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## **The moral landscape of pediatric oncology : an empirical study on best interests, parental authority and child participation in decision making**

Vries, M.C. de

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**Author:** Vries, Martine Charlotte de

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# Chapter 9

## SUMMARY



Few medical specialties encounter so many ethical challenges as pediatrics does. It is a specialty that inherently has features that are morally charged. Pediatric ethics examines the broad issues of (1) the concept of the child's best interest; (2) parental responsibility and authority in decision-making about the life and health of a child; (3) the emerging desire and capacity for self-determination of an older child, and (4) the professional obligation of a pediatrician to act in the best interests of the child. Much is written about these issues, but often the literature on these topics is either 'academic' and theoretical in nature, or casuistic. It remains difficult to utilize what is written in the reality of pediatric practice. In this thesis we reflect on the question how the concepts of best interests, parental authority and child participation can and should be translated and made operational in the everyday encounter between parents, physicians and children. We therefore combine theoretical conceptions of the best interest standard, child participation and parental authority with a close look on how these concepts actually function in pediatric practice, and how they are conceived by actors in the pediatric field. Taking the view that people's actual moral beliefs, intuitions, experiences and reasoning in a (medical) practice yields information which is meaningful for the operationalization of ethical concepts, we refine an existing empirical ethical methodology that successfully combines empirical research and ethical reflection, namely Reflective Equilibrium. Subsequently, we use this methodology to study one specific pediatric medical practice, namely pediatric oncology. Our goal is to describe in detail the forms that the concepts of best interests, child participation and parental authority take in the studied pediatric oncology practice. Furthermore, we reflect on the question whether the insights gained in this particular research setting can be translated to pediatric oncology in general and, where possible and appropriate, even to pediatrics in general.

*Chapter 1* gives a general introduction to the thesis. We describe the philosophical quintessence of pediatrics and the aims of the thesis. We subsequently explain our reasons to use an empirical ethical approach. Empirical ethics denies the structural incompatibility of empirical and normative approaches, and believes in their fundamental complementarity. It is an answer to the critique of bioethics for being too abstract, too general, too dogmatic, too top-down as well as too far removed from clinical reality, insensitive to the peculiarities of specific situations. The alliance with practice is a prerequisite for practicing ethics well-informed and pro-actively and for avoiding armchair philosophy. Attention to the experienced reality of pediatric practice however raises the question how to integrate experiences from clinical practice in ethical theory and analysis. Although intuitions and experiences are highly valuable as moral markers, it is generally stated that in ethics they need to be subjected to systematic, rational analysis in order to prevent

violation of the so-called 'fact-value distinction'. In other words, if one wants to use information from practice, one needs to reflect on the methodology applied to integrate this information in normative-ethical analysis and decision making. This reflection is done in chapter 2, in which we justify the use of Reflective Equilibrium.

We end chapter 1 with a description of the pediatric oncology practice and of the interview study, which produced the empirical data we incorporate in our reflective thinking. Our interview study comprised a qualitative multicenter project in which we explored patients', parents' and physicians' experiences with the informed-consent process for treatment and research decisions in pediatric oncology. We invited patients (aged 8-18 years;  $n=24$ ) attending the pediatric oncology units of two Dutch university hospitals, and their parents ( $n=26$ ), to participate in semi-structured in depth interviews about the informed consent process. We also interviewed all pediatric oncologists ( $n=15$ ) from the two hospitals.

*Chapter 2* describes our methodology of Reflective Equilibrium (RE) in detail. First, we discuss the use of RE as method of justification in ethics. RE tries to facilitate a real dialogue between theory and practice by not assigning a preferential status to either of them. Considerations on different levels of abstraction have an equal status at the start of the ethical enterprise. Justification is a reflective testing of our moral beliefs, moral principles, theoretical postulates, and other elements, to make them as coherent as possible. Coherence is achieved by an interaction between the different elements in RE, which can have an effect on all these elements. Thus, some elements need to be altered or removed, others kept. The equilibrium reached is a dynamic one; it can change due to new elements in the reasoning process. In RE the reasoning is normally done by one individual, whom we will call: 'the thinker'.

Second, we describe the adjustments we made to the traditional RE method, to come to our own methodology: the Network Model with Third Person Moral Experiences. In this model, empirical data, namely the moral experiences of the various actors in a practice, are added to the elements used in reflective thinking. We explain the need to include empirical data in RE (especially third-person experiences): one reduces the risk of self-justification, prejudiced judgments and bias by the 'thinker', and subsequently increases the credibility of the RE reached. The risk of self-justification is one of the main weaknesses of the RE model: coherence is not a sufficient guarantee for credibility or moral truth. By including third-person experiences, one reduces the risk of self-justification in two ways: since the experiences of many are brought into the RE process, there is a good chance of getting a pluralistic view on the matter at hand. Furthermore, minority positions can also gain attention in the process of reasoning. The process of weighing and

balancing judgments, principles, background theories and empirical data can let us identify judgments that are apparently wrong or prejudiced. In this way, the RE process itself can function as a filter, which can separate reliable from unreliable judgments of the ‘thinker’. The ‘thinker’ consequently gains a distanced view, while remaining attached to the concrete situation. 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 so-called ‘conversion’).

*Chapter 3* is a theoretical introduction to the ethical concepts studied empirically in chapter 4. Pediatric oncology has a strong research culture. Most pediatric oncologists are investigators involved in both clinical care and research. Consequently, various concepts studied in research ethics are relevant for our investigation. We describe the ethical criteria for valid informed consent: knowledge, competence and voluntariness. We pay extra attention to the concept of therapeutic misconception, i.e. the tendency to mistake the scientific aim of the trial for the therapeutic aim of a treatment. Subjects may have difficulty to recognize that the aim of the trial is to obtain scientific information, and that potential benefits for the subjects themselves are formally a mere by-product of gaining such information. We conclude with the fundamental point of departure in research ethics, namely the important distinction between the treatment relationship which exists between clinician and patient, and the research relationship which exists between researcher and subject.

In *Chapter 4* we discuss the ethical consequences of the unprecedented integration of research and care in pediatric oncology from the perspective of parents and physicians. We use an empirical ethical approach, combining (1) a narrative review of (primarily) qualitative studies on parents’ and physicians’ experiences of the pediatric oncology research practice, and (2) comparison of these experiences with existing theoretical ethical concepts about (pediatric) research. Analysis of the 22 studies reviewed revealed that the integration of research and care has consequences for the informed consent process, the promotion of the child’s best interests, and the role of the physician (doctor vs. scientist). True consent to research is difficult to achieve due to the complexity of research protocols, emotional stress and parents’ dependency on their child’s physician. Parents’ role 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 mis-

conception endangers correct assessment of participation, making parents inaccurately attribute therapeutic intent to research procedures. 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. We conclude that the challenges that a lack of parental equipoise and the therapeutic misconception pose may be very difficult to overcome. Thorough attention to the quality of communication of research information could improve understanding of the research perspective. We summarize points of awareness with respect to research discussions and give recommendations to improve communication.

*Chapter 5* describes the various interpretations by parents, children and physicians of the best interest of the child in the course of a pediatric oncology treatment. In pediatrics, the 'best interest' standard has become the prevailing standard in decision-making. 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. We first summarize the various problems with the standard. Subsequently, we describe the most commonly used solution to these problems, namely the definition of the best interest standard as a standard of reasonableness by Loretta Kopelman. This definition states that we must 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. 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. Differences in values can lead to different views by families and physicians of what is in the interest of a child. With our interview study we aimed at gaining insight into the views of parents, children, and physicians in the pediatric oncology setting. The 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. The medical view on what is best for a child prevails. 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. When family and professional views differ widely, the question inevitably arises whose perspective should prevail. Integrating the empirical data and theories on shared decision making we present a model of 'communicative ethics' to make the differing views a subject of discussion. In the model of communicative ethics, the various views of what is best for a child are given a prima facie character. 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.

*Chapters 6 and 7* deal with the possibilities of true child participation. *Chapter 6* discusses child participation in decision making concerning research participation. Various regulations and guidelines stipulate the importance of involving adolescents in this decision-making. Literature shows that in the context of pediatric oncology this involvement is difficult to achieve due to emotional stress, the complexity of research protocols and limited time. Still, a remarkable number of adolescents with cancer enter onto a trial during their illness. We performed an empirical study to determine physicians' attitudes towards enrolling adolescents in research and towards involving adolescents in decision making concerning research participation. The physicians' views can be brought together into four themes: (1) physicians regard most adolescents as not capable of participating meaningfully in discussions regarding research; (2) physicians do not always provide adolescents with all information; (3) proxy consent from parents is obtained and is deemed sufficient; (4) physician-investigator integrity: physicians judge research protocols as not being harmful and even in the best interest of the adolescent. In other words, physicians justify not involving adolescents in research discussions by referring to best interest arguments (adolescents' incompetence, proxy consent, and investigator integrity), although this is not in line with legal regulations and ethical guidelines. Integrating theoretical knowledge from research ethics and our empirical data, we argue that the fundamental differences between a research and treatment relationship should be seen as an incentive to truly involve adolescents in decision-making and not simply rely on best interest considerations. Physician-investigators should assess the capabilities of adolescents on a case-to-case basis and, when appropriate, should thoroughly explain the differences between research and standard care.

In *Chapter 7* we present another discussion on child participation in decision making. This time the focus is on parental discretion to regulate information disclosure to their child, thus influencing true child participation. In pediatric oncology, the risk of infertility due to treatment constitutes an important problem. For sexually mature male adolescents, sperm cryopreservation is an option, but discussing the topic is complex because of the sensitive nature and the limited time frame. In our empirical study, both parents and physicians spontaneously mentioned the problem of infertility discussions as an example of involving children in decision making. Although physicians and parents agreed that infertility would have a major impact on the future quality of life, they sometimes disagreed on whether the topic should be discussed with adolescents. Physicians always wanted a separate discussion with adolescents because of the sensitive nature and the experience that parents sometimes misjudged the stage of maturity of their son. Parents, however, wanted control over whether physicians discussed the topic with their child and what was said. Physicians did not accept this control and, when necessary, were willing to bypass the parents and discuss the topic with the adolescent even when parents refused consent. Integrating our empirical data with ethical theories on the child's 'right to an open future', parental authority, and child participation, we conclude that physicians face the difficult task of balancing between their ideas of what is in the (future) interest of the adolescent and accommodating parental wishes. We discuss the concept of '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. Parents and physicians jointly discuss the ways to encounter the child, whether to involve the child in the decision-making process and the information given to the child. We conclude however in the fertility case that, because of the private character of sexuality and the potentially inadequate maturity assessment by parents, semen cryopreservation should be discussed separately with adolescent and parents. In addition, there should be an open communication with parents to address potential discomforts.

Finally, in *Chapter 8* the principal results of this thesis are put into perspective. We focus on two issues. First, we give methodological considerations by answering additional methodological questions, of which the most important is: 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. We conclude therefore that speaking of generalizability within our use of RE is a bit odd. We do argue however, that, by using the 'Third Person' perspective, which implies mainly a rationalization of the RE that has been reached, we arrive at a relatively stable framework, that 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. Knowledge is irreducibly hypothetical, also 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.

Second, we reflect on the implications of our empirical study for our thinking about child participation, the use of a best interests standard and parental authority. We take the themes from the interviews together and try to integrate them in a reflective equilibrium with existing theories, norms and principles. We conclude that 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. We can (almost) never assume a completely clear-cut scenario in which one viewpoint prevails. 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, in our methodology: a hypothetical equilibrium, but not tolerable 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. Eventually, 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.

