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Chapter 8

GENERAL DISCUSSION
In the following paragraphs, the principal results of this thesis are put into perspective. We will focus on two issues: first, we will give methodological considerations: does our methodology prove valuable for answering ethical questions in practice, and what are the limitations?; and second, what are the implications of our study for our thinking about child participation, the use of a best interests standard and parental authority in pediatric oncology and in pediatrics in general? Finally, directions for future research are given.

METHODOLOGICAL CONSIDERATIONS

The use of third person moral experiences in empirical medical ethics. Reflective equilibrium and empirical data

A familiar criticism of bioethics charges it with being more conceptual than practical - having little to do with the ‘real world’ and its moral issues. In order to answer this criticism and to keep its feet on the ground, bioethics has started to utilize methods from the social sciences. Empirical research data are believed to provide the bridge between conceiving a moral vision of a better world, and actually enacting it (Solomon 2005). This belief is not without counteraction, causing a debate about the question whether empirical studies can truly inform ethical reasoning (Pellegrino 1995, Düwell 2009). By using empirical data, are we not confusing the descriptive, the analytical-metaethical, and the normative domains of ethics? In short, ethics is not a democratic process. In this field of tension and debate, empirical ethics is still developing, and studies actually using empirical data, as well as studies on how to combine the ‘is’ and ‘ought’ are increasingly published (Salloch et al 2012).

In chapter 2, we defended our version of a Reflective Equilibrium (RE) method, namely the Network Model with Third Person Moral Experiences, which allows for a two-way relation between empirical and normative data. We concluded that various aspects can strengthen the search for coherence between the various data used (theories, principles and considered moral judgments) and eventually the credibility of the moral judgment of the ‘thinker’. All these aspects have to do with using empirical data.

Our methodology can be questioned. First, one can ask why we use coherence as starting point to develop our methodology, and not deductivism or inductivism. Deductivism and inductivism both have attracting features (Beauchamp and Childress 2009). Deductivism rightly notes that once we have a fairly settled body of guidelines, in many cases a direct appeal to these guidelines leads to satisfactory moral judgments. And inductivism rightly emphasizes the role of new experiences and problems to refine guidelines. On the other hand, accounts only from the ‘top’ (principles, rules) and the
‘bottom’ (cases, individual intuitions) both have their problems. The content of rules and principles is often too abstract to determine the acts we should perform. Principles need to be made specific for cases. Furthermore, a top-down model creates a potentially infinite demand for final justification. And no single normative theory has shown yet to be a sufficient basis for moral justification. Case analysis needs illumination from general principles or norms to link and interpret various cases. Furthermore, a solely bottom-up approach cannot identify unjust practices or prejudice by the persons who make the judgments about cases. Eventually, neither general principles nor paradigm cases can guide the formation of justified moral beliefs. As Beauchamp and Childress (2009) state: ‘there is no fixed order of inference or dependence from general to particular or from particular to general’ (p 381). That is why we support a coherence theory. Justification is a reflective testing of our moral beliefs, moral principles, theoretical postulates, and the like, to make them as coherent as possible (Rawls 1971; Daniels 1979). If we want to develop realistic ethical constructs, we need to understand the ethical norms as well as the empirical data.

Then, is it truly possible to reach a reflective equilibrium? How do we refrain from merely looking for evidence for our own (prejudiced) opinion, and conveniently disregarding other evidence? As discussed in chapter 2, the subjective character and therefore the credibility of considered judgments are often questioned. With our interpretation of the initial judgment of the ‘thinker’ as a hypothetical equilibrium we at least try to be transparent about what elements or premises constitute this judgment. Furthermore, judgments can alter during the RE process. In this way, the RE process itself can function as a filter, which can separate reliable from unreliable judgments. The process of weighing and balancing judgments, principles, background theories and empirical data can let us identify judgments that are apparently wrong or prejudiced. The ‘thinker’ consequently gains a distanced view, while remaining attached to the concrete situation (cf. Nagel 1986). The Network Model with Third Persons Experiences gives the opportunity for the ‘thinker’ to stay susceptible to a wide range of experiences and facts, and to accept that his own judgments can change due to the RE process (the ‘conversion’).

Finally, how much time does reaching a RE need? Is it not too time consuming, and therefore not practical in a medical setting, especially when we include empirical data (which we have to find first)? We admit that there is no reason to expect that the process of revising moral judgments and specifying and balancing principles will come to an end in a perfect equilibrium. It is continuous work in a dynamic process. Our basic postulate is therefore that moral experiences, values, virtues and norms are part of a constantly moving process in which we create stability by using moral frameworks which are inherently temporary. Instead of a fixed rationalized framework built on principles we there-
fore face a never-ending search for coherence which is challenged by counterexamples to our beliefs, and by novel situations, technological possibilities and scientific insights that challenge the relative stability of our moral framework (Beauchamp and Childress 2009; Rawls 1971).

Qualitative research: moral experiences and considerations of parents, children and physicians in treatment and research decisions in pediatric oncology

In order to enrich the deliberation of ‘the thinker’ in RE with the norms and practical wisdom of the field of pediatric oncology, we collected experiences of relevant actors in our qualitative interview study. Several aspects of how we conducted our qualitative study warrant discussion. Many of them have already been discussed in chapters 3, 5, 6 and 7. First, our interview study used a retrospective design. This means there can be uncertainty whether the parents’, patients’, and physicians’ recollections were accurate representations of how they felt and what their thoughts were at the time of diagnosis and during treatment decisions. Examining parents’ and children’s narratives of decision making is not tantamount to studying decision making per se. The introspective gap between ‘true’ decision-making processes and those that subjects report is a limitation in this realm of research, and could introduce biases. Second, the study had small sample sizes. These two limitations could be partially surmounted by other study designs, like direct observation of decision making, recorded conversations between parents, child and physician, or mixed methods research in combining questionnaires with qualitative methods, but only by departing from the complexity and weight of real-world decision-making experiences. Future research with larger samples and a prospective design will be able to ascertain the relationship between the specifics of the informed consent discussion and parental, child and physician recollection. Third, we interviewed only parents and children who were willing to participate in the study. This may have resulted in an overrepresentation of families who had outspoken ideas on patient-parent-physician interaction or who had encountered substantial differences between family and professional views on the research topics. Although this kind of bias constitutes a well-known pitfall for quantitative methodology, in qualitative research it poses less of a problem, as our aim was to explore the moral content of experiences in decision making in pediatric oncology, and we were not so interested in quantifying the variety of experiences in statistics. Finally, 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 in its social demographics and well spread over the western part of the country. For our purpose to explore the moral experiences of families and physicians, the interviews were saturated
with participants from various moral backgrounds. The only group missing were immigrants (with limited comprehension of the Dutch language). Furthermore, the topic was compact enough to reach saturation across the sample: during the last interviews, no new information was yielded.

Eventually, one central question remains: can our results be generalized to pediatric oncology in general and even pediatrics in general?

Generalizability refers to the applicability of findings to settings and contexts different from the one in which they were obtained. The goal of our RE, however, and thus of the use of empirical data herein, is firstly to understand what is happening in a concrete situation of decision-making. The equilibrium reached does not exist outside this concrete situation, since the description of and experiences within the context of the situation are an integral part of the equilibrium. In that sense, speaking of generalizability within our use of RE is a bit odd. As described in chapter 2, the RE enterprise is continuous work in progress, in which we readjust an equilibrium reached whenever new data come along. Although the results of the RE in terms of a moral framework - e.g. how principles like the respect for autonomy are experienced, used and evaluated by the actors – cannot be generalized, the construct of the RE can prove to be an adequate instrument in the ethics of decision-making in pediatric oncological care. Our empirical data are robust enough to be used in a RE, and can also be the starting point to develop our understanding of the use of the concepts of best interests, child participation and parental authority in the concrete context of pediatric oncology. This understanding can subsequently be used as a new starting point, a so-called hypothetical equilibrium (see chapter 2) for reaching a new empirical reflective equilibrium, after obtaining new empirical data in other pediatric contexts. The process which evolves could imply that we end up with an unworkable situation, in which we are ad infinitum looking for a new equilibrium. By using the ‘Third Person’ perspective, which implies mainly a rationalization of the RE that has been reached, we however arrive at a relatively stable framework, which stands until new empirical data force us to rethink the equilibrium. In that sense parallels can be made with the falsifiability principle of Karl Popper (1959). Knowledge is irreducibly hypothetical, including moral knowledge, and we have to look for data that contradict it. In other words, as long as our empirical reflective equilibrium is not totally shaken, stirred or refuted, it stands as an understanding of the use of the concepts of best interests, child participation and parental authority.
DISCUSSION OF RESULTS

Best interests, child participation and parental authority
This thesis has highlighted several issues which combined show the shapes that the concepts of best interests, parental authority and child participation take in pediatric oncology. In every chapter, we confronted the experiences of relevant actors, collected in our interview study, with existing theoretical ethical concepts about pediatrics and child welfare. In other words, the theoretical ethical concepts were the starting point and were subsequently enriched by the emergent themes from the interviews. The experiences of parents, children and physicians give us unique insights in pediatric oncology practice and the way ethical concepts function in this practice. Because we use empirical findings we come much closer to the reality of the ethical challenges faced than a theoretical view could.

Central themes that emerged from the interviews were:

1) The nature of the pediatric oncology practice, with its almost complete integration of research and treatment. In this context, it is a demanding requirement to bring diverse moral commitments together, like putting the patient’s interests first, clinical equipoise, generation of new knowledge, true informed consent and voluntariness.

2) Interpretations of best interests. 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.

3) Difficulties to demarcate parental authority to balance future and present interests in decision making. Sometimes parental authority goes no further than to guide a child to adulthood with as many opportunities open as possible. In other situations, parents have substantial discretion to act on personal views.

4) Difficulties to ascribe decision making capacities to children. The same adolescent in one situation can be deemed capable and in another situation incapable of decision making.

In what follows we will take these themes together and try to integrate them in a reflective equilibrium.

The concept of the child’s best interest at the interface of clinical care and research
The ‘best interest’ standard has become the prevailing standard in pediatric decision-making (Kopelman 1997). Like most of bioethics’ ventures, best interests can be formulated in ways that sound appropriate or even compelling. However, as shown in chapter 5, close examination of the standard reveals significant problems with its definition and application in practice.
There have been many attempts to formulate 'objective' criteria for the best interest standard in pediatrics. Some authors claim that every child has a right to reach adulthood with as many opportunities left open as possible. Maintaining future options is a well-known theme in pediatric ethics, and various authors have argued that physicians and parents act unethically if they make choices that constrain a child's range of future options (Feinberg 1992; Davis 2001). Feinberg (1992) proposed recognition of a child's 'right to an open future', in which a child has a right ‘while he is still a child [] to have [ ] future options kept open until he is a fully formed self-determining adult capable of deciding among them’. Feinberg’s ‘right to an open future’ relies upon giving the child the opportunity to take advantage of those talents that her genetic traits, her ‘initial bias from heredity’ confer. In chapter 7 on discussing fertility issues with male adolescents diagnosed with cancer, we showed an example of using the child’s right to an open future. In our interviews, physicians stated that they would always discuss fertility preservation, because they wanted to maintain future options for the adolescent.

Other authors, like Kopelman (1997; 2010) describe the best interest standard as a standard of reasonableness. The best interest standard ‘requires us to focus on the child and select wisely from among alternatives, while taking into account how our lives are woven together. It instructs us to try and 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.’ (Kopelman 1997)

However, calling on an uncertain future or on ‘informed, rational people of good will’ still does not solve the problem of what the best interest standard should require when the actual clinical practice is so maddeningly complex and varied as is pediatric oncology. First, chapter 3 showed that in pediatric oncology there is an unprecedented integration of research and care, which leads to an intertwinement between patient interests and research interests. In this setting, uncertainty (for example, over which arm one will be randomized in) is a new dimension. Furthermore, the starting point of treatment within a research setting is what children have in common, not how they differ. Parents’ role on the other hand is to promote their child’s best interests, also when they are asked to consider enrolling their child in a trial. Parents are almost never in equipoise on trial participation, which leaves them with the agonizing situation of wanting to do what is best for their child, while being fearful of making the wrong decision. Furthermore, a therapeutic misconception endangers correct assessment of participation, making parents inaccurately attribute therapeutic intent to research procedures. Chapter 3 and 6 showed that
physicians prefer the perspective of a therapist over a researcher. Consequently they may truly believe that in the research setting they promote the child’s best interests, which maintains the existence of a therapeutic misconception between them and parents.

Second, chapter 5 showed that in the course of a pediatric oncology treatment we can distinguish a medical and a patient-family domain. At that point, the notion of best interests turns out to inherently be a matter of balancing different values, and not only of medical judgment. In the course of treatment, as the initial shock of diagnosis subsides, children and parents begin to more actively participate in decision-making. 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. The interpretation of what constitutes best interests starts to contain more than only the medical perspective. 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.

Third, chapter 7 showed that, when thinking about the interests of a child, there is always a friction between future and present needs, which is not so easily settled, even when future needs seem evident, like fertility preservation.

In conclusion, the pediatric oncology context is so complex that it depends on the point of view one takes (research versus treatment, medical versus personal, future versus present), how one interprets what is in the interest of the child. And every point of view can be refuted or put in perspective by another point of view. Only a comprehensive analysis of all points of view gives insight in what best interests can mean in the pediatric oncology practice. In short, and to phrase Hegel (2000): ‘Das Wahre ist das Ganze’.

In adult medicine, multiple models have been proposed to resolve disagreement over what constitutes the best interest of the patient, including informed decision making and shared decision making (Bensing 2000; Charles 1997). Both these models use an ethical paradigm in which the principle of respect for autonomy has general priority to the principle of beneficence. Physicians are expected to respect an adult patient’s autonomous wishes to refuse treatment, even if those wishes are not what the physician thinks is in that patient’s medical interests. This ‘adult’ paradigm puts a strong focus on patient participation in clinical decision making by taking into account the patients’ perspective, and tuning medical care to the patients’ needs and preferences (Bensing 2000).
In contrast, in the ‘pediatric’ paradigm, the principle of beneficence has general priority to the principle of respect for autonomy (Miller 2003, p 2-3). However, since the complexity of the context and our pluralistic beliefs about child-rearing and child welfare do not lead to a uniform interpretation of what is in the best interests of the child, also in the ‘pediatric’ paradigm we need to find a way to discuss the weight of various perspectives, and to give guidance as to how a decision should be reached, which considerations apply, and how future, as yet unknown life perspectives should be weighed.

To do that, we need to discuss the various ways to look at parental discretion and child participation.

**How far does parental discretion go? Parental authority and physicians’ professional autonomy**

The family is a cardinal moral institution and a major source of moral as well as bioethical controversy (Wang et al 2010). It seems obvious to state that the primary responsibility of parents is to care for and to protect their children, and that parents are devoted to promote the interests of their children. Some philosophers therefore state that parental authority can only be instrumental to the best interest of the child. This interpretation can already be found in Kant’s philosophy (Kant 1986). According to Kant, a child is not the property of parents. Parents cannot freely decide over their children, but have the duty to provide for and take care of their children. Their rights as parents derive from this duty to care: they have the right to keep the child with them and raise it. Childhood is defined as a passing phase of impaired maturity.

‘Der Mensch aber braucht eigene Vernunft. Er hat keinen Instinkt und muß sich selbst den Plan seines Verhaltens machen. Weil er aber nicht sogleich imstande ist, dieses zu tun, sondern roh auf die Welt kommt, so müssen es andere für ihn tun.’ (Kant 2005, p697)

It is in the interest of the child to be disciplined, cultivated, civilized and moralized to grow into maturity (Schapiro 1999). The possible wishes and desires of parents are only dealt with indirectly, as far as they promote or harm the interests of the child.

Other thinkers share this view. Dupuis (Dupuis 1991, p175) for example states that the aim of parental authority is to guide a child to self-determination, not to assign an inalienable dispositional right over their children. And Leenen (2007, p168) adds: parental authority exists not for the sake of the parents, but for the very reason to protect the child. In the early eighties, Feinberg (1992) developed his, abovementioned, influential theory on ‘the right to an open future’. It was a reaction on the US Supreme Court decision that permitted the Amish, a self-sufficient religious farming community in America,
to end their children’s public schooling at 14, two years short of the legal limit. According to the Amish, sending their children to public schools would undermine their community as they would be influenced by the modern secular world. The Court majority accepted the Amish argument that the continued existence of their 19th century religious farming community was at stake: if their children attended public high school, they would be less likely and less able to take up their roles in the community. Feinberg criticized the US Supreme Court decision. He argued that the Amish violate their children’s ‘right to an open future,’ namely, the right to be ‘permitted to reach maturity with as many open options, opportunities, and advantages as possible.’ This complex right has as its general basis the right to autonomy or self-determination, that is, ‘the sovereign authority to govern oneself, which is absolute within one’s own moral boundaries’. The child’s right to autonomy is a right-in-trust, to be fully granted when a child has developed the capacities necessary for its exercise. On this view, it is a principal parental duty to help a child to develop the capacity for autonomy, and in that sense parenthood is only instrumental to reaching the goal of self-determination, with as many options open as possible. In Feinberg’s footsteps, Davis (1997) formulated it as follows: ‘All parenthood exists as a balance between fulfillment of parental hopes and values and the individual flowering of the actual child in his or her own direction. (...) Good parenthood requires a balance between having a child for our own sakes and being open to the moral reality of that the child will exist for her own sake, with her own talents and weaknesses, propensities and interests, and with her own life to make’. In chapter 7 we showed an example of describing parental tasks as instrumental to the child’s right to an open future. When the moral focus is on preserving as many options as possible for the future child, then the physician’s task is to do all that is possible to protect a child’s future health, using only medical facts as starting point for proposed treatments. In these situations the pediatrician’s responsibility to his or her patient exists independently of parental desires or proxy consent (Committee on Bioethics 1995).

Other authors repudiate the thought that parental authority is only instrumental. Schoeman (1985) claims in this context that: ‘Certain decisions seem legitimate when made within the context of a family, even though they seem to violate the liberal principles for treating incompetents’. And: ‘the family is to be thought of as an intimate arrangement with its own goals and purposes. It is inappropriate to impose upon that arrangement abstract liberal principles’. A family has his own complex of values, relationships and goals that is highly autonomous. In the discussion in the early eighties on the schooling of Amish children, the American philosopher William Ruddick came to a nuanced conclusion. He did not support either the Amish viewpoint, since it gives parents too
much power over their children’s future lives, nor Feinberg’s right to an open future, that
gives parents too little power (Ruddick 1988). To steer between the parental extremes of
parental self-perpetuation and parental self-denial, Ruddick developed a family-centred
use of the best interest standard, the ‘Life Prospect Principle’ (Ruddick 1988). In his
theory he uses an analogy of gardener and guardian when talking about parents and the
way they have to fill in the interests of their child. The gardening analogy reflects the fact
that a child is a parent’s product, the result of intentional effort, but a product with the
unique capacity to become the equal of its producers. Hence, child-producers may not
treat children as if they were and would remain artifacts or property. Children have the
capacity for becoming autonomous beings, and a presumed interest in becoming that
imposes restraints on their producers and requires protection. Hence, the virtue of the
(legal) metaphor of parents as guardians. A parent is, as it were, a Guardian-Gardener,
a provider of ‘life prospects’. This reflects a child’s product-origin and its autonomous
future, while respecting parental productive hopes (Ruddick 1979). A child cannot be
fully distinguished from his parents and surroundings. ‘In short, there are no criteria for
individuating child from parent, or for defining the beginning or end of parenthood and
childhood. In various respects at various times, parent and child are not distinct indi-
viduals’ (Ruddick 1979, p124). That means that we cannot easily use an individual noting
of interests. The child’s interests are always intertwined with those of his parents. This
description fits more with the view on parental authority as described in chapter 5, where
we described that families have substantial discretion to act on personal views, as long
as their decisions do not fall below a certain threshold of acceptable care. In this view,
the physician needs to put medical facts into the context of familial values, and needs to
discuss how to weigh the medical facts in this specific context.

**Child participation**

Children develop powers of self-determination as they mature, and this affects all inter-
actions between adults and young people. Pediatrics is special as compared to other spe-
cialties that deal with incompetence (like geriatrics) in the hope that the incompetence
ends, and in the investment in bringing a child to competence.

Several studies have assessed and reviewed children’s capacity to participate in medi-
cal decision making (Dorn *et al* 1995, Mårtenson and Fägerskiöld 2008, Ondrusek *et al*
1998). The data on this topic have been ambiguous. All that these studies suggest is that
the major period of rapid change and individual variability in children’s capacities occurs
between age 9 and 14 years. Some have concluded that relatively young children can
participate meaningfully in the assent process (Committee on Bioethics 1995), whereas
others raise doubts about what children can understand (Wendler and Shah 2003; Par-
tridge 2010). When interpreting these studies, it is important to realize that the way in which researchers define assent drives their conclusions. It greatly depends on the capacities one requires for children to be deemed capable of providing assent (Miller and Nelson 2006). The closer the definition of these capacities comes to the capacities needed to be an ideal adult, the older the child will be before it can meet the criteria. In fact, it also depends on the broader social context of ascribing moral capacities and rights to children (James and Prout 1990; James et al 1998; Jenks 1996). Childhood as an institution (not individual children) is a set of beliefs and practices determining how children are treated and how they respond (Hilliard 1981). It differs radically in time and place; individuals aged twelve years are treated as responsible adults in one society and as fairly helpless dependants in another. Beliefs about childhood influence assessment of competence and also whether adults inform children and encourage them to take decisions, and whether children want and feel able to learn, choose and act. The care of children in hospitals is affected as much by changing beliefs about childhood, as by the changing medico-legal context (Alderson 1996).

Our study confirmed that it is not so straightforward to ascribe decision making capacities to children, even though the Netherlands have specific regulations that stipulate the age at which minors should be involved in decision-making concerning their treatment (Ministry of Health 1995). In chapter 7 on discussing infertility risks and semen cryopreservation with adolescents, physicians in general deemed the adolescent capable of participating in these discussions. In chapter 6 on involving adolescents in decision making concerning research participation, however, physicians deemed (the same!) adolescent incapable of participating in these discussions, even leading to the provision of a lower level of information to adolescents than to their parents. In both situations, physicians seem to be directed by their interpretation of what is in the best interest of the child in the concrete context at hand. Concerning research, physicians deemed research protocols in the best interest of their patients, and therefore they were confident to include an adolescent in a trial. Physicians recognized that the intense emotional context in which decision-making occurred, the extremely complex research protocols being explained to families, and the relatively short time frame during which treatment decisions had to be made introduced barriers to integrating adolescents into decision-making. Physicians therefore used attention to the best interest (also ensured by proxy consent and investigator integrity) as a substitute for the adolescent’s true consent. Quite the reverse, in the context of fertility discussions, physicians used their interpretation of what is in the best interest of the child (namely future fertility preservation) as a reason for involving adolescents in the decision making process, even though the topic was delicate.
In chapter 7 we described the term strategic control: the parental control over physician-child communication. Parents tend to filter and modulate what children are told by their physicians, relegating children to a passive role in medical decision making. Literature shows that physicians normally deem this mode of communication acceptable (Levetown 2008). Chapter 6 shows that for research discussions physicians use the same ‘strategic control’, when informing adolescents. Other studies in pediatric oncology describe the same tendency from physicians to protect children from too much information (Olechnowicz et al 2002; Young et al 2003). In other words, parents and physicians determine the ways to encounter the child, whether to involve the child in the decision-making process and the information given to the child.

Concluding, in the complex, emotional practice of pediatric oncology, there seems to be a constant weighing by physicians of burdens versus benefits in involving adolescents in decision making. This explains why the same adolescent in one situation can be deemed capable and in another situation incapable of decision making. In pediatric oncology, respect for adolescents accounts for their developing capacities as well as their vulnerability due to their illness and the emotional situation they are in.

A uniform decision making framework: the moral landscape of pediatric oncology

We can conclude from the above paragraphs that in the case of parental authority, physician’s professional autonomy and child participation there are different points of view. Again, as was the case with the interpretation of best interests, it depends on the concrete context which view is acceptable. Due to the complexity of the pediatric oncology context and due to our pluralistic beliefs about child development, child-rearing, child welfare and parental discretion herein, we cannot present a uniform interpretation of what is in the best interest of the child and how far child participation and parental discretion should go. Using RE, we may however come to a uniform decision making framework. Our RE framework describes the moral landscape of pediatric oncology as a complex interaction between seemingly incompatible viewpoints: research versus treatment, medical versus personal, technological perfection versus communication skills, future versus present, family versus individual, competent versus incompetent. In this moral landscape, physicians are challenged to provide medically effective care while respecting the wishes of the parents and children involved. Inevitably there are conflicts. Some conflicts are minor and would be resolved by more compassion or flexibility on the part of physicians (for instance, more respect for family beliefs and values), and by a similar adjustment on the part of the parents and children. Some conflicts are severe, as when parents refuse lifesaving therapy. These are discussed in chapter 5. And some conflicts are in the middle zone, raising challenging questions of which decision should
be taken when doctors and families disagree. As described in chapter 5, in these middle zone situations, the model of ‘communicative ethics’ can guide us. The aim of communicative ethics, as described by Moody (1992), is that all parties involved, including the patient (when possible), come to an agreement about shared goals and talk about decisions to be made. The emergence of personal views that are potentially different from the professional perspective can be recognized, understood, and, if necessary, dealt with (Coyne 2007). The various viewpoints are given a prima facie character (Beauchamp and Childress 2009, p14; Kopelman 1997, p276). We can (almost) never assume a completely clear-cut scenario in which one viewpoint prevails. As stated above, even the basic rules ‘put the patient’s interests first’ or ‘child participation needs to be encouraged’ are not absolute when we consider the moral landscape of pediatric oncology. It is an acceptable starting premise, a hypothetical equilibrium, but not acceptable as final conclusion. For a final conclusion we need to weigh it against other viewpoints. It is a demanding requirement first to identify and then bring together the diverse moral commitments that function in pediatric oncology. Sometimes an external party (for example an ethicist) is needed to function as the ‘thinker’ and to make the moral landscape explicit, and position the various viewpoints.

Due to the complex and high-tech character of oncology treatments the physician has a substantial role in the decision-making process. Parents and children can be reluctant to act as advocates for their own views in this setting (Young et al 2002). 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 et al 2006). The physician can also discuss limits to these wishes, as long as mutual understanding, awareness, and reasoning are maintained (D’Aloja et al 2010; Bensing 2000; Kai 1996). Eventually, it is the duty of all actors to reach consensus about what course of action is appropriate. When someone’s view is outweighed or overridden, it does not simply disappear. It leaves a ‘moral trace’ (Beauchamp and Childress 2009, p16), which should be reflected in the course of action eventually taken. A ‘communicative ethics’ structured in this way leads to a shared decision in which the contribution of all actors is considered. Furthermore, in our RE the third person moral experiences are rationalized in a way that remains focused on the specific context, while at the same time makes it open for accountability to people who were not involved in the decision making process.
CONCLUSION

There is still a great deal to learn about the complex processes that underlie joint decision-making in the context of pediatrics. Process-oriented qualitative methodologies, such as those employed in this thesis, lend themselves well to an examination of the multiple factors that contribute to this decision-making.

The moral landscape drafted in our RE can prove to be an adequate instrument in the ethics of decision-making in pediatric oncological care, and maybe in pediatric care in general. When the shared intention to act in the best interest of the child is based on a decision making framework that understands it as a matter that comes about in true consultation, the decision making process can nurture and enlarge children’s and parents’ understanding, trust and confidence, through the sharing and transferring of insights and responsibilities between physicians, children and parents.

FUTURE RESEARCH

The empirical reflective equilibrium we reached gave us an understanding of the use of the concepts of best interests, child participation and parental authority in the concrete context of pediatric oncology. As mentioned, this understanding can subsequently be used as a new starting point, the so-called hypothetical equilibrium for reaching a new empirical reflective equilibrium. We therefore need to obtain novel empirical data in other pediatric treatment and research contexts. We are currently gathering new empirical data from children who are asked to participate in medical research to answer the question whether these children can and want to be approached as moral subjects concerning research participation. These data can subsequently modify our hypothetical RE about child participation in research. We are planning a new empirical study on the ethical issues regarding puberty suppression in adolescents with gender identity disorder. The data gathered in this study will give us insight in whether children are competent to make far-reaching decisions, the role of parents and the role of society to define illness and health.

Not only new research will inform our RE. In the future we will also need to be aware of new realities, like the development of ‘personalized’ medicine, and the impact of whole-genome sequencing technology. All these realities will influence a future equilibrium reached.

Eventually, the aim of future projects and modifications of our RE will be to develop a stable decision making tool which incorporates the best interest standard, parental authority and child participation, and is practical in a wide range of treatment decisions.