. Well, I don't want him to suffer, but I do want to delay that as long as possible. Because if that's being delivered through the portacath then he'll be acting sick. Then he won't want to have a bath, and then he can't do anything. Then he'll become stiff and…*
> *I: And is that a reason for you to say I want to start that as late as possible?*
> *R: Yes... let's first see if we can manage the pain this way. When we really can't any more then, well, then you have to. Because then it's no good if he can't do anything but lie on the sofa racked with pain…*

Intentions

The professionals' role

Trouble-shooters or skilled companions
All professionals stressed the importance of relieving the child's suffering. However, within this we identified two dominant styles related to their intentions. Professionals were rather, 'trouble-shooters' or rather 'skilled companions'. For 'trouble-shooters' palliative care is equivalent to symptom control. Many of them had difficulty with our main question: "What do you consider good palliative care given the situation of this specific family?" 'Trouble-shooters' did not think in terms of good palliative care. For them, problems were at the forefront of their care, and symptoms were concrete, mainly physical problems, that they could solve. Palliative care was part of the job and their attitude and proposed solutions were often shaped from a normal or a curative perspective. The mother of Bas, for example, was kept waiting by her GP even though she had phoned because her four-year-old son had suddenly started screaming with pain. He was to die four days later. The GP (R21) concluded:

> *Yes, immediate panic at anything that is not expected. And yes, you tell each parent of course to first wait an hour, half an hour …and then you call an hour later and whatever it was is over. But she (mother) couldn't do that then.*

Trouble-shooters exhibited a normative attitude, leaving little room for understanding or negotiation and often resulting in the conclusion that parents acted wrong. During the last days of Martin's life, the homecare nurse (R11) spoke about his drip feeding:

> *…if the end is approaching, stop the tube feeding, why would you still be giving that…it's just procrastination as far as we're concerned. But they wouldn't hear of it.*

Professionals with a ´skilled companion´ attitude were primarily goal-driven, aiming at the child's QOL and a peaceful death. Symptom treatment was considered a precondition for both goals and possible solutions were judged on their contribution to QOL and/or a good death. Skilled companions often enacted a broader perspective of QOL meaning that they included aspects that were important for the child and not only focused on the absence of physical complaints. 'Skilled companions' were well aware that to establish adequate symptom treatment, solutions that from a medical perspective were appropriate should fit the goals agreed with the parents. The solutions should also be adapted to the parents' ability to cope with loss. Because of this they achieved to optimize the treatment of symptoms through a process which involved creating a dialogue with the parents and guiding them step by step.

The parents' role and the interaction with professionals

The parents spoke about a dual primary goal of making the best of the remaining time together, during which they could still experience the unique identity of their beloved child, while at the same time maximizing the child's well-being which included lessening the child's suffering. Sooner or later in accordance with the parents' ability to give up their resistance to the loss of their child, the emphasis shifted from enjoying what is still there of their child to doing everything to lessen the child's suffering. The latter was marked by a change in their perception of the suffering from symptoms, resulting in a stronger need for the best possible symptom treatment.

Tensions between parents and professionals

Both parents and professionals reported tensions in their views of symptom treatment.

Tensions arose when parents experienced professionals to communicate treatment solutions rather directively. We found this left parents feeling overwhelmed. They sometimes accepted solutions they felt uneasy with but more often they withdrew from the professional. 'Trouble-shooters', especially, often accepted that contact was limited, even completely finished, or that some topics became a no go area. In the interviews they clarified this attitude as respecting the parents' autonomy. As a consequence the parents request became paramount instead of the child's needs.

> *Look, it's their child; it's their situation, their family. And if they want minimal intervention,. . .*
> *(. . .) if that's the way they want to do it, then I respect that (GP R12)*

Hence these professionals lost their most important informants, while the parents lost an expert view on symptom treatment. This had huge negative consequences for the child's symptom treatment as is illustrated in the case of Willem (Box 2).

By contrast the 'skilled companions', once faced with emerging tension, tried to continue the dialogue. Parents appreciated the professionals' willingness to take into account their perspective. For the professionals, however, this introduced new dilemmas. There often was a discrepancy between the parent's wishes and needs versus their professional perception of the child's need for symptom treatment, especially during the terminal stage. This was viewed in two ways.

In the first place parents, reassured by the information from the oncologist that their child would not have to suffer or to be aware of the end of his/her life, requested a decisive action, such as to stop drip feeding, intensify sedation or maximize pain medication. These parents indicated they could not give positive meaning to their child's situation. They discussed the possibility to intervene actively to relief the child's suffering and or to hasten death. During the interviews the GPs sometimes wondered whether it was the child's or the parents' suffering that caused this request for treatment especially when suffering from pain was absent. In general EOL decisions, and in particular aggressive pain management or sedation, appeared to be difficult themes at home.

GPs, who at home were responsible for the decision-making and implementation of symptom treatment, felt more reticent about intervening than parents who were prepared for these decisions by the oncologist.

Box 2 Willem (2 yrs, brain tumour)

During 6 weeks before death Willem alternated between being conscious and a state of sub-coma. The oncologist had informed them, his death was imminent. Consequently his parents expected him to die every moment during these weeks.
Both father and mother felt uncomfortable with their GP and had clung to their oncologist and paediatrician for support, which was provided by telephone. Both the oncologist and the paediatrician had indicated they should now transfer to their GP. Consequently the parents relied increasingly on their own expertise. The day Willem died he got severe fever. The GP, who was now called in, had not seen the child for at least 2 months and was entirely unaware of the seriousness of Willem's condition. He diagnosed laryngitis and tried to send the child for X-rays and treatment. His parents felt overruled and felt relieved when the paediatrician refused the child, questioned the curative approach and explained the parents preferred the child to die at home. 4 hours later Willem passed away. In hindsight the mother reported Willem had not wanted to be touched for weeks anymore and disliked being cared for. She wondered whether her son had not suffered too much, especially from pain. The father regretted not having initiated more contact with the GP. The GP evaluated his involvement positively because the child had died at home and he had respected the parents in doing it their way.

Second and more often, we found that parents struggled with a proposed or already started symptom treatment that in their opinion entailed losses, such as the loss of communication. For professionals this too raised the question of how far they should weigh the parents' needs especially when the parents' attempts to cope with loss hampered adequate symptom treatment, as is illustrated in Box 3 by the case of Jasmijn.

Knowledge, expertise and skills

In practice symptom management depended on the knowledge, expertise and skills of the individual professional and parent. The way they took responsibility and their intentions determined whether and how these were applied.

Box 3 Jasmijn (2 yrs, neuroblastoma)

According to the GP, Jasmijn was extremely agitated, very restless and suffered from pain during the whole day. Here she decided the child's symptom control should get priority. The parents indicated they feared losing communication but agreed from the perspective of relieving suffering from pain. In consultation with the parents, an experienced palliative care colleague and an expert paediatric homecare nurse it was decided to start with the administration of Haldol®, Dormicum® and morpine by infusion. This was combined in one infusion system to facilitate the parents, who continuously comforted Jasmijn by walking around with her or taking her on their lap. Because of prolonged signals of pain the infusion rate was increased. Consequently Jasmijn became more deeply sedated. The parents felt increasingly uncomfortable and restarted the discussion about the sedation. GP: 'The father called me: '*it doesn't feel right to us, it's all going too fast and well…soon we'll lose her.'*

The GP decided to return to oral pain medication and to see what happened. According to the parents, Jasmijn had another wonderful week they enjoyed together after which it seemed more appropriate to start palliative sedation. Because Jasmijn felt uncomfortable during the procedure she fell asleep crying. Jasmijn died the day afterwards. Late in the evening of her death her parents felt uneasy Jasmijn cried during their last moment of communication and wondered whether they could not have one moment of contact with Jasmijn. They discussed it with the nurse and stopped the Dormicum®. Jasmijn however kept sleeping till the early morning and then passed away.

Afterwards the GP said: "'*In hindsight I think I was ahead of the parents in terms of process. As far as the child was concerned, I thought she was ready. Well, you're not only dealing with the child, but also with the parents, aren't you? Yes, she lived longer and maybe very important things happened during that period, I don't know that, but I sometimes had the feeling I needed to watch out that Jasmijn's best interest was served.*

The professionals

GPs and homecare nurses, in particular, mentioned their lack of knowledge of paediatric oncology and expertise in paediatric palliative care: *We do have enough expertise with dying, but not enough with dying children*. Some professionals solved this gap by organizing coaching on the job, for instance by consulting the oncologist or more experienced colleagues regularly. In one case the GP invited a paediatrician to join her when visiting the child. In another case the GP and the homecare nurse scheduled their visits simultaneously, in order to discuss symptoms and further policy. However, most of the GPs did not do so. As a consequence symptom treatment could easily become insufficient. Below we present some examples.

Identification, assessment and treatment
To identify and assess symptoms, many professionals relied mainly on the parents' report. Much assessment, problem-solving and advice, however, was communicated by telephone due to the reactive 'call me if you need me' strategy and the distance between home and the POW. Some professionals reported feeling trepidation when faced with assessing or examining a child, pitiful and prostrate, laid out on a sofa or in bed. Some GPs were not even aware that they had not examined the child until they were interviewed:

> *I: Did you have sufficient opportunity to examine Job yourself in order to determine if he was in pain?*
> *R: Well, I didn't really myself...well, just asked the parents...so not myself. . . (GP R41)*

Many GPs did not systematically assess the multitude of possible symptoms during the last stages. Consequently their attention was focused on problems that were already manifest, that is the symptoms parents' brought in and symptoms that could be expected based on the oncologist's prognosis and in particular those problems the GP felt uncertain about. During the interview the GP (R23) of Job realized he had paid too little attention to his pain and feeding problems:

> *Other issues were more prominent. It's difficult with children because you're still orienting yourself and don't know everything. In this case the risk of getting stuck played much more of a role. I was very alert to signals of increased intracranial pressure.*

Also the professionals' limited frame of reference complicated the interpretation of signals and delayed adequate symptom treatment. It was found that primary care professionals felt entirely overwhelmed by situations that are common in paediatric oncology, such as breakthrough pain or a fast process of deterioration and dying. Many GPs had difficulty judging the child's condition. They relied on the oncologists' predictions.

> *The oncologist had said that it was a very progressive, aggressive leukaemia. I thought it would be a month. That's what the oncologist had said: "the treatment will be effective for another month (...) and only then will the symptoms present themselves"... but it actually all went much faster. (GP R41)*

Pain was considered a problem for most children in our study. Pain however was only recognized the moment the child mentioned it, cried or screamed. Child-specific expressions of pain such as restlessness or immobilization however were seldom recognized as pain. Also sudden agitation or increased restlessness which can precede the actual process of dying were not recognized as such.

The parents

Some parents indicated they had simply got used to a degree of suffering from symptoms. In hindsight several parents expressed feeling shocked when looking at pictures of their child in the last stages. As one mother (R21) said: *"Our perspective had changed. You get used to it. Everything had become normal, but of course it wasn't. I was not aware of the seriousness of his condition."*

While some professionals had emphasized the child's QOL was paramount now, parents had learned that some suffering could be justified or was inevitable, also in the palliative phase.

Many children had received life-prolonging palliative treatment and although oncologists chose to apply therapies that threatened the child's QOL as little as possible, side-effects were accepted to reach maximal prolongation of life. While their professional caregiver had emphasized the child's QOL was paramount now, parents who were socialized in that some suffering could be justified or was inevitable, also during the palliative phase, did not make this shift in view.

As discussed above, parents had reasons to tolerate some suffering of their child in order to prolong their time with the child. And although the treatment had formally shifted to addressing symptoms, some symptom-directed treatment also implied inevitable painful procedures such as inserting a pleural drain. A few parents mentioned they compared the child's suffering to the level of suffering during curative treatment or to earlier moments of severe suffering. They appraised the current suffering of the child as tolerable.

> *He had attacks of terrible pain. And at a certain point they would last for an hour or so. And in the beginning it was an hour and a half or two hours . . . oh, it's just an hour. . . well, an hour. . .. if you think of it now ... an hour, four times a day... that's a lot, of course... you keep shifting your perspective.* (Mother R21)

Discussion

During the stages of deterioration and dying the early identification, assessment and treatment of symptoms of children cared for at home depends on the responsibility taken by both the parent and the professional. Both of these parties' intentions, skills, knowledge and expertise are important. Professionals often adopted a 'reactive' attitude, thereby initiating a shift of responsibility towards the parents. Parents in turn experienced symptom treatment at the EOL as being responsible for directing the child's death and thus were reticent about starting such treatments that would have consequences they perceive as losses. As a result the child's symptoms were often not properly treated.

Parents felt helped by professionals who took the lead in symptom management, while at the same time starting a dialogue in the child's best interest. Some parents tried to act almost unreservedly in the child's interest. But most parents experienced difficulty in doing so because of the threat of the loss of their child. As a consequence starting a dialogue was easier said than done. Some professionals who had succeeded in creating a dialogue ascribed this to their relationship of trust with the parents. We saw, however, excellent examples of professionals from out-of-hours local services who took the lead the first moment they came in, without losing the parents' trust.

Parents were positive about professionals who assessed the child's condition thoroughly and discussed their professional perspective, while also taking the parents' perspective seriously. In addition, parents valued those professionals who preserved as much as possible of what the parents perceived as the child's identity and zest for living. They valued too those professionals who took into account the parents' needs and did not put pressure on them by running too far ahead when discussing or making decisions about treatment. These professionals were especially sensitive to what the possible solutions meant for the parents. This could be seen in terms of gains such as lessening the child's suffering and improving QOL, but also in terms of losses including the loss of time spent together or communication. They suggested solutions which parents could handle and supported the parents coping by providing a rationale or meaningful arguments for treatment. This helped parents. Moreover parents felt they shared responsibility, while they still felt a sense of control.

The study has strengths, but also some limitations. The study was strengthened by interviewing the majority of the respondents during the palliative phase. This probably brought our findings closer to reality than interviews in hindsight.

Given the palliative undertone of the study, and because the oncologists were responsible for asking the parents' permission to be approached by the researcher, it is conceivable that we had better access to parents who coped relatively well with the loss of their child. Consequently, difficulties in interaction can lead to even less adequate symptom treatment than was encountered in this study. The number of cases that fitted the inclusion criteria was small. This limited the opportunity to sample theoretically [16, 22]. In addition, assessing the adequacy of symptom treatment or the parent-professional interaction in advance in order to sample theoretically is hardly possible. Nevertheless our sample was multi-centred, included fathers and mothers equally and showed wide variation concerning the parent's coping with loss and the professionals' attitude. This increased the validity of our study.

In paediatric oncology dying at home is considered best for the child's QOL [23-27]. This cannot be said for symptom treatment during the final stages. This study shows that, even when the appropriate intentions, skills, knowledge and expertise were present, adequate symptom treatment could only come about when responsibility was taken by professionals. Like most western countries, the Netherlands lacks nation-wide well-organized paediatric palliative homecare services [28]. Clinicians and researchers have stressed the need for comprehensive paediatric palliative care services as a precondition for home based end-of life care [29-32]. It could be that a transmural team improves on all three identified domains, resulting in better symptom management. Most palliative care services, however, are evaluated on their facilities, organizational aspects, the preferred place of death, or parental satisfaction with care [25, 28, 31, 33]. There is a need to evaluate these services also on quality outcomes such as the child's suffering from symptoms, symptom treatment and/or the parents' ability to cope.

When cure and prolongation of life by cancer directed treatment are no longer possible, the child's QOL becomes paramount. Hence clinical parameters are replaced by the more subjective evaluation of QOL. The experts on the child's well-being are considered to be the parents and, depending on the child's developmental capacity, the child itself too. There is a tendency therefore to follow their beliefs and preferences. This has reinforced a shift from the paternalistic medial decision model to the more patient-centred decision models [34, 35]. This, for example, means increased shared decision-making, in which the parent and clinician collaborate and informed decision making, in which the clinician provides information and the actual choice is made by the child and parents. This study, however, laid bare that for many children being cared for at home during the palliative phase the full responsibility for symptom management has been transferred to the parents. Unfortunately, this results in the fact that both informed as well as shared decision making is lacking.

This is especially true because we found that symptom treatment during the last stages of the EOL is influenced by the parents' ability to cope with the loss of their child. This can subordinate the child's need for symptom treatment to the parents' needs. This can result in either passivity, resulting in delayed or under treatment, or a pressure on the professional to intensify treatment. The child's best interest is served by continuation of shared decision-making, certainly during the palliative phase.

Prolonged physical pain and a difficult moment of death are known to affect bereaved parents for many years [36]. Acting in the child's interest is an important aspect of parenting during EOL [37] and supports a positive evaluation of parenthood [38]. This study shows that being informed does not automatically imply that parents work towards adequate symptom treatment. It is known that parents' have difficulty speaking about their child's death [18, 39]. Many parents however felt helped by coaching on the job, talking about their child in general and searching for solutions for problems that were already manifest. Consequently we do not consider professional guidance on symptom treatment to be a threat to the autonomy of the parents, which was suggested by some of our respondents. Parents know their child best, however, for them parenting and caring towards the child's death is uncharted territory and implies a conflictual position regarding the most difficult assignment to deal with actual loss of their precious child. Hence it can be a relief to share responsibility in decision-making. Symptom treatment has been traditionally improved through medical education. However, to achieve an early identification, an impeccable assessment and adequate treatment, the understanding of the parent's perspective and the maintenance of a dialogue with the parents aimed at lessening the child's suffering is of equal importance as it is to have professional knowledge and technical skills.

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Chapter 7

General discussion

Introduction

This study addressed the lived experience of parents of children with cancer and in particular of children who were cared for at home after all curative options were exhausted. The study was aimed at a better understanding of the parents' experiences, meaning giving, coping strategies and needs during the palliative phase. In addition the professionals' role in providing palliative care at home was explored.

Parents of children with incurable cancer are encouraged to care for their child at home. It is recognized that those parents play a major role in practical care and emotional support for their child. Even so there is hardly any insight in what it means to parent a child who is facing death and how this experience influences parental care-giving and decision-making during the palliative phase.

This is even more important now as, driven by medical improvements, the palliative phase has lengthened and increasingly has become a stage during which difficult medical decisions have to be made. The difficulty of making trade offs and decisions during the palliative phase is generally acknowledged. The increase of cancer-directed palliative treatment options forces those concerned to weigh quality of life and quantity of life. Parents play a crucial role in substantiating the quality and quantity of their child's life. How the parents' perspective and meaning giving develops throughout the palliative phase and what influences their perspective and decision-making is still not fully understood.

We have very little insight into the role of professionals at home even though an increasing number of children are cared for at home during the palliative phase and palliative home care services are developed all over the world. Hence we explored how palliative care, and in particular symptom treatment, were shaped by professional caregivers involved in the care of the children included in this study. We looked too at to what extent parents experience professional care as supportive.

A study on children with leukaemia who were treated with the intention of curing them was conducted first. This preliminary study helped us to grasp the essence of parenting a child with a life threatening illness and to refine our method of collecting data so we could use it in what we considered to be a more vulnerable situation such as that is conducting interviews with parents during the palliative phase.

The following research questions were addressed:

- What is the essence of parenting during the first year of treatment for parents who take care of their child diagnosed with leukaemia?

- What does it mean to parent and care for a child with incurable cancer and how do parents give meaning to their parental role throughout the palliative phase?

- What processes do parents go through when cure is not obtainable, and how do those processes influence the choices parents make for their child's treatment and care?

- What are, from the parents' perspective, the main factors that influence the parents' position between preserving their child and letting their child go at the end-of-life?

- How are symptoms treated amid the interplay between parents and professionals in the final EOL stages at home?

I will review the major findings of this study in this concluding chapter and consider them in a broader perspective. Their meaning for practice will be discussed. Before that a reflection is given on methodological issues.

Methodological issues

Qualitative interpretative methods were used in line with the explorative character of the research topic and the intention to shed light upon the internal perspective of our respondents. We followed specifically the qualitative inductive analysis as is described by Kvale [1] and a grounded theory approach as is described by Charmaz [2]. Below we will discuss the strong and weak aspects of our study.

Strengths

It was expected that the perspective of bereaved parents changes over time due to processes of coping with bereavement. In addition, we expected the parental perspective to change throughout the palliative phase. Because of this, we collected our data during the palliative phase, which probably brings our findings more close to reality than the strategy, often used, of collecting data after the child's death.

Parents were considered eligible for the study when the oncologist had told them that their child could not be cured. We considered the palliative phase to start at the moment that according to the primary oncologist cure was not or no longer possible. This was sometimes a point of interdisciplinary discussion and introduced an unavoidable aspect of subjectivity in our study entry. None of the children, however, returned to curative treatment between the moment of inclusion and his/her death. Wolfe et al [3] identified a considerable delay between parental recognition that their child has no realistic chance of a cure and the physician's understanding. We may have introduced some delay by adding the condition that the oncologist had informed the parents that curative treatment had failed. We conclude, however, that the inclusion procedure reflected clinical practice and prevented the inclusion of children who were still in the period of uncertainty between curative treatment and the palliative phase. This provided a clear starting point for the interviews, which added to the validity of the study.

To maximize our insight into the parents' process while minimizing the parents' burden, we developed a matrix approach by interviewing all parents one-time, face to face, and conducting one or two successive interviews with one third of the parents. In hindsight, we conclude that we gathered rich data that substantiated our insight into the parental process throughout the palliative phase. In addition, the matrix approach enabled us to provide a 'thick description' of all stages identified. This increased the validity of our findings.

Some parents requested to be interviewed after their child's death, because the disease progressed rapidly and/or they preferred to be there for their child. We initially considered this to be a weak point. However, data collection during the palliative phase added with data collected soon after the child died supported our data collection and data analysis. Firstly, it provided insight into the parent's experiences during the dying phase. Secondly, it facilitated constant comparison between cases. This facilitated, for instance, our provisional conclusions about changes in the parents' behaviour. These changes relate to: feelings of loss, our insights concerning the transition from preserving the child towards a 'letting go' perspective, the factors that influence this transition and the role of hope or the shift in strategies for control. Those bereaved parents had gone through the whole process very recently. They could reflect on their process from an inside perspective and could confirm or reject our preliminary insights. To decrease, as far as possible the problem of changed perspectives due to the parents coping with the loss of their child, we offered them an opportunity to talk freely about their current feelings of loss before we questioned them on their experiences during the EOL. We consider as signals of great openness the fact that those bereaved parents were still able to share with us their uncertain feelings about the care they provided, or the decisions they made during the palliative phase. Furthermore the degree of openness was shown by the fact that some of them discussed how they currently tried to deal with lingering doubts.

The interpretative approach of our analysis required a great degree of care to, on one hand, do justice to our respondents, and on the other, to prevent ourselves '*going native*', that is adopting the feelings of our respondents ourselves [4].
Hence, we conducted the analysis from data collection through to the theory generation with a team of researchers having different disciplinary backgrounds. This offered a forum for discussing different views by researchers who were familiar with the development of theoretical insights. Initial conclusions were discussed by professional experts, both in hospital and community settings, and a parent from the Dutch Childhood Cancer Parent Organization. This offered the opportunity to find support for our analytical insights and to identify possible gaps. A paediatric nurse scientist and a student in nursing science, who were not connected to the study, reviewed and approved aspects of our analysis.

Weaknesses

During the analysis we found that from the parents' perspective the palliative phase consisted of four stages. The code tree was redesigned accordingly. Subsequently, common themes for each stage were identified. However it was difficult to delineate sharply between these stages. This required a delicate approach, especially because the parents' view sometimes differed from the oncologists' and/or the researchers' perspective. In line with the aim of the study we gave priority to the parents' perspective. Difficulties in classifying fragments were resolved by discussing and searching for agreement between the two coders, who had conducted the majority of the interviews (MK, MKV).

A difficulty in developing a grounded theory in our study was the limitations of theoretical sampling. This was especially true with respect to parents who occupied a predominantly 'preservation' frame of mind and those who occupied a predominantly 'letting go' perspective. Although we had substantial variation in both groups, theoretical sampling could possibly have deepened our conclusions about the parents' transition from 'preservation' towards 'letting go'.

Some strong aspects of our design had downsides as well. For example, we had chosen to interview professionals actively involved in the cases under study. The sampling of professionals depended partly on the parents' experiences and evaluation of the professionals' role. Consequently, a small time lapse existed between the parents' interviews and the professionals' interviews.

In addition, they were interviewed by different interviewers in order to prevent a transfer of information between parents and professionals. No specific information related to the case was shared beforehand between the interviewers. The strength of this approach was to be found in the fact that the professional had to sketch the situation from his or her perspective. In contrast, the inability to discuss the situation openly, as identified from the parents' interviews, was considered a weakness. This problem was partially resolved by questioning professionals about the problems we had identified on the level of the aggregated analysis of the former interviews and to relate this to the information the professional had provided on the case under study.

Review of the major findings

'Being there' as a fundamental aspect of parenting a child with leukaemia during treatment

From the preliminary study among parents of children diagnosed with leukaemia we learned that parents wanted to 'be there' once their child's life becomes threatened (chapter 2). 'Being there' was identified as a parental response to the perceived vulnerability of the child and a parental need to meet the perceived needs of the child.

It served two purposes: protection and preservation. Protection meant guarding the child against the negative aspects of illness and treatment in order to safeguard his or her well-being. Parents felt their child appealed to their care and support and derived his or her power and stability from the parents when they behaved according to the concept of 'being there'. Preservation referred to the way parents influenced the child's perception of his or her situation so the child could cope better with difficult tasks.

At this stage, for instance, this meant sustaining the child's willingness to undergo cancer-directed treatment to maximize the chances of survival. The parents' life contained numerous expressions of 'being there'. These included; a trusting relationship with the child, their presence and physical contact, emotional support, advocacy for the child's interests, routines to increase the child's comfort and coping, and putting oneself second to the service of the child's needs. Although both fathers and mothers expressed the need to 'be there', mothers were involved more deeply in the life of their child. For them a feeling of empathy and staying together was important. Fathers tended to advocate and support their child in a more practical way. Fathers also seemed better able to leave 'being there' to mothers, than the other way around.

The need to 'be there' was the driving force behind the never ceasing involvement of parents with their child, even when they felt care-giving was beyond their strengths. This could be explained by the reinforcing power of being of meaning to the child. For parents 'being there' deepened the relationship with their child and made them feel their unique significance as parents.

Parenting a child with incurable cancer throughout the palliative phase

In this study we addressed parenting the child with incurable cancer throughout the palliative phase (Chapter 3). Irrespective of the length of the palliative phase we could still identify four stages from the parents' perspective: Stage one, becoming aware of the inevitability of death; stage two, making the child's life enjoyable; stage three managing the change for the worse, and stage four, being with the dying child. The four stages were marked by an increased physical decline and a decrease in the child's ability to participate in daily life. The essence of parenting during these stages was captured by 'being of meaning to the child', by 'preserving the parent-child relationship' and, by 'ensuring happiness for their child'. This took the form of 'being there' and 'having their child enjoying life'.

Parenting, while losing the child, brought many parents to the point of an existential crisis. Yet in response, parents were able to shoulder their responsibilities as caregivers. In doing so many parents endured, meaning they contained their feelings of loss, and postponed their grief in order to keep going. This was a precondition for parenting and helping their child to enjoy life. Despite their own distress, parents were able to hold on due to their ability to postpone grief, to enjoy the child's expressions of happiness, to look beyond the sick body and still see the child inside and the expressions of his or her identity, and the rewards experienced from caring and being there in response to the child's needs.

Similar to the leukaemia study (chapter 2) 'being there' was identified both as a parental response and a parental need. This served both as protection, aimed at the child's well-being, and preservation, to help the child to cope with difficult tasks. In the palliative phase, however, 'being there' could increasingly be characterized as the embodiment of not leaving the child alone in his suffering. By 'being there' parents had a meaningful answer through all stages of the palliative phase, despite their increased powerlessness due to witnessing the child's decline.

Parents had no alternative than to help their child to enjoy his or her life. This 'enjoying life' surpasses the regular parental aim of well-being or normal life. It was also about facilitating a life the child experienced as 'worthwhile to live'.

Parents were able to cope better with the stressful process of losing their child by giving significant meaning to their parenting and care-giving activities. Once the child died, having been there for their child appeared to be a major criterion in evaluating positively their performance as parents. Most parents redefined their parental role over time. Initial strategies such as facilitating an enjoyable life seemed to fail when either physical decline drastically progressed or the child gave up mentally. Sometime during the stage three or four most parents came to terms with the idea that parenting aimed at comforting the child and helping him or her to cope with imminent death also could be meaningful and differs from giving up on the child.

Most parents experienced an inner conflict between on the one hand their wish to create a worthwhile life and preserving their relationship with the child and on the other hand supporting their child in coping with death. Living toward the child's death meant facing the breaking of the bond with their child. Thus parental guidance and communication about the end-of-life could be inadequate. Rather than unwillingness, this is simply a matter of being unable to manage the existential threat of child loss - the difficulty of guiding their child in a direction the parents know he or she has to go without them.

The parents' process throughout the palliative phase: a transition of perspective and a switch in control

From a parental perspective the essence of the palliative phase was better characterized as coping with loss, than as the acceptance of death (chapter 4).

Feelings of loss have already forced themselves upon parents during the end-of-life (EOL) phase, mainly triggered by the child's physical decline, the child's becoming resigned to the fact he/she is going to die, the parental anticipation of what the loss of their child will mean in their future life and the treatment of symptoms at the EOL. In the lived experience of parents, loss happened in stages, was divided into separated parts characterized by moments of decision-making and adaptations to be made to daily life. Due to the fact that they had the choice to intervene, to withhold or to withdraw interventions, parents could fight or accept separate aspects of loss.

Dealing with loss can thus be seen as a process of giving up, step by step. The parents' difficulty in coping with feelings of loss resulted however in ambiguity for knowing death is inevitable did not preclude the avoidance of loss. This took the form of an internal struggle between 'letting go' and 'preservation'.

'Preservation' meant that parents avoided the reality of loss by sustaining life, aimed at maintaining, in fact improving, the existing situation and in particular of preserving what is still there of their child. Parents attempted to prolong their life with their child. 'Letting go' meant parents recognized the inevitability of death and they felt prepared to subordinate their need to avoid loss to the child's well-being and comfort. For most parents the balance shifted over the course of the illness from preservation towards letting go. It appeared that parents who adopted a letting go perspective were more receptive towards their child's real situation compared to parents who adopted a predominantly preservation perspective. This increased their ability to stay attuned to their child's needs. A timely completion of this transition appeared to be important for the child's well-being at the EOL and for a positive evaluation of their parenthood once the child had died.

Even so parents could have great difficulty making this transition, because it implied a change in the source of control. Parents who, at least temporarily, adopted a 'preservation' perspective found control in maintaining the status quo. Parents adopting a 'letting go' attitude experienced control in exerting parenthood aimed at the best interest of the child and the creation of a sense of togetherness with their child. In a nutshell, parents felt a desperate need to exert control but this transition placed their control in jeopardy. Consequently some parents simply could not face making this shift until the last hours of their child's life.

Factors that influence the parents' position between preserving their child and letting their child go at the end-of-life

Given the importance of a timely transition towards a 'letting go' perspective, we identified, from the parents' perspective, the main factors that influenced their position between preservation and letting go (chapter 5). Uncertainty, fragmentation, meaning focussing on details instead of drawing the whole picture from the observed physical changes, and anxiety supported preservation. Certainty, postponed grief, the perception of suffering, the ability to disentangle their own needs from their child´s needs and the ability to parent meaningfully, promoted letting go. Hope, a good parent-child relationship and the attitude of professionals could support movements in both directions.

In day-to-day life these factors were intertwined. Moreover, the degree of their influence changed over time and parents' sensitivity to some factors changed throughout their transition. A letting go attitude could only come about in close connection with the perceived reality and required an integration of all factors influencing the transition. This is best understood when one considers the relationship between the factors and the core process of the transition: the parents' suffering from loss. Our study revealed that certainty, the conviction that death is inevitable, is of great importance in moving towards a position of 'letting go'. Certainty arose from the child's physical deterioration and could be supported by providing honest information, by visualizing the illness process, and by 'framing' aimed at letting go. This 'framing' refers to the way professionals defined the child's situation in the context of illness and available options for treatment. Irreversible decisions also made the uncertain certain. In the process of becoming certain feelings of loss increased. Most parents fostered uncertainty in order to find relief. They made the certain uncertain by creating hope, or made the certain avoidable or ambiguous for instance by fragmentation. Fragmentation meant parents pushed back signals of the approaching death by focusing on details. This allowed them to avoid reading the signs and created room for ambiguity.

The increase of certainty forces parents to develop a manner of parenting that takes loss into account. We found that feelings of loss can be assuaged, temporarily or otherwise, by the parents' knowledge that they are doing the best for their child. Parents felt strengthened to do so when they were able to disentangle their own needs from their child's. In conclusion, to be able to let the child go, parents had to cope with feelings of loss and find meaning in occupying a letting go perspective. Parents felt helped in making the transition when they felt validated by professionals. By means of guidance and framing, professionals could intentionally influence some factors in support of a transition towards 'letting go'.

The roles of parents and professionals in the early identification, assessment and treatment at home of symptoms of terminal cancer among children

During the stages of deterioration and dying, the early identification, assessment and treatment of symptoms among children cared for at home depended entirely on factors related to the parents and the professionals (chapter 6). The responsibilities taken, their intentions, and their skills, knowledge and expertise all played a part. We found professionals often adopted a 'reactive' attitude, thus shifting responsibility towards the parents. A reactive attitude means professional caregivers come into action in reaction to the parents' initiative to report signals or problems. Parents in turn experienced symptom treatment as being a factor in the child's death and therefore showed reluctance to begin treatments that had consequences they perceived as losses. This often resulted in symptoms not being properly treated. Parents felt helped by professionals who took full responsibility for the child's symptom treatment, provided that they remained perfectly aware of the parents' perception and needs. Starting a dialogue aimed at the child's best interests, while preserving the parents' sense of control, appeared to be the most fruitful approach.

General conclusions

In this part we will bring together the main themes of this thesis: parenting, loss, and professionals; and consider them in a broader perspective alongside the current literature.

Parenting

Being there

Parenting was defined as: "performing the role of a father or mother by care-giving, nurturing, and the protection of the child through a complex process that involves bi-directional relationships between members of two generations" [5].

If a child becomes seriously ill, especially in the palliative phase, however, the protection and to a lesser extent the nurturing of the child are put under great pressure. From this thesis we learned that the parent-child relationship intensified once the child's life became threatened. This intensified relationship became apparent in the manner in which parents did the utmost to support the child's well-being and to provide care. Several studies indicated the parents' involvement was enhanced in reaction to the child's physical and emotional needs during cancer treatment [6-8]. An intensified relationship experienced by intimates of life-threatened or dying persons is also seen in adults, for example between spouses [9, 10]. The vehicle for this intensified relationship was the parents' need to 'be there' in response to their perception of the child's vulnerability and the tasks the child has to cope with, due to treatment and/or facing the end-of-life.

Consequently, we consider 'being there' as the essence of parenting a child whose life is threatened. The importance of 'being there is laid out in 4 aspects.

First, 'being there' enabled the parents to provide compassionate care, even when the child could not give much in return anymore. Due to the need to be there, most parents succeeded in caring through all stages and saw caring for their child themselves as a rewarding task. The latter was reflected in earlier research [11, 12]. Secondly, parents felt to be of meaning to the child throughout the palliative phase, because 'being there' could be transformed into meaningful answers in response to the child's needs through all stages. Consequently it preserved the parents' relationship with the child in circumstances in which otherwise they could not protect their child. Third, it appeared that enacting 'being there' helped the parents themselves to cope with the stressful process of losing their child. The final aspect we identified was that having been there for their child appeared to be a major criterion in evaluating their parenthood positively once the child had died. The importance of 'being there' was recently confirmed by Hinds et al [13] who found that parents mentioned 'being there' as an important aspect of being a good parent in decision-making for their dying child. Children themselves appreciate their parents 'being there' during the EOL [14]. Consequently, the parents' ability to 'be there' for their child should be preserved and empowered during the palliative phase.

Entangled needs and the child's best interest

Parents felt their child derived his or her stability and power from their parental stability, protection, presence and support. They themselves felt empowered by their child's coping. The same was seen in how parents stimulated and enjoyed the child's happiness (chapter 3). This apparently mutually beneficial relationship seems to fit with the intertwinement as described by Last & Veldhuizen. regarding the openness of communication between parents and children diagnosed with cancer[15]. Last and Veldhuizen formulated the 'law of double protection' (Dutch: 'de wet van de dubbele bescherming)', meaning parents reduce the child's negative emotions not only from an empathic perspective but also as a way to protect themselves against the child's emotions. This was not only seen among parents but in children too. Children preserved stability by not showing their emotions and thus preventing their parents from becoming distressed as a consequence. Thus parenting behaviour is a response to the child's needs, but it also fulfils the parents' own needs. This entails aspects that are needed as well as risks.

It is needed because it is an important strategy to maintain so long as the physical deterioration has not taken hold. For both the parents and the child, living while facing the EOL can only be carried on when its content is worth living for and can be enjoyed (chapter 3). From adults it is known that they want to live till the end [16]. Even in cases where there was open communication about the child's situation and impending death, this openness was not there all the time. It is for this reason that we also concluded that moments of a mutual pretence, a kind of understood and mutual self deception, where both know, but do not mention the impending death, could be fruitful in stage two.

The interrelation, however, also entails the risk of forcing each other to adopt a positive attitude that hampers a realistic perspective and honest exchange of views. The latter is of major importance because parents intend to follow the child's preferences [13] and professional caregivers intend to follow both, the parents' and the child's, preferences [17, 18]. Consequently care-giving and decision-making depended to a great extent on the parents' ability to give their child a voice. Our study showed that this ability could be hampered due to the parents coping with loss. Parents differed largely in expressing their child's perspective. Some parents took the child's perspective and appeared to be well aware of their child's perception, fears or coping strategies; others never mentioned the child's perspective spontaneously during the interviews. When those parents asked often indicated the child agreed.

In conclusion, many aspects of parenting appeared to serve purposes that can be considered child-centred as well as centred to the needs of the parents. Because of this the child's tasks are partly a result of the way parents direct their child's life and thus strongly influenced by the parents' assessment of the situation, their aims, needs and coping strategies.

The child's best interest is a fundamental aspect that should underlie parenting, parental decision-making and parental care-giving [19]. However, this study showed that parenting behaviour in the context of child loss is not by definition aimed at the child's best interest. We found initial support for the view that although parents intend to act beneficially toward their child, for many of them the immeasurable worth of having more time with their child prevails over the child's best interest [20, 21]. This does not necessarily mean that parents differ with respect to their view about parenting. Maurer et al [22] found no differences in the definitions of being a good parent between parents of children with incurable cancer who opted for enrolment on a Phase 1 Trial compared to parents who chose a, do not resuscitate/terminal care option. Both groups felt that as parents they were doing the right thing. Because of this an approach aimed at disentangling the parents' needs from their child's needs is probably more helpful in helping parents to act in the child's best interest than only to make an appeal to good parenthood.

The parents' internal conflict

Two aspects appeared to be extremely hard for the parents. The first was coping with loss due to current and anticipated losses and the second, their feeling that they as a parent played an active role in directing their child's illness course and death. In fact, when parents made decisions aimed at the child's quality of life or adaptations to ensure the child's comfort, they themselves in a way created the loss they feared so much. The parents' difficulty to do so became visible in our study. Many parents left no stone unturned to maximize chances to gain time for their child and with their child. Parents experienced this as an internal conflict: knowing death is inevitable, while needing to avoid loss. However, the parent's struggle with loss concerning their child is hardly touched upon in research, even though it is well known that parents have great difficulty in making this mental leap from 'cure' to 'quality of life', even if the long-term outcome is understood to be fatal [23, 24,3, 25-27]. The difficulty of shifting to palliative goals such as the quality of life and a good death is usually approached from the perspective of having to make a decision. In paediatric oncology the decision-making approach directs towards a choice between quality or quantity of life and possibly holds down the perceptive of the child's best interest. It shows that most parents weigh up and try to reconcile the dual primary goals of either a primarily cancer-directed goal of prolonging life or a primarily comfort-related goal of quality of life [28, 29]. For many parents the quantity of life takes priority [11, 29] even when this entails a substantial decrease in the child's quality of life [22]. The same studies, however, also include parents who even at an early stage are able to resign themselves to symptom-directed treatment. Recently Maurer et al suggested the variation in decision-making among parents could be explained by the degree of progression of the illness [22]. This was difficult to prove because aforementioned studies focused on specific EOL decisions, such as enrolling in a Phase 1 study, or the decision to shift from cancer-directed toward symptom-directed therapy. Our study added insight into parental changes throughout the palliative phase, and thus also throughout the course of the child's illness. We found that every new decision or even a small adaptation parents had to make contributed to the internal struggle of the parents. The central issue however was the parents' position between the endpoint of 'preservation', meaning they were prepared to compromise the child's well-being to some extent to avoid loss, and of 'letting go', meaning parents were able to subordinate their feelings of loss in service of the child's well-being. Consequently the degree to which the parents were able to face the impending loss of their child and were able to cope with their feelings of loss was the underlying factor that most influenced their decision-making and the way they directed the child's life (chapter 4). It appeared that parents who adopted predominantly a 'letting go' perspective were better able to take the child's perspective than parents who adopted predominantly a 'preservation' perspective. Throughout the palliative phase most parents moved from a predominantly 'preservation' towards a predominantly 'letting go' position. There were large variations in the course of this shift. Some parents completed the shift in the last hours before their child died.

From our interviews we identified several factors that influenced the parents' position between preservation and letting go (chapter 5). It showed that not one factor could be identified to explain the parents' position. It is a constellation of factors and their influence changes according to the position the parents already have on the continuum. Of the identified factors we will discuss hope, physical decline and the role of professional caregivers.

Searching for a better understanding of the parents decision-making some researchers suggested that observed changes due to the illness course supported a choice for quality of life [22, 30]. Also, hope was mentioned to be the driving force for parents who decided in favour of a more aggressive treatment in the palliative phase [29].

In our study hope was also identified as a strong factor towards 'preservation'. Depending on the goals parents set along the line of physical decline it could however also contribute to the shift to letting go. For instance, the hope that the child would not suffer. We also found that the observed physical changes by themselves did not help the parents to adopt a letting go perspective but rather their certainty about these changes being irreversible. The professionals could play a role here by helping to support the parents' certainty and helping them to transform their hope to more realistic goals through framing and guidance (chapter 5). This is particularly important now that several studies have indicated that the perspective of bereaved parents changes. In hindsight, a substantial number of parents evaluate EOL themes such as discussing death with their child and continuing cancer-directed treatment during EOL differently [31-33]. Although many parents choose treatment for their children with incurable cancer, in hindsight a majority of the parents rated the palliative cancer-directed therapy as troublesome for the child. They regretted the final palliative cancer-directed therapy and bereaved parents would often not recommend it [31, 33]. In addition the ability of bereaved parents to cope with child loss does not seem to differ according to whether the child dies after terminal care or during cancer-directed therapy in the palliative phase [34].

Managing loss

A timely transition to a 'letting go' perspective helped the parents to act in the child's best interest and to adapt accordingly. This was true for all factors including: 'being there' (chapter 4 and chapter 6); coping with the threat of breaking the bond with their child by death (chapter 3); guiding and helping their child to cope throughout the palliative phase (chapter 3) ; and contributing to a positive evaluation of their performance as parents once the child had died (chapter 3). Therefore it is of major importance to understand how the parents coped with loss and to search for a helpful approach.

From a theoretical stance concerning the loss of a relative, a distinction is made between coping with a loss that has already occurred, generally captured by bereavement literature [35], and by a loss that is anticipated which is captured by the theoretical framework of anticipatory grief [9, 36]. We will discuss our findings in relation to both concepts starting with anticipatory grief.

Anticipatory grief was initially defined as 'any grief occurring prior to a loss, as distinguished from the grief which occurs after a loss' [37]. The concept was developed by Rando [9, 36] into the broader theoretical concept of anticipatory mourning that refers not only specifically to reactive grieving in response to losses and the awareness of a life threatening or terminal illness in oneself or a significant other, but also to all types of actions undertaken to cope with or accommodate to that loss [9]. The major tenet of anticipated mourning is that it is a positive adaptive response to impending loss facilitating a better life with a life threatening illness, a more appropriate death and better post death mourning [9]. According to Rando anticipated mourning should be supported during the palliative phase. In contrast the parents in our study had little or no room for mourning. It was clear that parents safeguarded their own stability, by putting their own feelings, evoked by confrontations with loss, aside and protected themselves by postponing grief. This response enabled them to be strong enough to help maintain the child's stability, to do the utmost for their child and to continue family life. The most important thing was that it helped the parents to focus on the child's needs and to act according a 'letting go' perspective. This means of protecting oneself from suffering and overwhelming emotions, in order to do what needs to be done, is recognized as "enduring" [10, 38, 39]. According to our findings comforting strategies must be designed not to harm enduring behaviour. Hence the best clinical approach is to follow the parents' lead rather than trying to facilitate the expression of emotions.

Our study confirmed the idea that what the individual parent construes as loss, triggers grief irrespective of whether it is in response to a past, present or anticipated loss [40, 41]. From this perspective we think bereavement literature can also help to increase our understanding of how parents cope with loss during the palliative phase.

From bereavement literature we learned that coping with loss is not a linear process of working through your loss in order to return to previous levels of functioning. There is also no clear support for the hypotheses that people who actively confront their thoughts and feelings about the loss show a better long-term adjustment than those who adopt a strategy of avoidance [42]. This suggests that the parents' avoidant strategy is not by definition unhealthy when it concerns themselves. It, however complicates some aspects of their ability to guide and comfort their child during the palliative phase.

Stroebe and Schut [43, 44] formulated the Dual Process Model of Coping with Bereavement (DPM). The DPM defines two broad types of stressors in grieving. These can be classified into those that are oriented towards loss versus those oriented towards restoration. Loss-oriented stressors refer to the bereaved persons' concentration on, and processing of, some aspect of the loss experience itself. Restoration-oriented stressors refer to the focus on secondary stress factors that are consequences that need to be dealt with, such as managing a household or earning a living. The DPM postulates that oscillation between the two types of stress factors is necessary in order to cope through adaptation. Stroebe and Schut suggest the person may choose to take 'time off' from loss-oriented stressors [43]. They suggest that at times it may be too painful to confront some aspect of loss, leading to voluntary suppression or more involuntary repression. This applied exactly to what happened in this study when the parents reacted in response to loss. All parents were aware of their child's imminent death and noticed forewarnings of death, but they themselves decided whether they were able to allow the pain to be felt by themselves, let alone sharing accompanying emotions with others. In most parents' experience the physical decline ran its own, often rapid course. In contrast to coping with bereavement after a loss, the parents in our study felt forced to deal with more new losses again and again, because of the child's physical decline or his or her diminished coping ability. Parents simply lacked time and energy to achieve adaptive coping by oscillating to loss-oriented stressors. They predominantly remained on the level of dealing with the daily problems that needed to be dealt with. Consequently many parents who knew their child would die, kept this out of sight and/or chose to postpone grieve. It also explains the parents' rational and strong attitude and their difficulty in acknowledging the child's real situation or to anticipate their child's future needs (chapter 3, 4 and 5). We conclude that the parents' coping strategies were helpful for parents who had to cope with such losses as were encountered in our study. We also concluded that the parents ability to adapt to loss throughout the palliative phase is limited. However, whereas postponing grief facilitated a letting go perspective, the remaining coping strategies could easily complicate their parenting role. For example when it concerns the part of helping their child with the difficulties related to the imminent death and, more substantially, adopting a pro-active attitude aimed at their child's quality of life and preventing suffering. We emphasize this was not a matter of unwillingness, but a matter of being unable to act differently. In fact, asking the parents to make decisions that direct the child's death, and asking them to take full responsibility for the child's well-being was simply asking too much for a substantial number of the parents in our study to cope with. Finally, both coping with bereavement models and the theory of anticipatory grief, mention the importance of finding meaning as a strategy to cope with loss [9, 43, 45]. Folkman [45] mentions coping based on discovering meaning as a strategy to cope with events that have an unfavourable resolution or with no resolution at all. We found that for parents who made the shift towards letting go, this aspect of meaning was found in their feeling that they were acting completely in the service of their child, for instance by comforting the child and encouraging him or her to let go of life during the dying phase. This resulted in positive emotions although parents had never thought of this as positive before.

Professionals

Professional care-giving

The main parental task is to guide, support and comfort the child throughout the palliative phase, to help him or her to live a worthwhile life, and to die as comfortably as possible, while being sensitive to the child's preferences and ability to cope. Obviously, the palliative phase challenged the parents in fulfilling this task. This was, firstly, because they felt forced to cope with loss again and again, and secondly, because communicating with the child about deterioration and dying, and directing a course towards the child's death, could be felt as giving up on the child. This would signify the breaking of the bond with the child and as such was felt to be a threat to their relationship with their child.

Professional caregivers who want to give optimal palliative care for children cared for at home are challenged to help the parents to fulfil their parental task. Consequently, they have to fulfil the complex task of guiding parents to progressively incorporate the 'letting go' perspective. In doing so they are helping them during their transition to an acknowledgement of the child's real situation and to apply the care and treatment that fits with this situation, physically as well as psychosocially. Professional caregivers who took this responsibility forced parents to face loss. Hence it required diligent management of their relationship with the parents. Safeguarding the child from meaningless treatment and providing adequate symptom treatment challenges the parents' ability to cope with loss. Strategies to support the transition, such as increasing the parents' awareness of the observed physical changes and establish the certainty of their irreversibility by framing can threaten the parents in such a way that they lose control and/or withdraw from professional care.

With the exception of the few parents who made the transition to a 'letting go' perspective at an early stage, professionals had to walk a thin line, reconciling the child's with the parents' needs and at the same time supporting the parents' leading role. The latter is needed to preserve the parents' feeling of control. Tensions could easily arise and the risk of a parental breakdown increases due to the professionals framing and guiding towards a letting go perspective. Given the parents' difficulty in adapting to the losses that were forced upon them during the palliative phase, maintaining a dialogue with the parents and guiding them step by step is more fruitful than forcing them to make decisions in response to problems or unsuccessful treatment (chapter 4, 5 and 6). In addition, professional caregivers themselves must act and think proactively to organize all arrangements that may be needed but cannot yet be handled by the parents.

It was seen that professional caregivers struggled with the intensity and complexity of paediatric palliative care at home. They struggled with the organization of care, their uncertainty about the illness course, their limited knowledge and expertise, and with care situations that presented legal and ethical dilemmas. Although these themes seem similar to the complexity of care for adults with advanced cancer [46], the child specific aspects and the parents' attitude often complicated their task. Moreover, we found that many parents felt unable to ask for help in advance, while professional caregivers often did not recognize the parents' need for help. While some caregivers provided the guidance needed, others did not recognize the parents' strong or rational attitude being crisis reactions. This resulting in some professionals becoming too distant.

Distancing was also seen in adult studies [46, 47]. Distancing in response to the parents' attitude, may lead professional caregivers to ignore their responsibility for good palliative childcare. This should be prevented at all costs.

Many parents, felt abandoned from the moment palliative cancer-directed treatment finished. They preferred a continuation of involved professional care-giving similar to the care they received during active cancer treatment. In addition parents preferred professionals who took full responsibility for their child, provided that they respected their child's and their own preferences (chapter 6). Considering the Dutch situation it is remarkable that at the start of life, during pregnancy and childbirth structural quality care is routine, while at the end-of-life care-giving is largely dependent from the parents' initiative and the responsibility taken by the individual professional caregiver. We support the idea that paediatric palliative care requires specific skills and should be better guaranteed at home. An expert paediatric transmural care team could bridge the gap between home and clinic and guarantee the co-ordination and continuation of professional care-giving throughout the palliative phase. The team can also serve as a role model for professional caregivers in primary care. They can have a consultative role, but can also appeal to the responsibility of professionals involved in paediatric palliative care, by facilitating, educating, and, when necessary, activating them.

Our study shows that it is questionable whether parents are helped by having the decisive voice in end-of-life decisions directed towards their child's death such as withdrawing or withholding treatment or intensifying symptom treatment. A recent survey among Dutch paediatricians showed that, compared to other disciplines, in paediatric oncology, a relatively high percentage of parents was given such a decisive voice (41%) in EOL decision-making. In 17% the oncologist took the decision and in the remaining 41% the intended decision was presented as a medical decision for which parental permission was sought. Our study suggests that the latter could be the best approach concerning EOL decisions directed towards the child's death. Professionals must be sensitive to what possible measures mean for the parents. The parents can think about the measures in terms of lessening the child's suffering and improving QOL, but also in terms of losses, including the loss of time spent together or the loss of communication. Creating a dialogue was shown to be the a more fruitful approach. This enabled the professionals to identify solutions which parents could handle and to achieve greater understanding of why acting according to a letting go perspective was more desirable. This helped parents. By being involved in the dialogue, the parents felt they shared responsibility while at the same time retaining a sense of control.

The model of palliative care in paediatric oncology.

Professional caregivers and researchers in paediatric oncology have embraced the new model of palliative care called 'integrated care' in which care directed towards a cure and palliative care are integrated [48, 49]. It is presumed this would result in more children having access to palliative care because the transition from cure to care would be smoother, it would take away the stigma of terminal care [49] and facilitate advanced care planning [17, 28, 50]. This integrated care is most often favoured by parents who hope that their child's life can be prolonged, while also wanting their child to have as much comfort as possible [3, 28, 51]. For most parents the chance of survival and the hope of saving the child make it worthwhile to allow the child to undergo aggressive treatment, despite its burden and side-effects. The gradual shift from cure towards palliative care, however, risks sustaining unrealistic expectations instead of making changes into the direction of goals more appropriate to the child's condition. In our study the message that their child could not be cured appeared to be a landmark. In response many parents tended to reconsider what is best for their child (chapter 3). The information that a cure was out of reach appeared to be part of the process of becoming certain and led to the start of a new stage in which the quality of life is paramount (chapter 4). It is conceivable that professional caregivers also need this landmark in order to change their perspective or to feel that the time to provide prognostic information has come [52]. We conclude that parents need help in directing and managing loss rather than integrated care. We suggest that integrated palliative care in fact runs the risk of directing parents away from parenting in the child's best interest, in favour of the parents' interest.

Practical implications

Parents deserve our absolute respect for the way they facilitate a worthwhile life for their child and provide compassionate care twenty four hours a day, seven days a week. Without their parents none of the children in this study could live and die at home. Consequently, the starting point for any involvement during the palliative phase should be to help not judge the parents.

In the palliative phase the child's needs, well-being and comfort come first. Professionals should help parents to fulfil the child's needs by encouraging them to consider the child's best interest. Our study shows that, in spite of the parents' best intentions, it is not easy and not evident for them to accomplish this task.

To do so parents are helped by being facilitated to stay attuned to the child's real situation This requires, in the first place, the provision of clear information in a manner that creates certainty about the child's condition and situation and which corrects 'fragmenting', -the process by which parents are allowed to shy away from looking at the whole negative picture. This facilitates the process of redefining or reframing hope for realistic outcomes. We identified two critical moments in the palliative phase where parents have great difficulty staying attuned to the real situation: the moment parents are informed their child could not be cured and the transition from stage two to stage three. Secondly, parents are helped when professionals support them to adopt a letting go perspective, an attitude parents never by themselves think of as positive. Adopting the letting go perspective can be facilitated by explaining that letting go is not the same as giving up on the child. Parents who have already adopted a letting go perspective also require continuous support in order to be able to continue to do so. Parents who have difficulty in adopting the letting go perspective can be helped by differentiating between their child's and their own needs. It is fruitful to clarify what are the child's needs and the parents' intentions. Anticipating the needs that may arise throughout the palliative phase and discussing satisfying answers in advance can help parents to live up to their intentions in the later stages when the parents' may be confronted with more intense feelings of loss.

Special attention should be paid to respecting and preserving the parent-child relationship and facilitating meaningful parenting by 'being there'. When the parent-child relationship becomes threatened, parents feel unable to accompany their child on its way towards death. In this context it may be helpful to hold discussions with the parents as they will be providing difficult information or proposing decisions that bring the child's death closer. Some parents prefer the role of comforter, other parents feel they themselves can tune the information better to the child's needs and prefer to do it themselves.

Professionals should facilitate the parents in 'being there' as they are deprived of other means to protect the child. Being there is the expression of the unique and special relationship parents have with their child. Parents who feel secure about their ability to be there have a better foundation with which to accompany their child towards death and to deal with the experience that death will inevitably break the bond with their child. In our opinion, professionals should not damage or threaten this unique and special parental role.

To achieve optimal child care during the palliative phase, professional caregivers should create an open dialogue with the parents and maintain this dialogue, even when tensions arise or parents withdraw from professional caregivers.

The dialogue is fostered if professional caregivers invite the parents to share their perspective, including their perception of their child's situation, their aims, their concerns, fears and needs. A thorough understanding and acknowledgement of the parents' position is the starting point for a fruitful parent-caregiver relationship. This lays the foundation for the best search for agreement on goals and strategies to act in the child's best interest.

Despite their fear of losing their child and the experience that caregivers provided information that was difficult to cope with, parents remained positive about professionals who took full responsibility for the child's well-being and comfort. In addition, parents preferred professionals who took the lead with respect to symptom treatment provided that they preserved and respected the child's identity and the child's zest for living as perceived by the parents, and were sensitive and completely open to the parents' perspective. They preferred professionals too who had not forced the parents by running too far ahead when communicating about treatment or in making decisions about treatment. We conclude that this can only be done by seeing the child in person, assessing the child´s condition thoroughly and using external evaluation by experts or instruments for symptoms and suffering. For parents it can be impossible to adopt a proactive attitude, anticipating situations which one most vehemently dreads. Consequently, it is the professional's task to think and act proactively to be prepared for all situations.

Because of the threat of loss, parents have a strong need for control and wish to preserve their actorship. They feel helped by professionals who will not call their autonomy into question or question their positive intentions.

In day to day care many parents endured, that is they contained their feelings of loss, and postponed their grief. Enduring should preferably not be harmed, for example, by actively triggering emotions. Many parents prefer to stay calm and to concentrate on what needs to be done or on what is best for their child. If they allow their emotions to surface too much this can hamper parenting and care-giving in the child's best interest and the progress towards letting go. Of course professionals must also be sensitive to the parents' emotions or their desire to express them and comfort them when emotions are shown. In line with this parents appreciated sensing that the professionals were touched by their child's situation. It convinced them that the professional would go out of his or her way to do the best for their child and allowed parents to view professionals as fellow human beings.

Parents are often told that their child will not have to suffer. Parents therefore remain unprepared for the sometimes difficult to control symptoms they encounter during the terminal stage. Hence, these symptoms take them more or less by surprise and they are unprepared to deal with them. Some feel as if a promise to the child, that he or she will not have to suffer, is broken. Hence, special attention is required to prepare the parents for specific characteristics of the dying process, especially the possibility of restlessness, a delirium and gasping.

For professional caregivers paediatric palliative care at home is not a matter of solving problems but of taking the responsibility for optimal childcare. This requires also guiding the parental process. To do so professionals need substantial expertise and knowledge. If they lack these, they should honestly confess their weak points and explain their strategies to guarantee the quality of care. And last but not least professionals should be clear about their own intentions and aims.

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Chapter 8

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Summary

Although many children with cancer can be cured, approximately 25% will die of their disease. These deaths are usually anticipated and preceded by a period of palliative care focused on the end of life, in clinical oncology usually referred to as the palliative phase.

Parents of children with incurable cancer are encouraged to care for their child at home. It is recognized that those parents play a major role in the practical care of and emotional support for their child. Even so there was little insight into what it meant to parent a child who is facing death and how this experience influenced parental care-giving and decision-making during the palliative phase.

This is even more important now, as, driven by medical improvements, the palliative phase increasingly has become a stage during which difficult medical decisions have to be made. The difficulty of making tradeoffs and decisions during the palliative phase is generally acknowledged. The increase of cancer-directed palliative treatment options forces those concerned to weigh quality of life and quantity of life. Parents play a crucial role in substantiating the quality of their child's life. How the parents' perspective and the meaning they give to their role develops throughout the palliative phase is still not fully understood. In addition, little insight exists into the role of professionals in care giving at home, even though an increasing number of children are cared for at home during the palliative phase.

This thesis addresses the lived experience of parents of children with cancer and in particular of children who were cared for at home after all curative options were exhausted. The main study (PRESENCE-study) was aimed at a better understanding of the parents' experiences, the meaning they give to their role, their coping strategies and needs throughout the palliative phase. Besides this we sought to know how palliative care, and in particular symptom treatment, was shaped by professional caregivers. A preliminary study of parents of children with acute lymphoblastic leukaemia (ALL) who were treated with the intention of curing them was conducted first.

For the preliminary study (**Chapter 2**), a grounded theory study was undertaken at a Dutch university hospital. Data were collected by one-time individual in-depth interviews with a purposive sample of 23 parents (12 mothers and 11 fathers) of 12 children, who were care-dependent (≤12 years) and within their first year of treatment for ALL.

From this study we learned that the essence of parenting a child with a life threatening illness is captured by 'being there'. 'Being there' was identified as a parental response to the perceived vulnerability of the child and a parental need to meet the perceived needs of the child. 'Being there' served two purposes: protection and preservation. Protection meant guarding the child against the negative aspects of illness and treatment in order to safeguard his or her well-being. Preservation referred to the way parents influenced the child's perception of his or her situation so the child could cope better with difficult tasks. At this stage of cure-oriented treatment, for example, this meant sustaining the child's willingness to undergo cancer-directed treatment to maximize the chances of survival.

The parents' lives contained numerous expressions of 'being there'. These included a trusting relationship with the child, their presence and physical contact, emotional support, advocacy for the child's interests, routines to increase the child's comfort and coping, and putting oneself second to the service of the child's needs. Although both fathers and mothers expressed the need to 'be there', mothers were involved more deeply in the life of their child. For them a feeling of empathy and staying together was important. Fathers tended to advocate and support their child in a more practical way. Fathers also seemed better able to leave 'being there' to mothers than the other way around.

The need to 'be there' was the driving force behind the never ceasing involvement of parents with their child, even when they felt care-giving was beyond their strength. This may be explained by the reinforcing power of being of meaning to the child. For parents 'being there' deepened the relationship with their child and made them feel their unique significance as parents.

For the PRESENCE-study interpretative qualitative methods were used. Data were collected from a purposive sample of parents of children aged 16 years or younger with any type of cancer and who were cared for at home. They were recruited from five university paediatric oncology centres after the oncologist had informed them that the remaining treatment options were not curative. Single and repeated individual in-depth open interviews were conducted with 23 mothers and 21 fathers of 23 children resulting in 57 interviews. Caregivers who were professionally involved in the care of the children included in the study were purposefully selected while aiming for maximum variation with respect to discipline and the support experienced by the parents. This resulted in 43 interviews with 38 professionals concerning 20 children. Three studies were based on the analysis of the parents' stories. For a fourth study, data from both the parents and the professionals were analysed.

In **Chapter 3** we investigated what it meant to parent and care for a child with incurable cancer and how parents gave meaning to their parental role throughout the palliative phase.

From the parents' perspective the palliative phase could be divided in four stages: Stage one, becoming aware of the inevitability of death; stage two, making the child's life enjoyable; stage three, managing the change for the worse, and stage four, being with the dying child.

The essence of parenting throughout these stages palliative phase was captured by 'being of meaning to the child', by 'preserving the parent-child relationship' and, by 'ensuring happiness for their child'. This took the form of 'being there' and 'letting their child enjoy life'.

Similar to the leukaemia study (chapter 2) 'being there' was identified both as a parental response and a parental need. In the palliative phase, however, 'being there' could increasingly be characterized as the embodiment of not leaving the child alone in his suffering. 'Being there' provided parents with a meaningful form of action, despite their increased powerlessness due to witnessing the child's decline. Once the child died, having been there for their child appeared to be a major criterion in positively evaluating their performance as parents.

Parents felt they had no alternative other than to help their child enjoy his or her life. This 'enjoyment of life' surpasses the regular parental aim of well-being or normal life. It was also about facilitating a life the child experienced as 'worthwhile to live'.

Facing their child's death brought many parents to the point of an existential crisis. Yet in response, parents were able to shoulder their responsibilities as caregivers. In doing so many parents endured, meaning they contained their emotions, and postponed their grief in order to keep going. This was a precondition for parenting and facilitating their child in enjoying life. Parents were also able to hold on due to their ability to enjoy the child's expressions of happiness, to look beyond the sick body and still see the child inside and the expressions of his or her identity, and the rewards experienced from caring and being there in response to the child's needs.

Parents were able to cope better with the stressful process of losing their child by giving significant meaning to their parenting and care-giving activities. Most parents redefined their parental role over time. Initial strategies such as facilitating an enjoyable life seemed to fail when either physical decline drastically progressed or the child gave up mentally. Sometime during stage three or four most parents came to terms with the idea that parenting aimed at comforting the child and helping him or her to cope with imminent death also could be meaningful and did not imply giving up on the child.

Many parents experienced an inner conflict between on the one hand their wish to create a worthwhile life and preserving their relationship with the child and on the other hand supporting their child in coping with death. Because of this conflict parents sometimes had difficulty with guidance and communication about the end-of-life.

In **chapter 4** we focused on the processes parents go through when cure is not obtainable, and how those processes influence the choices parents make for their child's treatment and care.

We found that feelings of loss already forced themselves upon parents during the end-of-life. These were mainly triggered by the child's physical decline and the parents' anticipation of what the loss of their child would mean in their future life. In the lived experience of parents, loss is characterized by moments of decision-making. Due to the fact that parents had the choice to intervene, to withhold or to withdraw interventions, they could fight or accept various aspects of loss.

Dealing with loss can thus be seen as a process of giving up, step by step. The parents' difficulty in coping with feelings of loss resulted however in ambiguity, for knowing death is inevitable did not preclude the avoidance of loss. This took the form of an internal struggle between 'letting go' and 'preservation'. 'Preservation' meant that parents avoided the reality of loss by sustaining life, aimed at maintaining, in fact improving, the existing situation and in particular of preserving what was still there of their child. Parents attempted to prolong their life with their child. 'Letting go' meant parents recognized the inevitability of death and they felt prepared to subordinate their need to avoid loss to the child's well-being and comfort. For most parents the balance shifted over the course of the illness from preservation towards letting go. It appeared that parents who adopted a letting go perspective were more receptive towards their child's real situation compared to parents who predominantly adopted a perspective of preservation. "Letting go" increased parents' ability to stay attuned to their child's needs. A timely completion of this transition appeared to be important for the child's well-being at the EOL and for a positive evaluation of parenthood once the child had died.

Even so, parents sometimes had great difficulty in making this transition, because it implied a change in the source of control. Parents who adopted a 'preservation' perspective found control in maintaining the status quo. Parents adopting a 'letting go' attitude experienced control in exerting parenthood aimed at the best interest of the child and the creation of a sense of togetherness with their child. In a nutshell, parents felt a desperate need to exert control but this transition placed their control in jeopardy. Consequently some parents simply could not face making this shift until the last hours of their child's life.

Given the importance of a timely transition towards a 'letting go' perspective, in **Chapter 5** we identified, from the parents' perspective, the main factors that influenced their position between preservation and letting go. Uncertainty, fragmentation, and anxiety supported preservation. Fragmentation refers to parents pushing back signals of the approaching death by focusing on details of the observed physical changes instead of the larger picture. Certainty, postponed grief, the perception of suffering, the ability to disentangle their own needs from their child's needs and the ability to parent meaningfully, promoted letting go. Hope, a good parent-child relationship and the attitude of professionals could support movements in both directions.

In day-to-day life these factors were intertwined. Moreover, the degree of their influence changed over time and parents' sensitivity to some factors changed throughout their transition. A letting go attitude could only come about in close connection with the perceived reality and required an integration of all factors influencing the transition. Our study revealed that certainty: the conviction that death is inevitable, is of great importance in moving towards a position of 'letting go'. Certainty arose from the child's physical deterioration and could be supported by honest information from healthcare providers, by visualizing the illness process, and by 'framing' aimed at letting go. This 'framing' refers to the way professionals defined the child's situation in the context of the illness and available options for treatment. Irreversible decisions also made the uncertain certain. In the process of becoming certain feelings of loss increased. Most parents fostered uncertainty in order to find relief. They made the certain uncertain by creating hope, or made the certain avoidable or ambiguous for instance by fragmentation. The increase of certainty forces parents to develop a manner of parenting that takes loss into account. We found that feelings of loss can be assuaged by the parents' knowledge that they are doing the best for their child. Parents felt strengthened to do so when they were able to disentangle their own needs from their child's or had found meaning in occupying a letting go perspective. Parents also felt supported in making the transition when they felt validated by professionals. By means of guidance and framing, professionals could intentionally influence some factors in support of a transition towards 'letting go'.

In **Chapter 6** we addressed the question of how symptoms are treated amid the interplay between parents and professionals in the final EOL stages at home

During the stages of deterioration and dying, the early identification, assessment and treatment of symptoms among children cared for at home depended entirely on factors related to the parents and the professionals. The responsibilities taken, their intentions, and their skills, knowledge and expertise all played a part. We found professionals often adopted a 'reactive' attitude, thus shifting responsibility towards the parents. A reactive attitude means professional caregivers come into action in reaction to the parents' initiative in reporting signals or problems. Parents in turn experienced symptom treatment as being a factor in the child's death and therefore showed reluctance to begin treatments that had consequences they perceived as losses. This often resulted in symptoms not being properly treated. Parents felt helped by professionals who took full responsibility for the child's symptom treatment, provided that they remained perfectly aware of the parents' perception and needs. Starting a dialogue aimed at the child's best interests, while preserving the parents' sense of control, appeared to be the most fruitful approach.

Finally in **Chapter 7**, the major findings were presented and considered in a wider perspective alongside the current literature. The findings were divided in three parts: parenting, loss, and professionals.

Once the child's life became threatened, parents responded to the perceived needs of the child by 'being there' and facilitating a life the child could enjoy. Besides reacting to their child's needs this parenting behaviour also fulfilled the parents' own need in coping with the stressful process of losing their child. The interrelation of the parents' and their child's needs entails the risk of forcing each other to adopt a positive attitude that hampers a realistic perspective and honest exchange of views. Besides difficulty in coping with current and anticipated losses, the parents' feeling that they as a parent played an active role in directing the course of their child's illness and death appeared to be extremely hard for the parents.

For parents the essence of the palliative phase could better be characterized as coping with loss than as the acceptance of death. The degree to which parents were able to face the impending loss of their child was the factor that most influenced their decision-making. We found initial support for the view that although parents intend to act beneficially toward their child, their difficulty of coping with loss can easily impede their ability to act in the child's best interest.

In contrast to coping with bereavement after a loss, the parents in our study felt forced to deal with more new losses again and again. Consequently their ability to achieve adaptive coping in the palliative phase was limited. Most parents endured, which enabled them to take care of their child and their family.

Professional caregivers who want to give optimal palliative care to children cared for at home should help parents to fulfil their parental task while keeping the child's best interest in mind. This can best be done by not disrupting enduring behaviour and by creating a dialogue with the parents while guiding them step by step. In addition, professional caregivers must think and act proactively to make all the arrangements that may be needed but cannot yet be handled by the parents.

Samenvatting

Ondanks de toegenomen mogelijkheden in diagnostiek en behandeling, geneest ongeveer een kwart van de kinderen met kanker niet. Palliatieve zorg kan worden gegeven vanaf het moment dat een levensduurbedreigende of levensduurbeperkende ziekte wordt gediagnosticeerd. Dit proefschrift gaat echter over de palliatieve fase. Hiermee bedoelt men in de oncologie doorgaans de periode vanaf het moment dat duidelijk wordt dat genezing niet haalbaar is, tot het moment van overlijden.

Algemeen wordt aangenomen dat kinderen in deze periode thuis het best op hun plaats zijn. Een toenemend aantal kinderen met ongeneeslijke kanker verblijft en overlijdt dan ook thuis. Hoewel ouders een belangrijke rol spelen in de zorg voor en begeleiding van hun kind, is er weinig kennis over wat het betekent ouder te zijn en te zorgen voor een kind wiens leven binnen afzienbare tijd zal eindigen. Bovendien is er nog weinig inzicht in hoe het perspectief van de ouder zich ontwikkelt gedurende de palliatieve fase.

Een goed begrip van de positie van ouders is des te meer van belang nu, als gevolg van nieuwe behandelmogelijkheden, steeds vaker een levensduurverlengende behandeling kan worden ingezet, waarbij kwaliteit en kwantiteit van leven moeten worden afgewogen. Daarbij is de palliatieve fase in toenemende mate een fase waarin ingewikkelde medische beslissingen moeten worden genomen.

Ook ten aanzien van de rol van hulpverleners die professioneel betrokken zijn bij kinderen tijdens de palliatieve fase is nog weinig bekend, zeker als het gaat om de zorg en behandeling in de thuissituatie.

Deze dissertatie gaat over de ervaringen van ouders die zorgen voor een kind met kanker en in het bijzonder over ouders die thuis zorgen voor hun kind en weten dat hun kind niet meer beter wordt. Met het hoofdonderzoek, de PRESENCE-studie, werd beoogd inzicht te krijgen in de ervaringen, de betekenisverlening, de copingstrategieën en de behoeften van ouders gedurende de palliatieve fase. Daarnaast is verkend hoe in de interactie tussen ouders en professionals de zorg voor het kind thuis vorm krijgt.

Voorafgaand aan de PRESENCE-studie werd een voorstudie gedaan (**Hoofdstuk 2**) naar de ervaringen en betekenisverlening van ouders van kinderen met acute lymfatische leukemie (ALL), die met een curatieve intentie onder behandeling zijn van een oncologische afdeling van een Nederlands academisch kinderziekenhuis. Overeenkomstig de gehanteerde kwalitatieve onderzoeksmethode, de gefundeerde theoriebenadering, werd een doelgerichte steekproef samengesteld van 23 ouders (12 moeders en 11 vaders) van 12 kinderen met ALL. De kinderen waren zorgafhankelijk (≤ 12 jaar) en in het eerste jaar van hun behandeling en varieerden in leeftijd en in behandelfase.

Deze studie liet zien dat wanneer een kind door ziekte in zijn leven wordt bedreigd, het 'er zijn' voor het kind als de essentie van het ouderschap naar voren komt. 'Er zijn' is het antwoord van ouders op de kwetsbaarheid van hun kind als gevolg van zijn ziekte en de belastende behandeling. Tegelijkertijd is het 'er zijn' ook een behoefte van ouders in reactie op de behoefte aan steun, die ze bij hun kind waarnemen.

‘Er zijn’ is gericht op bescherming en behoud van het kind. Bescherming betekent dat ouders proberen het welbevinden van hun kind veilig te stellen door de negatieve invloed van de ziekte en de behandeling in de hand houden. Behouden verwijst naar de manier waarop ouders de perceptie van het kind beïnvloeden zodat het de moeilijke aspecten die samenhangen met zijn ziekte en de behandeling, (beter) kan hanteren. In deze curatieve behandelfase gaat het bijvoorbeeld om het in stand houden van de bereidheid van het kind om mee te werken aan de behandeling zodat de kans op genezing maximaal is.
In het dagelijks leven als ouder kent het ‘er zijn’ een veelheid aan uitingsvormen waaronder een vertrouwensrelatie creëren, aandacht geven en fysieke aanwezig zijn, emotionele ondersteuning geven, het belang van het kind voorstaan, routines toepassen die het comfort en de draaglijkheid van de situatie voor het kind vergroten en zich ten dienste van de behoeften van het kind opstellen. Hoewel zowel vaders als moeders aangaven ‘er te willen zijn’, uitten moeders dat meer door een sterke betrokkenheid bij het kind, waarbij empathie en ‘naast het kind staan’ belangrijke pijlers zijn. Vaders waren sterker geneigd tot belangenbehartiging en een meer praktische ondersteuning. Vaders leken ook beter in staat het ‘er zijn‘ over te laten aan hun partner dan andersom het geval was. De behoefte ‘er te zijn’ is voor veel ouders de stuwende kracht achter hun niet aflatende betrokkenheid en zorg. ‘Er zijn’ bekrachtigt zichzelf. Dit hangt ondermeer samen met het gevoel van de ouder dat zijn of haar ‘er zijn’ van unieke betekenis is voor het kind en dat het de relatie met het kind verdiept.

Met de PRESENCE-studie beoogden we inzicht te krijgen in de ervaring en de betekenisverlening van ouders en professionele hulpverleners. Daarvoor is gebruik gemaakt van interpretatieve kwalitatieve onderzoeksmethoden. Via vijf kinderoncologische academische centra werden ouders van thuisverblijvende kinderen (≤ 16 jaar) ongeacht het type kanker geïncludeerd, vanaf het moment dat de behandelaar hen had geïnformeerd over het ontbreken van verdere curatieve behandelmogelijkheden. Eenmalige en herhaalde individuele interviews resulteerden in 57 interviews met 23 moeders en 21 vaders van 23 kinderen. Daarnaast vonden 43 interviews met 38 professionele zorgverleners plaats die betrokken waren bij deze kinderen. De analyse van de ouderinterviews resulteerde in drie studies. Voor een vierde studie werd gebruik gemaakt van data verkregen van zowel de ouders als de professionals.

In **hoofdstuk 3** hebben we een antwoord gezocht op de vraag wat het voor ouders betekent ouder te zijn van en te zorgen voor een kind dat niet meer beter wordt en hoe ouders betekenis geven aan hun rol als ouder gedurende de palliatieve fase.
Vanuit het perspectief van de ouder kan de palliatieve fase in vier stadia worden ingedeeld: stadium een, bewustwording van de onvermijdelijkheid van de dood; stadium twee, het kind van het leven laten genieten; stadium drie, het managen van de omslag naar aftakeling en stadium vier, ‘er zijn’ voor het stervende kind.

Door alle stadia van de palliatieve fase heen zijn er drie dingen van groot belang voor de ouders, namelijk van betekenis zijn voor het kind, een goede relatie met het kind behouden en het kind verzekeren van een zekere mate van geluk. In de praktijk krijgt dit de vorm van 'er zijn' voor het kind en het bewerkstelligen van een leven waarvan kan worden genoten.

Net als ten tijde van de behandelfase, is ook in de palliatieve fase het 'er zijn' een reactie op de behoeften van het kind alsmede een vervulling van de behoefte van de ouder. Gaande de palliatieve fase is het 'er zijn' echter steeds meer de belichaming van het streven van de ouders hun kind niet alleen te laten staan in zijn lijden. Door 'er te zijn' beschikken ouders over een betekenisvol antwoord in een situatie waarin ze zich toenemend machteloos voelen en getuige zijn van de fysieke achteruitgang van hun kind. Er voor het kind 'te zijn geweest' is een van de belangrijkste criteria voor een positieve evaluatie van hun rol als ouders na het overlijden van hun kind.

Voor ouders was het enorm belangrijk dat hun kind niet in een poel van verdriet de dood tegemoet leeft, maar juist ten volle van het leven kan genieten. Zorg dragen voor genieten betekent hier naast een leuk leven of welbevinden bewerkstellingen, vooral een leven faciliteren dat het waard is geleefd te worden.

De wetenschap dat ze hun kind gaan verliezen en de confrontatie met signalen die de naderende dood van hun kind aankondigen, brengt veel ouders op de rand van een existentiële crisis. De meeste ouders onderdrukken hun emoties, zodat ze in staat blijven te doen wat nodig is, zoals zorgen voor hun kind en het gezinsleven op gang houden. De meeste ouders voelen zich gesterkt door hun vermogen te genieten van de momenten dat hun kind plezier heeft, hun vermogen verder te kijken dan de fysieke aftakeling en daardoor juist wel de uitingen te zien die karakteristiek zijn voor hun kind en die in hun ogen zijn identiteit weergeven. Het geeft ouders een positief gevoel als ze ondanks alles toch goed voor hun kind kunnen zorgen.

De meeste ouders herdefiniëren hun ouderrol wanneer het kind fysiek sterk achteruitgaat of het mentaal gezien opgeeft. Op dat moment faalt bijvoorbeeld hun streven om het kind van het leven te laten genieten. Ergens in stadium drie of vier ontstaat het gevoel dat zorg dragen voor het comfort van hun kind en het kind helpen zijn naderende dood op enige manier hanteerbaar te maken, niet betekent dat je je kind opgeeft. Voor veel ouders bleek het voorbereiden van hun kind op de naderende dood een bedreiging voor het streven de relatie met hun kind goed te houden en een voor hun kind plezierig leven op gang te houden. Om die reden zagen ouders er soms van af met hun kind over het levenseinde te praten.

Hoofdstuk 4 is gericht op de processen die ouders doormaken en de invloed van deze processen op de besluitvorming en zorg.

Voor alle ouders gold dat zij worstelden met gevoelens van verlies als gevolg van het dreigende levenseinde van hun kind. Verliesgevoelens hingen vooral samen met de fysieke achteruitgang van hun kind en de anticipatie van ouders op wat het verlies van hun kind in de toekomst voor hen betekent. In de beleving van ouders hangt het proces van het verlies van hun kind sterk samen met de door hen te nemen beslissingen of aanpassingen in het dagelijks leven. Door op deelgebieden al dan niet te kiezen voor interventie, accepteren ouders of bevechten ouders het verlies. Daarmee geven ze richting aan het verloop van het einde van het leven van hun kind.

Het hanteren van verlies kan worden gezien als een proces waarbij op deelaspecten telkens iets moet worden opgegeven. Veel ouders konden hun verliesgevoelens buitengewoon moeilijk hanteren. Als gevolg daarvan was er vaak sprake van dubbelheid. Weten dat het onvermijdelijk is dat het leven van hun kind eindig is sluit niet uit dat ouders proberen het verlies met alle macht en kracht te vermijden. In de interviews kwam dit naar voren als een voortdurende interne strijd tussen een attitude gericht op 'laten gaan' of op 'behouden'.

'Behouden' betekent een attitude waarbij de ouders de realiteit van het verlies vermijden door zich te richten op het zo goed mogelijk in stand houden van hun kind, op stabilisatie of liever nog verbetering van de huidige situatie. Daarmee trachten ouders hun leven met hun kind zo lang mogelijk voort te zetten. 'Laten' gaan betekent een attitude waarbij de ouders de onvermijdelijkheid van de naderende dood erkennen en bereid zijn hun behoefte om het verlies te vermijden ondergeschikt te maken aan het comfort en het welbevinden van hun kind. Gaande de palliatieve fase zagen we dat de meeste ouders een transitie maakten van 'behouden' naar 'laten gaan', waarbij voor de meeste ouders de balans op enig moment volledig doorslaat naar een attitude van 'laten gaan'.

Onze analyse liet zien dat ouders die een overwegend 'laten gaan'-perspectief hanteerden. meer open stonden voor de reële situatie en het perspectief van hun kind. Hierdoor konden ze beter afstemmen op wat gegeven de situatie nodig was en op de behoeften van hun kind. Wanneer ouders deze transitie tijdig doormaken komt dat ten goede aan het welbevinden van het kind tijdens de palliatieve fase. Daarnaast draagt het bij aan een positieve evaluatie van hun rol als ouders na het overlijden van hun kind.

Toch hadden veel ouders grote moeite met het doormaken van deze transitie, omdat dit ook een verandering in hun belangrijkste bron van houvast vraagt. De ouders met een 'behouden'-attitude vonden houvast in het voortzetten van de status-quo. De ouders met een 'laten gaan'-attitude haalden hun houvast uit het gevoel in het belang van het kind te handelen, en de gezamenlijkheid die ze met hun kind ervoeren. Kortom in een situatie waarin ouders als gevolg van een transitie een enorme behoefte hebben aan *control*, ondermijnt deze transitie de basis voor hun gevoel van *control*.

Gegeven het belang van een tijdige transitie naar een 'laten gaan'-perspectief, hebben we in **hoofdstuk 5**, vanuit het perspectief van de ouders, de factoren vastgesteld die hun positie tussen 'behouden' en 'laten gaan' beïnvloeden.

Onzekerheid, fragmentatie en angst ondersteunen een 'behouden'-perspectief. Fragmentatie betekent dat de ouder signalen die wijzen op een naderende dood naar de achtergrond plaatst door zich te concentreren op de details in plaats van het gehele plaatje. Zekerheid, uitgesteld verdriet, het lijden van hun kind, het vermogen onderscheid te maken tussen de eigen behoeften en die van hun kind en het vermogen betekenis te verlenen aan het ouderschap, resulteerden in bewegingen richting 'laten gaan'. Hoop, een goede ouder-kindrelatie en de opstelling van de professionele hulpverlener kunnen resulteren in bewegingen in beide richtingen.

In het dagelijks leven zijn deze factoren met elkaar verweven. Beter gezegd, de invloed van de verschillende factoren verandert gaande het proces. Ook de gevoeligheid van de ouders voor enkele van deze factoren wijzigt gedurende de transitie. Een ‘laten gaan’-attitude kan alleen tot stand komen in nauwe afstemming op de perceptie van de realiteit en vraagt om een integratie van alle genoemde factoren. Onze studie laat zien dat zekerheid, dat wil zeggen de overtuiging dat de dood van hun kind onontkoombaar is, van grote invloed is op de beweging richting ‘laten gaan’. Zekerheid wordt verkregen door signalen van fysieke achteruitgang en wordt gesterkt door eerlijke informatie van professionals, visualisatie van het ziekteproces en door *framing* gericht op een ‘laten gaan’-perspectief. *Framing* refereert aan de manier waarop professionals de situatie van het kind schetsen in de context van de ziekte en de beschikbare mogelijkheden voor behandeling. Onomkeerbare beslissingen maken wat onzeker was zeker. In dit proces van zekerheid nemen de gevoelens van verlies toe. Om verlichting te vinden zijn ouders geneigd enige onzekerheid te koesteren. Ze maken het zekere onzeker door het creëren van hoop of maken het zekere vermijdbaar of dubbelzinnig, bijvoorbeeld door fragmentatie. De toename van zekerheid dwingt ouders op termijn een ouderlijke rol te zoeken die het verlies incorporeert. Gevoelens van verlies kunnen enigszins worden ondervangen door het gevoel dat wat ze doen het beste is voor hun kind. Ouders voelden zich beter tot de transitie in staat wanneer ze in staat waren onderscheid te maken tussen hun eigen behoeften en die van hun kind, of wanneer ze een positieve betekenis konden toekennen aan het bezigen van een ‘laten gaan’-perspectief. Ouders voelden zich ook gesteund in het maken van deze transitie wanneer professionele hulpverleners deze benadering legitimeerden. Professionals kunnen, door middel van framen en gidsen, welbewust invloed uitoefenen op de geïdentificeerde factoren, zodat een transitie naar een ‘laten gaan’ perspectief wordt ondersteund.

In **hoofdstuk 6** beschrijven we hoe in de laatste stadia, in de thuissituatie de symptoombehandeling tot stand komt in de interactie tussen ouders en professionele hulpverleners.
Tijdens de stadia van aftakeling en sterven, hangt de vroegtijdige identificatie, beoordeling en behandeling van kinderen in de thuissituatie volledig af van factoren gerelateerd aan de ouder en de professional. De mate waarin zij verantwoordelijkheid nemen, hun intenties, kennis, deskundigheid en praktische vaardigheden spelen daarbij een rol. Uit onze data bleek dat professionele hulpverleners vaak een reactieve benadering hanteren, waardoor veel verantwoordelijkheid voor symptoommanagement verschuift naar de ouders. Onder reactief verstaan we dat professionals voornamelijk in actie komen in reactie op signalen van de ouders. Ouders daarentegen ervaren sommige aspecten van symptoombehandeling als een beïnvloedende factor in het proces van achteruitgang en sterven. Met name bij symptoombehandeling die voor de ouders verliezen met zich meebrengen zijn ouders terughoudend, ook met het inroepen van de professional. Als gevolg hiervan komt symptoombestrijding soms niet of niet goed tot stand. Ouders voelen zich over het algemeen gesteund wanneer de professional volledige verantwoordelijkheid neemt voor adequate symptoombehandeling bij hun kind op voorwaarde dat deze professional rekening houdt met de perceptie en behoeften van hen als ouders. Een benadering waarbij een dialoog met de ouders wordt geïnitieerd, gericht op het belang van het kind en waarbij de autonomie van de ouders wordt

gerespecteerd lijkt het meest vruchtbaar in deze situatie.

Tenslotte hebben we in **hoofdstuk 7** de belangrijkste bevindingen in een breder perspectief geplaatst en afgezet tegen de literatuur. Deze bevindingen zijn onderverdeeld in drie aspecten: ouderschap, verlies en professionals.

Wanneer hun kind door kanker in zijn leven wordt bedreigd, reageren ouders op zijn behoeften door 'er voor hem of haar te zijn' en door het leven zo in te richten dat hun kind er van kan genieten. Behalve dat deze benadering een reactie is op de waargenomen behoeften bij hun kind, vervult deze ook een behoefte bij de ouders. Het helpt hen het moeilijke proces van hun kind verliezen, te hanteren. De verwevenheid van de behoeften van de ouders en de door hen waargenomen behoeften van hun kind kan ertoe leiden dat een dusdanig positieve benadering in stand wordt gehouden dat die zich los zingt van de realiteit en een eerlijke uitwisseling van behoeften en perspectieven tussen kind en ouder belemmert. Daarnaast zagen we in de palliatieve fase dat (geanticipeerde) verliezen en het gevoel dat zij een actieve rol hebben in de koers van het einde van het leven van hun kind, voor de ouders buitengewoon moeilijk te hanteren zijn.

Voor ouders kan de palliatieve fase beter worden gekarakteriseerd als een fase waarin het hanteren van verlies op de voorgrond staat, dan als een fase waarin de acceptatie van de dood op de voorgrond staat. De mate waarin ouders in staat zijn het verlies van hun kind onder ogen te zien bepaalt in hoge mate hun mogelijkheden tot proactiviteit en hun besluitvorming. We vonden support voor de opvatting dat hoewel in de palliatieve fase alle ouders de intentie hebben in het belang van het kind te handelen, dit wordt belemmerd door hun moeite verliezen in het hier en nu of geanticipeerde verliezen te hanteren.

In tegenstelling tot bij het hanteren van verlies na overlijden (rouw), zien we dat de ouders in de palliatieve fase steeds met nieuwe verliezen worden geconfronteerd. Dat forceert hen in die mate dat ze vaak niet toekomen aan het proces van adaptieve coping. Als gevolg daarvan zagen we dat de meeste ouders '*enduren*' (emoties onderdrukken om te kunnen doen wat gedaan moet worden), vooral om in staat te blijven te zorgen voor hun kind en hun gezin.

Professionele hulpverleners zouden voor optimale palliatieve zorg voor kinderen, bij voorkeur ouders moeten helpen hun ouderlijke taak te vervullen terwijl ze daarbij het belang van het kind in beeld houden. Dat kan het beste door '*enduring behaviour*' niet te verstoren, en in dialoog met de ouders hen stap voor stap te gidsen. Professionals zelf moeten daarbij vooral zelf proactief denken en handelen zodat ze voorbereid zijn op alles wat het kind nodig heeft, maar waar de ouders nog niet naar kunnen handelen.

Topiclist parents

Appendix 1

PRESENCE-studie **Topiclijst interviews ouders**

Versie 1
Datum 09-05-05

Openingsvragen

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

Vervolgvraag:
Hoe gaat het nu met [naam kind] / Waar liggen nu uw (grootste) zorgen om [naam kind]?

Thema's en vragen ter verkenning of verdieping

1 Taken, opgaven en stressoren

Zorgende ouder zijn	• Wat vindt u de belangrijkste dingen die u voor uw kind doet? • Wat kunt u aan anderen overlaten • Wat kunt u in geen geval aan anderen overlaten • Wat betekent de zorg voor uw kind voor u persoonlijk?

Opgaven en stressoren	• Zijn er situaties of dingen die u moeilijk vindt als het gaat om de zorg voor uw kind?
	  • Voorbeeld? Hoe gaat u daarmee om?
	• Wanneer u denkt aan uw kind en zijn ziek zijn wat houdt u dan het meeste bezig?
	  • Wat houdt u op het moment erg bezig?
	• Wanneer u denkt over de zorg voor uw kind wat zijn dan uw zorgen voor de komende tijd?
	  • Wat verwacht u van de komende tijd.
	  • Zijn er dingen waar u tegenop ziet? Dingen waarop u hoopt? Dingen die voor u van belang zijn? Dingen die u voor uw kind belangrijk vindt?

Coping, self-efficacy	• Sommige ouders in ons onderzoek hebben het gevoel op de een of andere manier, hoe moeilijk ook, de situatie wel aan te kunnen, andere ouders hebben het gevoel er bijna aan onderdoor te gaan. Hoe is dat voor u?
Zorgen en het eigen leven	• In hoeverre komen belangrijke dingen in uw leven in de knel als gevolg van de zorg voor [naam kind]?

Palliatieve zorg thuis	• Niet alle ouders zorgen thuis voor hun kind. Is dat een keuze?
	  • Staat u daar nog achter
	  • Hoe is het voor u in het dagelijks leven met deze zorg voor en om uw kind

2 Ouderschap: ouderrol en streven	

Ouderrol	• Wat voor ouder wilt u het liefste zijn voor [naam kind]?
	  • Wat maakt het u moeilijk en wat helpt u om de ouder te zijn die u graag wilt zijn?
	• Wat is het speciale dat u als ouder onderscheidt van alle andere mensen om [naam kind] heen?
	  • Welke verantwoordelijkheden als ouder vallen u zwaar?
	  • Zijn er dingen die voor uw gevoel als vanzelf gaan?
	  • Wat geeft u moed om door te gaan?

Streven m.b.t. kind	• Wat vindt u als ouder onder de gegeven omstandigheden heel erg belangrijk voor [naam kind]? • Wat probeert u voor en met uw kind te bewerkstelligen en hoe doet u dat?
Streven in relatie tot eventueel lijden/angst/depressie kind	• Kinderen kunnen verschillen in de manier waarop ze hun eigen situatie ervaren. Waar heeft u kind naar uw gevoel last van of waar heeft hij/zij het moeilijk mee? • Sommige ouders in ons onderzoek verzuchten wel: al konden we maar iets overnemen dat zou voor [naam kind] zo'n verlichting geven. Wat zou naar uw gevoel voor [naam kind] een grote opluchting of verlichting zijn? • In hoeverre hebt u het gevoel dat uw kind lijdt/bang is/down is onder zijn situatie? Waar merkt u dat aan? • Wanneer de ouder aangeeft dat het kind in zijn ogen een te zware last draagt: Hoe gaat u daarmee om?
Streven ouders in relatie tot 'switch' van curatieve naar palliatieve doelstellingen	• De dokter geeft u weinig hoop meer op herstel. Wat betekent dat voor u? Waarop heeft dat naar uw gevoel invloed? • Wat betekent dat voor uw gevoelens van hoop

3 Communicatie, contact, relatie met kind	
Ouder-kind contact	• Sommige kinderen laten heel duidelijk zien hoe ze zich voelen andere kinderen zijn meer gesloten. Sommige ouders hebben het gevoel dat hun kind zodanig open is dat ze een goed beeld hebben van hoe hij/zij zich voelt, anderen vinden moeilijker de aansluiting met hoe hun kind denkt en zich voelt. Hoe is dat in uw situatie?
Perceptie kind	• Hoe denkt u dat uw kind zich voelt onder zijn ziek zijn? • Hoe gaat uw kind om met zijn situatie? • Wat denkt u dat uw kind op dit moment belangrijk of prettig vindt?
Betekenisverlening relatie ouder met kind	• Welke dingen in de omgang met uw kind geven u een goed gevoel/geven het gevoel dat u het goede doet?
Stressoren/opgaven	• Zijn er dingen in de omgang met uw kind waar u zich naar onder voelt of die u moeilijk vindt?

4 Loslaten, afscheid nemen en dood	
Beleving ontberen van herstelkansen	• Wij hebben begrepen dat de dokter aan u heeft uitgelegd dat er geen behandeling meer is waardoor uw kind kan genezen. Kunt u iets vertellen over hoe dat gegaan is en hoe dat voor u was? • Sommige ouders zeggen dat ze al langer wisten dat het niet de goede kant opging, terwijl anderen ervan overtuigd waren dat het goed zou gaan. Hoe was dat bij u? • Wat betekende het gesprek met de dokter voor u?
Invloed veranderd behandelperspectief op ouder	• Verpleegkundigen merken dat er verschillen zijn in de manier waarop ouders zich staande houden wanneer hen duidelijk wordt dat de kans op genezing voor hun kind steeds verder afneemt en wanneer met hen wordt gesproken over de onmogelijkheid hun kind te genezen. Het is voor dit onderzoek en de begeleiding van andere ouders van grote waarde wanneer u ons iets meer wilt vertellen over hoe u dat hebt ervaren? • Mogelijk hebt u hierin ondanks alles een eigen weg gevonden, mogelijk bent u er helemaal nog niet uit en voelt u zich steeds verder belaagd door de ziekte van uw kind? Misschien kunt u ons iets vertellen over uw ervaringen? • In hoeverre heeft dat bericht uw houding ten opzichte van uw kind veranderd.
Hoop	• Waar hoopt u op?
De dood tegemoet leven	• Verpleegkundigen en artsen praten er soms over dat ze ouders zoals u moeten helpen in een situatie die geheel tegen hun gevoel in gaat, namelijk toeleven naar de dood van hun kind. Zij zien hoe moeilijk dat is voor ouders. Er is veel behoefte te weten hoe ouders dat ervaren en wat hen kan helpen. Ziet u zichzelf als een ouder die probeert zo goed mogelijk de dood van zijn kind tegemoet te leven of staan voor u andere dingen meer op de voorgrond? • Kunt u als ouder eigenlijk wel de dood tegemoet leven?
Loslaten/afscheid nemen	• Loslaten/afscheid nemen zijn woorden die voor ouders zoals u mogelijk steeds meer inhoud krijgen, wat betekenen ze voor u?

Anticiperen op overlijden	• In hoeverre houdt u zich bezig met het moment van overlijden van uw kind? (problemen, behoeften)
	  • Wat zou u daarbij heel belangrijk vinden
	  • Zijn er dingen waar u angst voor heeft/zorgen over heeft.
	• Staat u wel eens stil bij het moment waarop ..naam… er niet meer zal zijn. Waar denkt u dan aan?

Disclosure	• Wat voor beeld heeft uw kind naar uw idee over de ernst van zijn ziek zijn/over dood gaan?
	• Sommige ouders praten op het niveau van hun kind met hun kind over zijn naderende dood, andere ouders vinden het wenselijk om dat juist niet te doen. In hoeverre praat met uw kind over zijn of haar naderende dood of over afscheid nemen?
	  • Wanneer u hierover praat met uw kind, hoe doet u dat?
	  • Wat zijn uw overwegingen daarbij?
	  • Bent u daarin door iemand geholpen?

4 Loslaten, afscheid nemen en dood	
Support	• Welke mensen in uw omgeving hebben naar uw gevoel begrip voor hoe u zich bij al deze dingen rond de naderende dood en de zorg voor uw kind voelt?
Mogelijkheden tot steun	• Hulpverleners vinden het vaak moeilijk om ouders te helpen wanneer duidelijk is dat hun kind niet meer herstelt. Ouders kunnen erg verschillen in hun behoefte en hun mogelijkheden hierover te denken of te praten en vooruit te kijken naar wat nodig is. Hoe is dat voor u? • Als u hier (al) over spreekt met wie doet u dat het liefste en waarom juist met die perso(o)n(en)?

5 Coping en betekenisverlening	
Beleving	• In hoeverre is uw leven door dit alles veranderd?
Belasting/coping/betekenisverlening	• Voor sommige ouders overheerst de last van de situatie, andere ouders vertelden ons dat ze ook mooie of waardevolle ervaringen hebben. Hoe ligt dat voor u? • Wat betekent het voor u om deze zorg aan uw kind te geven

Coping	• U heeft ons inmiddels heel wat verteld over hoe het is om als ouder voor [naam kind] te zorgen. Ik vraag me een paar dingen af:
	  • Waar haalt u de kracht vandaan deze zorg te geven en al deze dingen te doen
	  • Hoe houdt u zichzelf staande in deze situatie
	  • Wat helpt u in die situaties die u moeilijk vindt?
	  • Kunt u hier een voorbeeld van geven?

6 Hulpverlener	

Steun	• Van wie ervaart u op dit moment waardevolle steun?
	  • Wat maakt die steun zo waardevol?
	  • Waarom denkt u dat deze hulp of steun voor u als hulp voelt?

Steunende of belastende hulpverlening	• Sommige ouders geven ons voorbeelden van de steun die ze hebben van hulpverleners, anderen geven ons voorbeelden van hulpverlening die hen eerder belast dan verlicht. Hoe zijn uw ervaringen? • In hoeverre kunt u zich laten leiden door hulpverleners, ervaart u hen als mensen die u de weg kunnen wijzen?
Behoeften	• Waar zou u zich op dit moment door geholpen kunnen voelen?
Kwaliteit van zorg	• Zouden hulpverleners op dit moment hun zorg aan u op bepaalde punten kunnen verbeteren? • Wat verwacht u van hen in de komende tijd?
Spanningsvelden	• Hulpverleners vinden het vaak moeilijk ouders in een situatie als de uwe te helpen. Zij moeten nogal eens kiezen tussen wat wijs of nodig is en wat zij denken dat ouders aankunnen. Hoe kunnen hulpverleners in uw geval het beste met u omgaan? • Hebt u voorbeelden van situaties waarbij u eigenlijk nog niet aan iets toe was en de betrokken arts of verpleegkundige toch in staat bleek u als het ware 'mee te nemen' in de richting die u als het aan u lag liever nog wilde vermijden?

7 Partner en gezin	

Mate van gelijkgezindheid partners	• Uit eerder onderzoek weten we dat het voor sommige ouders erg moeilijk is het samen eens te blijven over de zorg en de dingen van het dagelijks leven. Andere ouders lukt dat vrij gemakkelijk. Hoe ligt dat in uw situatie?
	  • Hebt u naar uw gevoel aansluiting met uw partner en hoe ervaart u uw contact met uw partner?
	  • Heeft het verschil in opvatting of omgaan met de situatie naar uw idee gevolgen voor de wijze waarop u in staat bent voor [naam kind] te zorgen?

Gezinsbalans	• In hoeverre is er ruimte om bezig te zijn met de dingen die de andere leden van het gezin aangaan? • Wat vindt u op dit moment zelf belangrijke dingen voor uzelf, voor uw partner, of de overige gezinsleden, gezin als geheel?
Sociale omgeving	• Zijn er mensen in uw omgeving die u het makkelijker maken? • Zijn er mensen in uw omgeving die het voor u juist moeilijker maken?

Topiclist professional caregivers

Appendix 2

PRESENCE-studie	Topiclijst interviews hulpverleners Versie 1 Datum 09-05-05

De openingsvraag

Kunt u iets vertellen over die situatie en wat daarin uw betrokkenheid is geweest?

Thema's en vragen ter verkenning of verdieping

1. Wat is gegeven de situatie van dit gezin hetgeen je als hulpverlener met dit gezin zou willen bereiken?	
Relatie duiden	• Hoe is uw geschiedenis met dit gezin? • Hoe zou u het contact met de ouders willen omschrijven? • Hoe zou u het contact met het kind willen omschrijven? • Wat ervaart u als belangrijk in het contact met deze zorgvragers? • Zijn er opmerkelijke dingen geweest?
Beschrijvend inzicht in behoeften ouders	• Hadden de ouders specifieke zorgvragen? • Wat waren volgens u belangrijke zorgbehoeften van de ouders? • Wat vragen de ouders van u aan hulp? • Wat vindt u dat de ouders nodig hebben? • Hebt u inzicht in wat de ouders voor hun kind willen bewerkstelligen? • Hoe willen de ouders het leven met hun kind inrichten? • Kunt u hier voorbeelden van noemen? • Wie neemt beslissingen betreffende de zorg voor het kind? • Hoe komen beslissingen rond de informatie aan het kind tot stand? • In hoeverre is het kind geïnformeerd over zijn situatie? • Hoe beïnvloedt dat uw werk als hulpverlener?
Beschrijvend inzicht in perspectief ouders	• Hoe staan de ouders, volgens u, in hun moeilijke opgave, voor hun kind te zorgen die gaat overlijden? • Hoe gaan zij daar volgens u mee om? • Welke invloed heeft dat op uw werk als hulpverlener? • Kunt u hier een voorbeeld van noemen? • Hebt u enig idee hoe de ouders de zorg die u geeft, ervaren? • Waaruit blijkt dat? • Hebt u enig idee hoe de ouders de zorg ervaren van andere hulpverleners? • Waaruit blijkt dat?
Doel hulpverlener	• Wat wilt u als hulpverlener voor dit gezin bereiken? • Wat vindt u belangrijk voor hen en waarom?

2. Wat doet de hulpverlener om dit te bereiken?	
Uitgangspunt hulpverlener	• Hoe stelt u vast en beslist u wat u voor deze ouders kunt betekenen? • Vanuit welke visie / uitgangspunt doet u dat? • Gebruikt u vaste richtlijnen of eigen methoden hiervoor? • Wie staat voor u centraal in de zorgvraag (kind, ouder of gezin)?
Omgaan met Ervaringen en behoeften	• In hoeverre kunt u tegemoet komen aan de behoeften van de ouders? • Hoe doet u dat? • Hoe belangrijk vindt u dat? • Wat vraagt het van u als hulpverlener? • Wat vraagt het van u als persoon? • Zijn er behoeften waaraan u niet kunt of wilt tegemoet komen? • Hebt u grenzen ervaren in de wijze waarop u in kunt gaan op de behoeften van een gezin? • Hoe bent u daar mee omgegaan? • Hoe is dat voor u? • Kunt u dit verduidelijken met een voorbeeld?
Taken hulpverlener	• Kunt u vertellen hoe u omgaat met de manier waarop ouders het leven met hun kind in willen richten (bv: waar het gaat om normalisatie)? • Hoe ziet u uw rol hierin? • Kunt u vertellen hoe daar binnen uw beroepsgroep over wordt gedacht?
Reflectie hulpverlener	• Waar zijn naar uw mening deze ouders echt mee geholpen (geweest)? • Hoe ziet u uw bijdrage daarin? • Wat hebben de ouders van u geleerd? • Wat hebt u van deze ouders geleerd?

3. Wat maakt dat de hulpverlener goede zorg kan geven?	
Visie	• Sommige hulpverleners voelen zich aangetrokken tot zorgsituaties waarin palliatie centraal staat, anderen vinden het een buitengewoon zware opgave. Kunt u vertellen hoe dat voor u is? • Hoe was het voor u om voor een gezin te zorgen waarbij het kind gaat overlijden? • Hoe anders is dat dan de palliatieve zorg voor een volwassene?
Deskundigheid, reflectie	• In hoeverre lukt het u om de voor dit gezin goede zorg te geven? • Waar heeft dat mee te maken? • Welke factoren spelen, wat u betreft, daarin een rol? • Waarom vindt u dat? • Kunt u een situatie noemen waarover u zeer tevreden bent?

3. Wat maakt dat de hulpverlener goede zorg kan geven?		
Randvoorwaarden	Organisatie met andere hulpverleners	• Zijn er meerdere hulpverleners betrokken bij de zorg voor dit gezin? Zo ja, wie zijn dat dan? • In welke mate werkt u met hen samen? • Kunt u vertellen hoe de afstemming van zorg is geregeld tussen de verschillende hulpverleners? • Hoe verloopt deze afstemming? • Zijn er dingen waar u tegenaan loopt, wat betreft deze afstemming en organisatie van de zorg? • Hoe gaat u daar mee om? • Wat zijn naar uw gevoel de gevolgen voor deze ouders van de manier waarop de zorg voor dit gezin is geregeld? • Op welke wijze hebt u daar invloed op?
Randvoorwaarden	Samenwerking met andere hulpverleners	• In hoeverre hebt u contact met andere professionals die betrokken zijn in deze situatie? • Hebt u enig idee over het spoor dat deze anderen met de ouders bewandelden? • Wie had daarin de leidende rol? • Zijn er ooit spanningen geweest tussen u en andere hulpverleners betreffende deze situatie? • Zijn er dingen die onderwerp van discussie zijn geweest, zo ja waarom? Welke beslissing is uiteindelijk genomen? En waarom? • Zijn er aspecten die u (graag) met uw collega's had willen bespreken en waarom? • Kunt u iets noemen waarover u uw collega's hebt geconsulteerd en wat was de uitkomst?

4. Wat maakt goede zorg moeilijk, wat beperkt goede zorg?	
Deskundigheid	• Kunt u zich een moment herinneren dat u het gevoel had te kort te schieten in de zorg voor dit gezin? • Hoe was dat voor u? • Waaraan heeft dat gelegen? • Welke factoren spelen daarbij een rol, volgens u?
Dilemma's	• Zijn er momenten geweest in dit gezin waarin u even niet meer wist wat wijsheid was? • Kunt u vertellen over een situatie die u moeilijk hebt gevonden? • Hoe bent u daar mee omgegaan? • Zijn er naar uw mening aspecten geweest in dit gezin die u wellicht gezien / ervaren hebt, maar waarbij u het gevoel had weinig te kunnen betekenen? • Wat betekende dat voor u? • Hoe ging u daar mee om? • Hebt u ervaren dat er spraken was van tegengestelde behoeften, belangen of meningen tussen (een van) de ouders en het kind? • Hoe bent u daar mee omgegaan? • Hoe ziet u uw taak als hulpverlener daarin? • Uit ervaringen van andere hulpverleners blijkt dat zij het soms zeer moeilijk vinden dingen aan te kaarten die praktisch gezien van belang zijn, of die vooruitlopen op wat komen gaat en gelijktijdig rekening te houden met waar de ouder zich bevindt in het proces van verlies en verdriet? • Hoe ligt dat voor u? Kunt u dat verduidelijken? • Hoe gaat u bijvoorbeeld om met hoop in relatie tot de onvermijdelijkheid van de naderende dood? • Zijn er in deze situatie momenten geweest dat u andere opvattingen had dan dat de ouders voor hun kind wilden? • Kunt u daar iets meer over vertellen? • Hoe bent u daar mee omgegaan? • Wat is de uitkomst van die situatie? • Hoe was dat voor u als hulpverlener? • Hoe was dat in uw ogen voor de ouders? • Hoe was dat in uw ogen voor het kind?

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Curriculum Vitae

Marijke Catharina Kars was born on December 15, 1961 in Vroomshoop, and grew up in Gramsbergen, the Netherlands. After graduating from secondary school at the christelijk atheneum 'Jan van Arkel' in Hardenberg, she obtained a bachelor's degree in nursing (HBO-V) in Zwolle in 1984. Her interest in paediatric nursing was aroused during her work as a home care nurse in Dordrecht, where she was involved in youth health care. She obtained her Certificate of Paediatric Nursing and her Certificate of Paediatric and Neonatal Intensive Care Nursing at the Gemeenteziekenhuis in Dordrecht and the Sophia Children's Hospital in Rotterdam, respectively. Since 1990 she has worked as a nurse and later on as a nurse manager, at the paediatric intensive care unit of the Wilhelmina Children's Hospital in Utrecht.

She studied Nursing Science at the faculty of Health Sciences, Maastricht University and obtained her Master of Science Degree in 1997. In that year she got the opportunity to focus more on research. Under supervision of Prof. dr. Mieke Grypdonck and Prof. dr. Mia Duijnstee she completed two qualitative research projects: A study on parenting children with leukaemia at the Wilhelmina Children's Hospital and as a researcher of the department of Nursing Science of the UMC Utrecht, a study on parenting children with a chronic disease. In 2003 she took the initiative to write a grant proposal on palliative care in paediatric oncology. In 2005, based on this grant from the Dutch Cancer Society, she started the research described in this thesis. The study took place under the supervision of Prof.dr. Hans van Delden and Prof. dr. Mieke Grypdonck of the Julius Center for Health Sciences and Primary Care. Driven by the findings of this study, and as a member of Stichting Pal, she was closely involved in laying the foundation and the development of a project called: 'Transmural Paediatric Case Management' to be started in June 2012. Currently she is a member of the steering committee of this project.

Since 2008 she is a lecturer in the pre-master and master programmes of Clinical Health Sciences of the UMC Utrecht. Among other courses, she coordinates and teaches methods of qualitative research.

Marijke Kars is continuing her research activities at the UMC Utrecht.

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