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PART C

Best Interests
WHAT CONSTITUTES THE BEST INTEREST OF A CHILD?
VIEWS OF PARENTS, CHILDREN, AND PHYSICIANS IN A
PEDIATRIC ONCOLOGY SETTING

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ABSTRACT

Background. In pediatrics, the ‘best interest’ standard has become the prevailing standard in decision-making even though it proves difficult to apply in practice. Differences in values can lead to different views by families and physicians of what is in the interest of a child. Our aim was to gain insight into the views of parents, children, and physicians in a pediatric oncology setting.

Methods. We conducted a qualitative multi-center study, using in-depth semi-structured interviews with 21 children aged 8-18 years undergoing cancer treatment, 26 parents, and 15 pediatric oncologists.

Results. At the onset of treatment, parents, children, and physicians had the same views on what is in the interest of the child: survival by following the treatment protocol. In the course of treatment, however, a transition takes place. For families, what constitutes the best interests expands beyond medical considerations, to include the wish to lead a normal life, having control over certain aspects of treatment, and maintaining one’s identity (e.g., through religion). These aspects sometimes collide with medical aspects, leading to different professional and familial views about what course of action is appropriate.

Conclusions. In order to recognize personal views and avoid conflicts, physicians should explicitly discuss parent and family concerns and opinions in the course of treatment. We present a model of ‘communicative ethics’ to make these issues a subject of discussion. The role of the family in determining what is in the best interest of the child should only be limited when it implies a substantial medical risk of (irreversible) harm to the child.
INTRODUCTION

In pediatrics, the ‘best interest’ standard has become the prevailing standard in decision-making (Kopelman 1997). Often there is no discussion about what constitutes this standard. It is used as if its meaning is self-evident and uncontroversial. For a number of reasons, however, the best interest standard proves difficult to apply (Diekema 2004; Elliston 2007). Close examination of the standard reveals significant problems with its definition and application in practice (Elliston 2007). First, the standard seems incoherent, in that it invokes an absolute duty to do the best for each patient (Veatch 1995). Buchanan and Brock (1989, p88), in their statement of the standard, define absolute duty as ‘acting so as to promote maximally the good of the individual.’ The best interest standard would then require the surrogate to act so as to always make the decision most favorable to the child. This is impossible because children have conflicting claims, needs, and interests, and often ‘the best’ is not attainable. Some therefore suggest that the best interest standard should not be used as a maximizing principle, but rather as a minimum threshold of acceptable care (Archard 2003, p41; Diekema 2004). To act in the best interest of the child then means that the care provided should not fall below this threshold (Kopelman 2007).

The best interest standard is also criticized for being too individualistic, attending to the interests of only one person, making their interests paramount, and placing burdens on the interests of others. Moreover, the standard would be blind to the fact that children exist in families and their individual interests are not clearly divisible from those of the family. A child’s interests cannot be completely distinguished from those of his or her parents, but are always intertwined with those of parents and siblings. Parents may have competing duties to themselves or other children that should also be considered, as Ruddick (1979, 1989) points out.

Kopelman (1997) tries to invalidate these criticisms by defining the best-interest standard as a standard of reasonableness. This means that it is used to find the most acceptable of the available choices. It instructs us to try to pick the option that most informed rational people of good will would regard as maximizing the child’s net benefits and minimizing the net harms to the child without ignoring the rights, needs, and interests of others. Used in this way, the best interest standard does not require people to act in accord with what is literally best for a child. Sometimes this means that the least bad alternative for the child should be selected. In this way, a best interest standard seems reasonable to use, when its purpose is to offer good and practical guidance about how to make decisions for those unable to decide on their own (Kopelman 2010).
However, problems can still arise in the use of this standard, namely when reasonable and informed people of good will cannot agree on the interpretation of what is in the best interest of a child. Little controversy exists regarding the interpretation of what is good when medical interventions are available that are reliably expected to prevent serious, far-reaching loss of the patient’s health at a reasonable cost (McCullough 2010; Placencia and McCullough 2011), such as treating a bacterial pneumonia with antibiotics. Often, there is professional agreement about these sorts of paradigmatic cases, the relevant outcome data, and the physician’s best medical judgment to determine the interpretation of what is best for the child (Leuthner 2001; Pellegrino 1987; Placencia and McCullough 2011; Tan 2002). In other situations it may be more difficult. For instance, it is not easily determined whether it is in the best interest of a child to be vaccinated, circumcised, or treated with complementary therapies. In these and other cases, the notion of best interests is inherently a matter of balancing different values, and not just medical judgment (De Vries, Houtlosser and Egeler 2005; Elliston 2007; Lindemann Nelson and Lindemann Nelson 1995; Kopelman 1997). Best interests are determined not only by outcome data and physician assessment but also by the moral values of the various stakeholders. Introduction of these non-medical facts, values, and preferences may lead to differences in interpretation by parents, children, and physicians, and may result in conflicts (Hinds et al 2000).

Until now, most discussions of the best interest standard have focused on neonatal care and end-of-life decision making (Kopelman 2010; Leuthner 2001; Placencia and McCullough 2011; Paddeau 2012). Within pediatric oncology the standard has not received much attention, except when it focused on the end-of-life and the palliative phase (Hinds et al 2005; Kars et al 2011). When there are no curative options left, family values and preferences become very important. Outside this palliative phase, however, personal values and preferences of parents and children can also play a role in the pediatric oncology setting, when decisional problems related to treatment and care are encountered and it is not directly clear what is best for a child (Masera et al 1998).

The purpose of this study was to gain insight into the views of parents, children, and physicians on what is best for the child in a pediatric oncology setting during the curative treatment phase. Specifically, we focus on (1) describing what medical and non-medical factors are important for families and physicians when thinking about what is good for a child and (2) the eventual role of these factors in decision-making. By ‘medical’ we mean the interpretation from a biomedical view, taking only objective medical data (e.g., outcome data) and the physician’s best medical judgment into account. By ‘non-medical’ we mean an interpretation which takes into account the personal situation of the patient and family values of what is deemed important.
METHODS

Our analysis was based on a data set that was part of a larger qualitative multicenter project in which we explored patients’, parents’, and physicians’ experiences, roles, and considerations in treatment decisions in pediatric oncology. In this project we invited patients (aged 8-18 years) attending the pediatric oncology units of two Dutch university hospitals, their parents, and their physicians to participate in one-to-one, semi-structured in-depth interviews. Interviews were conducted 8-10 weeks after initial diagnosis or diagnosis of relapse. The methodology of the overall project has been described extensively elsewhere (De Vries and van Leeuwen 2010). The project was approved by the Institutional Review Boards at both study-sites (Leiden University Medical Center and VU Medical Center). Informed consent was obtained from all participants.

All physicians, parents, and children were interviewed by the first author. Initial interview topics were formulated after examination of the relevant literature and a preliminary observational study, during which the interviewer spent three months in the children’s oncology ward of one of the university hospitals and followed the daily routine and the discussions between parents, children, and physicians. Consistent with standard qualitative research techniques, the interview topics evolved as the interviews progressed through an iterative process to ensure that the questions captured all relevant emerging themes (Britten 1995; Guest, Brunce, and Johnson 2006). The interviews contained general topics and no closed-ended questions. Examples of interview questions relevant for the results reported here are given in Table 7.

The physician interviews lasted between 30 and 60 minutes. The in-depth interview topics covered work experience; general goals of pediatric oncology; the physician–patient-parent relationship, especially concerning decision making during treatment; considerations deemed important in treatment decision making; patient and parent autonomy; and physician’s ideas on what is in the best interest of a child.

The child interviews lasted between 30 and 45 minutes. The parent interviews lasted between 60 and 90 minutes. Both were conducted at the hospital. The interview topics covered general characteristics of the patient; the history of the disease; discussions with physicians about the recommended treatment; parents’ and child’s attitudes to these discussions; considerations deemed important in treatment decision making; and the perceived role of parents and children in decision making during treatment.

All interviews were audio-taped and transcribed verbatim. Data analysis was based on the constant comparative method (Malterud 2006; Strauss and Corbin 1998). We used an iterative process wherein we continually went back to the field to collect more data.
Table 7 Examples of interview questions

**Children**
Can you remember when you were first told that you had cancer? Who told you and what was said?
Can you remember what was said about possible treatments? How was eventually decided what treatment you would get? Was there any choice?
What were important issues for you during discussions about treatment? Do you think the medical team knew what was important for you?
Do you think that you should have an influence in what is decided about your treatments?
Do you have regular meetings / talks with your physician? What do you talk about?
Can you tell me what is important for you now, while on the way in your treatment? Are there things the medical team has to take into account? If yes, do you feel you can discuss these things with the medical team?

**Parents**
Can you describe the conversations you had with the physician about the cancer diagnosis and treatment options?
What considerations were important for you when treatment options were discussed? Did you discuss these considerations with the medical team?
Did you have any influence in the decision making process? Did your child have any influence in the decision making process?
Now your child is receiving treatment, do you have regular meetings with the treating physician? What do you talk about? Are there important issues for you that the medical team has to take into account? If yes, do you feel you can discuss these things with the medical team?

**Physicians**
Can you describe the topics discussed when you talk to parents and children about the cancer diagnosis and treatment options?
What considerations are important when treatment options are discussed for a child with cancer? Are there other considerations, next to medical ones?
Do you know the considerations parents and children have? Do you explicitly ask for their considerations?
How much influence do parents get in the decision making process?
How much influence do children get in the decision making process?
Do you ever experience conflict between yourself and a family, or within families about treatment decisions?
Can you describe the topics discussed when you talk to parents and children during the treatment phase?
What constitutes the best interest of a child?

The following process of data gathering and analysis was used: (1) interviews; (2) transcribing the interview data; (3) open coding, which involved identifying relevant concepts in the text; (4) constantly comparing open codes, looking for conceptual similarities and differences; (5) identifying emerging themes and a theoretical framework; (6) continued sampling and interviewing as theoretical categories emerged and novel questions arose; and (7) continued coding and comparison of codes until nothing new was added to the theoretical categories. Two authors independently coded the full transcripts. An independent researcher (not one of the authors) coded two transcripts to check for consistency and adequacy of the framework. The two authors and the independent researcher engaged in a discussion on the themes each of them had identified from the transcripts. No inconsistencies were found. When no new thematic content was found in the interviews, subject enrollment was stopped. This process, called thematic saturation, is a well-described qualitative method to avoid unnecessarily large and repetitive data sets (Denzin and Lincoln 2000; Guest, Brunce and Johnson 2006).

We used qualitative software (Kwalitan 5.0) for multiple text management, including coding, locating, and retrieving key phrases (Peters 2000). Finally, representative quotations were chosen to illustrate the themes identified. These quotations are included in the text. Quotes were translated from Dutch to English by a native English speaker.

RESULTS

Characteristics of the sample
The sample consisted of 15 physicians, 24 children, and 26 parents of these children. Figure 1 (page 19) shows eligibility criteria and the recruitment process for children and parents. Parents had a mean age of 40 years (range 32-50 years). Their children had a mean age of 13.4 years (range 8-18 years). The parents’ occupations varied, indicating social diversity. All families were of Dutch origin. Demographic and clinical characteristics of the parents and their children are given in Tables 1 and 2 (page 20-21).

The group of physicians comprised the entire medical staff of both pediatric oncology units (9 and 6 physicians, respectively). They were the primary providers for the children who participated in the study. Physicians had a mean age of 42.1 years (range 32-52 years) and worked in pediatric oncology for a mean of 7.6 years (range 1.5-20 years); 7 (46.7%) were male. Physician characteristics are shown in Table 3 (page 21).

Framework of the results
The concepts that were identified in the qualitative analysis resulted in a framework that
comprises the following three themes: best interest as deference to medical judgment, transition in the views of what is good for a child, and non-medical goals as a part of the best interests of the child.

**Best interest as deference to medical judgment**

At the onset of treatment, parents, children, and physicians had the same ideas on what is in the best interest of the child: survival by following the treatment protocol.

_“[In the beginning] I just wanted to get all the courses of chemotherapy. I just wanted to be sure that the cancer would stay away. Now at the end of treatment I sometimes think ‘I don’t want this course [of chemotherapy], it takes so long and it is so hard.’ But I just have to do it.” – Male patient, 12 years, Acute Myeloid Leukemia (AML)_

_I always tell parents and children that it is essential that we are a team. And that we, as a team, have one main goal: to fight the cancer.” – Physician 1_

At diagnosis, choices seem limited as there is typically a standard treatment approach, described in (inter)national protocols. All study participants felt there was no choice in treatment options. The way to proceed is to follow the medical protocol.

_“There was no choice. Well, there was a choice, but that would have been weird. There was only one right choice, to follow the protocol. If I had chosen not to do it, that would have been suicide.” – Male patient, 15 years, AML_

_“There is a clear distinction between the medical responsibility and the parental responsibility. It is not that parents have no say in the matter, but in the end the treatment decision is taken on medical grounds, so it is a decision by the medical team.” – Physician 6_

Physicians state that it is very difficult or even impossible for parents and children to fully discuss treatment options in the period after diagnosis. Parents and children feel ill-equipped to judge all medical information, and put their trust in the physicians, who are seen as experts.

_“The first twenty-four hours after you have told the diagnosis, parents are numb and hear nothing anymore. And it is exactly then that we have to discuss treatment options. But whatever you say, it doesn’t reach them.” – Physician 6_
We had to let go, although we found that hard to do. But the disease was something we were not able to manage ourselves, it is an area we didn’t know anything about. We had to let go, and just trust the physicians in their good intentions. – Mother of male patient, 15 years, with Ewing Sarcoma

I let the people decide who know best and have my interests in mind. These people are my parents and the physicians. If I were to choose myself I would take the easy way, for example skipping one of the chemo courses, because of the side effects. That’s why it is better that other people decide. – Male patient, 13 years, with osteosarcoma

Because parents and children feel they have no choice but to follow and agree with the physicians, it comes as a shock to them when they do have to decide on certain issues such as fertility preservation.

That he had to think about the question whether he could produce semen or not, that was really shocking. [...] Of course, to hear that you have cancer is also very shocking. But in a way that just happens to you. It’s just a fact. While for this issue we had a choice, we had a choice what to do. – Father of male patient, 13 years, Ewing Sarcoma

**Transition in the views of what is good for a child**

In the course of treatment, when parents and children regain some control over the situation, other objectives emerge, in addition to the goal of survival. They start to distinguish between the treatment protocol in the strict sense and the care surrounding it. The treatment itself is not questioned. The surrounding care, however, makes parents and children feel that choices can be made in the course of treatment. This leads to a re-evaluation of what they think is important.

At the start of treatment there was no choice. But at some point real choices came up. And at that point we wanted to be heard. (...) It is not up to the physicians to determine how much influence parents get. It is up to the parents themselves. We needed time to get things sorted out, but at one point we realized that, well this is it and we have to make the best of it. And at that point we noticed things we wanted to be done differently. It’s a process all parents go through. – Mother of male patient, 15 years, with Ewing Sarcoma

Three weeks ago I had to get a new course of chemotherapy. Normally you cannot choose whether you will stay on the ward or in a private room. But it was a new medicine for me and I did not know how I would react. Maybe I would vomit all day, so I refused to be put
on the ward with three other children and maybe a bunch of visitors. Furthermore, it was
close to my birthday, so I wanted to come to the hospital earlier, to be home in time to
celebrate. In the beginning, I was afraid to ask these sorts of things, but now I just want
control over these things. – Male patient, 14 years old, with Ewing Sarcoma

The interpretation of physicians is quite different. They feel that parents and children
have limited influence on medical care.

It’s only the little things that parents can get a grip on. We’re tied to the protocol. That
is the only way protocols can function. If everyone would do it in a slapdash manner, we
wouldn’t have any answers whether we do better than before. Small changes can easily
be a violation of protocol, even little logistic changes like starting chemotherapy later due
to a birthday or holiday. There is not much room for change. – Physician 3

Non-medical goals within the best interest of the child
Parents and children stated that next to the medical treatment, which is aimed at surviv-
al, they develop other goals, namely ‘to lead a life as normal as possible’ and to protect
their identity and (family) values. In the course of treatment, families pick up on their
own routines, like their ways of raising their children. This can interfere with the rules
and the way things are normally done on the hospital ward. Parents have their own ideas
about how to handle their child, but often little room is left for their views.

We know our child best. Better than all nurses and physicians on the ward. Of course we
know him best, but this is not recognized. They just don’t react to our comments. They do
as they think is right. – Father of male patient, 11 years, with ALL

The physiotherapist was just teasing my son. He tried to make my son do nice things. But
what is nice for him [the physiotherapist] is not nice for us. We are not used to watching
television for a bit of distraction. My son needs to be addressed fitting his environment.
Disco, soccer and television are not his environment. To really connect with my son you
need to come up with something else. So I asked the physiotherapist why he wanted so
badly to provide my son with distraction this way. Although it is not normal for us and we
don’t like it. – Mother of male patient, 13 years, osteosarcoma

Parents also experience disagreement with physicians on whether or not certain aspects
of care belong to the treatment protocol in the strict sense or not, and thus whether they
have an influence on it. For example, in the case of nutrition and nasal tube feeding,
there is often disagreement between families and medical team about what is best for the child. Their child’s diet is one of the few areas where parents feel they can exert some direct influence or control. Some parents have specific beliefs about the role of nutrition in recovery from disease.

Certain juices, like carrot juice, beetroot juice, have a positive influence on his blood count and his immune system. So he drinks these juices every day, we are really onto that. Just as a support. They [the physicians] have no problem with that. But when I asked one of them whether she uses the positive influence of nutritional supplements, she said: no, because we do not believe in it. – Father of male patient, 13 years, Ewing Sarcoma

Whether or not to start nasal tube feeding is also an important aspect of care where parents want to exert control.

After the treatment the medical team wanted [patient] to go home with nasal tube feeding. But we refused. We had gained enough experience with her eating habits after chemotherapy. I call myself an expert in cooking things that [patient] likes. She eats enough when she is at home. In the end we really had a fight with the physician and the nurses about the nasal tube. But we left the hospital without. – Father of female patient, 14 years, Ewing Sarcoma

Physicians, however, think of nasal tube feeding as part of medical treatment and therefore consider it to be their responsibility.

Nasal tube feeding is a medical procedure and I think physicians need to decide on starting it. There is enough evidence that a good nutritional state adds to the chance of survival, so I think it is a medical decision. Chemotherapy is better tolerated for example. Of course we consult the parents, but I think it is part of treatment to secure the nutritional state of the patient. – Physician 3

Children therefore often feel there is no real choice when nasal tube feeding is proposed.

I asked whether I could try and eat more. But they [physicians] said it was better to have the tube feeding, because I wouldn’t succeed in eating enough. That’s what they told me. And anyway, even if I had refused, they would have put in the nasal tube, I’m sure of that. – Female patient, 14 years, ALL
For some parents and children, religion is an important aspect of their identity and how they cope with illness. Religion opens a different (non-medical) perspective to the disease, which parents want to share with their physician.

Some friends say that it is stupid to talk about God with a physician who doesn’t believe. But for me it is very important. He [the physician] tells me what he thinks, so I tell him how I think about it. This physician for example tells my son repeatedly that the cancer is just bad luck. So I felt that I had to tell him [the physician] that we don’t see it as just bad luck. There is a meaning in it, although I don’t know which. And the progress my son makes is of course due to the drugs and the treatment, but also because he is in the prayers of our friends and because God is watching over him. – Mother of male patient, 14 years, Ewing Sarcoma

Religious beliefs sometimes become a factor in (curative) medical decision making.

Well the nurse came to take him to the operating room. But I said I won’t have it. The portacath cannot be removed. It was a religious thing for us, he had prayed all night and the fever had subsided. He was convinced that prayer is helpful. And then the nurse said they were going to remove the portacath anyway. My first thought was that my son would never trust God again. So I asked the nurse to take the temperature again and to consult with the physician. The nurse slammed the door in anger. But the physician reluctantly gave us the benefit of the doubt and the portacath didn’t have to be removed at that moment. And the fever didn’t come back. – Mother of male patient, 13 years with osteosarcoma

As a consequence of differing views between the medical team and the families, some parents feel that they have to stand up for their child to get things arranged the way they think is best.

I have become like a lioness fighting for her cub. Oh, yes, I’m not nearly as friendly as I was at the start of treatment! I developed an aspect of myself I knew I had in me, but I never needed before. At the start of treatment I let things happen, I thought that it was all alright. But now I’m more onto things. I question whether certain things are necessary. You grow into that. – Mother of female patient, 10 years, Hodgkin

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1 Because of persistent fever, the patient’s portacath, as a potential locus of infection, was scheduled to be removed.
DISCUSSION

At diagnosis, choices are limited as there is typically a standard treatment approach, described in (inter)national protocols. Because parents are often in shock by the diagnosis, and time is of the essence in terms of making treatment decisions, the most common reaction is to defer to what the pediatric oncologist views as necessary to act in the best interests of the child, which is providing life saving treatment. However, as children and parents become familiar with the treatment and medical environment, as shock subsides, and as additional choices to the treatment become apparent, children and parents begin to more actively participate in decision-making. At that point, a transition takes place with regard to the views of what is best for the child. Factors other than medical considerations become important.

This study shows that at the start of treatment children, parents, and physicians have the same view on what is best for the child: being treated according to the best available treatment protocol. Parents and children feel ill-equipped to judge the medical information, and most of the time they let physicians decide on treatment options. Deference to physician authority is a common rule of thumb, especially at the start of treatment. Reinforced by the technological character of the cancer treatment and the psychological turmoil due to the diagnosis, the medical view on what is best for a child prevails. Accordingly, children and parents experience a lack of control. This is also reported by other authors (Levi et al 2000; Lowe, Bravery and Gibson 2008; Patiño-Fernández et al 2008).

In the course of treatment, parents and children become ‘layman-experts’ in the treatment protocol. That changes their opinions. Parents and children regain some control and become partners in discussions with physicians. In contrast to the initial ‘submission’, families become to feel more certain, and think of themselves as more or less equal discussion partners when talking to the physician (De Vries et al 2005). This phenomenon is also described by Decker, Phillips, and Haase (2004), and Tuckett et al (1985). Parents no longer focus only on the protocol, and the way children are generally treated, but also on their child with his or her own ways to cope with the situation. This leads to a re-evaluation of what they think is important. Also, children were able to discuss their considerations in the decision making process. The interpretation of what constitutes best interests starts to contain more than only the medical perspective (see e.g. Kirschbaum 1996). As reported by Young et al (2002), parents discover that their child’s interests are also affected by control over certain aspects of care (e.g., nutrition), the wish to lead a life as normal as possible (e.g. particulars in upbringing and schooling), and the wish to maintain one’s identity and family values (e.g. through religion). These
values can sometimes collide with medical protocols, leading to different professional and family views as to what course of action is appropriate.

Physicians regard parents and children as having limited influence within the treatment protocols. For families, however, it is no longer taken for granted that the best interest of their child can be determined objectively on medical grounds. Best interests turn out to encompass spheres other than the medical, including part of the life perspectives of parents and child (Carroll et al 2012; Ruddick 1979, 1989). The influence of this family perspective in the decision-making process initially concerns mostly minor medical decisions, like timing the administration of drugs, placing a new nasal tube, or planning new admissions (e.g. not on the child’s birthday). Such routine actions in following protocols may become major issues for patients and parents. Fried et al (2002) and Spinetta et al (2009) showed that it is important to recognize how these personal aspects in decision making help parents and children to regain some control over the situation, and that respect for those issues may be equivalent to the respect for more fundamental views on life and its meaning.

Sometimes the views of parents and children and the medical perspective differ widely. In our examples, this concerned whether or not to start nasal tube feeding and the removal of a portacath. As described by Hinds et al (1997), and Hinds et al (2000), such differences may lead to dissatissfaction or even conflicts between parents, the child, and the medical team. Coyne (2007) found that health professionals held the view that parents and children were supposed to follow implicit rules of the ward. Parents who held a view that is not congruent with these rules disrupted the organization of the ward and were labeled ‘problem’ parents. James and Hilde Lindemann Nelson (1995) even spoke of a ‘rivalry of care’ regarding the conflict between the ethical approaches of families and physicians.

When family and professional views differ widely, the question inevitably arises whose perspective should prevail. In order to avoid discussions about who is in power to apply an abstract standard of best interests, ‘communicative ethics’, such as described by Moody (1992) can be followed, meaning that all parties involved, including the patient (when possible), come to an agreement about shared goals and talk about decisions to be made. The aim of the communicative ethics approach is to develop and maintain a shared vision on the course of treatment (D’Aloja 2010; Elwyn et al 2000). The central questions are ‘What is best for this patient at this moment?’ and ‘How to share decisions?’ instead of ‘Who should decide?’. In the model of communicative ethics, the various views of what is best for a child are given a *prima facie* character (Beauchamp and Childress 2009, 14; Kopelman 1997, 276). It is the duty of all actors to reach consensus about the resulting definition of the best interest of the child. The emergence of personal
views that are potentially different from the professional perspective can be recognized, understood, and, if necessary, dealt with (Coyne 2007). This model is in line with models of family-centered care and shared decision-making.

Due to the complex and high-tech character of oncology treatments the physician has a substantial role in the decision-making process. Young et al (2002) showed that parents are reluctant to act as advocates for their own views in this setting. To recognize the personal views of parents and children, physicians need to actively discuss parents’ preferences, customs, and concerns, especially in circumstances when there are tradeoffs possibly involving individual values and preferences (Elliston 2007; Hardart 2000; Tan 2002; Whitney 2006). The physician can also discuss limits to these wishes, as long as mutual understanding, awareness, and reasoning are maintained (D’Aloja 2010; Bensing 2000; Kai 1996).

In some particular circumstances, parental views of what is good for their child may lead to actions that inflict harm. Dedication to their child, which is the prerequisite of good parenting, may then stand in the way of making a responsible, correct decision (Baines 2008). An absolute focus by parents on the survival of their child may, for instance, lead to the demand that painful treatment be continued long after any prospect of cure. In cases like this, parental interpretations can constitute a substantial medical risk of irreversible harm, and then a limit to their influence is reached (Diekema 2004; Kopelman 1997). The moral and legal focus should then be on the professional’s point of view of what is medically in the best interest of the child. In these situations, it must be acknowledged that the pediatrician’s responsibility to the patient exists independently of parental desires or proxy consent (Committee on Bioethics 1995). Parents can use their own values to decide what is best for their child, but their decisions cannot fall below a certain threshold of acceptable care (Kopelman 2007).

Limitations

Our study is subject to some limitations. First, there is a possible bias due to the refusal rate of parents and children to participate (21%). This may result in an overrepresentation of families who encountered substantial differences between family and professional views on what constituted the best interest of the child. On the other hand, this is more of a problem for quantitative than for qualitative research, as our aim was to explore possible differences in interpretation of best interests, and we were not so much interested in exact numbers regarding the existence of such disagreement. Second, there could be a regional bias in the results, because the study is based on respondents from only two of the eight hospitals in our country where children with cancer are treated. However, the group of respondents was diverse enough for our purpose to explore the differences in
interpretation of best interests between families and physicians. At the same time, the topic was compact enough to reach saturation across the sample: during the last interviews, no new information was yielded.

**Conclusion**

In conclusion, the interviews give insight in how families define what is good for their child and how they contemplate their child’s best interest. Especially in the course of a long treatment, ‘what is best for the child’ is subject to change, and for families, the answer encompasses spheres other than the medical. It includes parts of the life perspectives of parents and child. Our data suggest that the Best Interest Standard is not defined only by abstract, philosophical, or legal terms. Eventually, the shared intention to do good to children should be guided by a standard that understands best interests as a matter that comes about through consultation. This consultation can be shaped by a ‘communicative ethics’. Future research should focus on the best way for physicians to recognize personal views and act on them without losing professional autonomy.