

Chapter 1

The Child's Body and Bone Marrow Transplantation: Introduction



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Abstract Questions concerning the ethical status of children, and their position and their relationships within families, have been widely debated in recent moral philosophy and biomedical ethics, as well as in pedagogic sciences and sociology. This volume is intended to contribute to these interdisciplinary debates from a very specific angle. Combining philosophical, ethical and qualitative empirical research, it focuses on a medical practice that brings out a particularly challenging and complex social and familial situation, thus illuminating family responsibilities and their conflicts, children's dependency, the child's body with all its meanings, and the specific roles of family members in a transformative situation. The practice concerned is the transplantation of bone marrow between siblings who are children at the time of transplant. These renewable haematopoietic stem cells, derived from the marrow of the hip bone, can serve as a medical therapy for the sick brother or sister.

Keywords Children as donor · Stem cell transplantation · Responsibility · Family · Ethics

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children's dependency, the child's body with all its meanings, and the specific roles of family members in a transformative situation. The practice concerned is the transplantation of bone marrow between siblings who are children at the time of transplant. These renewable haematopoietic stem cells, derived from the marrow of the hip bone, can serve as a medical therapy for the sick brother or sister.

Bone marrow transplantation is a standard treatment for leukaemia, Fanconi anaemia and other possibly fatal diseases of the blood system. If a person has a matching tissue type, they can act as donors (or be treated as donors) even if they are as young as 1 year old. Since it began in the 1970s, this procedure has raised ethical questions about the autonomy and welfare of the donor child, and concerns about the instrumentalization of the donor's body. For genetic reasons, the siblings of patients are often matching donors, (much less frequently, parents are suitable for donation) and if the patient has childhood cancer, sibling donors are often children as well. The extraction of bone marrow poses only a small *medical* risk to the donor but is in other ways a significant intervention into the donor's bodily integrity that carries multiple meanings and affects family interactions, both in their present lives and in the future.

Paediatric stem cell transplantation involves the healthy child who acts as a donor, and the ill child who needs the corporeal remedy for treatment. Two different sources of blood stem cells are used: the bone marrow stem cells or peripheral blood stem cell donation (less often used in children). Irrespective of precise source, stem cell transplantation constitutes a pressing ethical challenge in paediatric practice, because it lacks a direct or indirect medical benefit for the donor.¹ A sibling's stem cell transplant, however, frequently saves the life of the ill child recipient, or is at least curative.

Stem cell transplantation between young children creates a paradigm situation for biomedical ethics that needs to be studied and discussed from a variety of points

¹ There are two different methods of collecting haematopoietic stem cells: peripheral blood stem cell (PBSC) donation and bone marrow donation (BMD). In the case of *PBSC donation* the donor is first given medication – a growth factor (G-CSF) – for about 5 days. This hormone stimulates the growth of haematopoietic stem cells and their passage from the bone marrow into peripheral blood. A common side-effect of this treatment is the development of flu-like symptoms, which can be treated with paracetamol, for example. The cells are then collected from the donor by a procedure called stem cell apheresis. The donor's blood flows in a continuous loop from one arm vein, through a cell separator and back into the body via a vein in the other arm. This method of stem cell collection takes about 3–4 hours. In some cases it has to be repeated the following day in order to obtain the required number of stem cells. However, in most children younger than 12 years the forearm veins are too thin for the venous catheter, and a central venous catheter therefore has to be placed. For this reason, and also because they have a smaller total volume of blood, children often tolerate bone marrow donation better. In *BMD*, which is performed under general anaesthetic, no more than 20 ml per kg body weight of a mixture of bone marrow and blood is harvested from the hip bone (posterior iliac crests), with the donor lying on her stomach. The procedure takes about one to one and a half hours. Side-effects include mild pain, stiffness when walking, haematomas in the region of the collection site, and the usual potential side-effects of a general anaesthetic. The bone marrow regenerates completely within a few weeks. Sometimes iron tablets are prescribed (see Kline 2006; Müller 2015).

of view. It represents a range of conflicts of interest which are difficult to disentangle. It involves a medical intervention into the body of a healthy child, in order to help a brother or a sister who desperately needs the stem cells. This cannot easily be justified as being in the donor's own best interests. It is also debatable whether a young child can meaningfully provide informed consent to the procedure. For legal reasons, parents need to consent as proxies. Medicine that tries to save a life is in a genuine dilemma: some interests of the donors must be sacrificed in order to help the patient. This poses multiple challenges for the families who live with these transplants. This book systematically investigates these issues.

As we have learned in the nearly 9 years of work that eventually led to this book, this is an extremely rich and fascinating topic. It has many implications that reach far beyond the bioethical question of the circumstances under which it is morally permissible to take bone marrow from one child's body to save the life of another, or the question of whether selecting a matching donor child using the technique of pre-implantation diagnosis to create a "saviour sibling" is permissible. Our study focused particularly on the act of donation and its role in the overall process. Any transplantation practice, however, involves more than one person: a donor and a recipient, and it affects other people too – the rest of the family and their close social environment. We first conducted a philosophical study with the title "The best-interest of the child in conflict?" (2012–2015, led by Christina Schües and Christoph Rehmann-Sutter, funded by the Thyssen Foundation). In this theoretical phase of our work we investigated the medical-ethical and social-philosophical aspects of bone marrow donation between siblings. Special attention was paid to the frequently used formula of "child's well-being". We wanted to clarify the meaning and function of this concept in the understandings of the problem and the construction of legitimacy of the practice of transplanting haematopoietic stem cells between siblings. In parallel, three interview studies were conducted as MD dissertations. Lina Busch interviewed the leading experts in paediatric oncology and medical law in Germany, who experienced the establishment of the procedure of bone marrow transplantation in Germany over recent decades. Lilly Schwesinger interviewed leading practitioners and bioethicists in the USA, in particular about their concept of risk with regard to the donor child. Sarah Rieken conducted a pilot study of ten in-depth interviews with five parent couples who had recently experienced bone marrow transplantation between their children. This interdisciplinary work produced a theoretical and ethical framework, and led to a first round of publications.²

On the basis of this preliminary work, we started a larger qualitative inquiry into family experiences. We obtained funding for this from the German Ministry of Education and Research. This time we chose a long-term retrospective approach, including 17 families who had experienced a transplant up to 20 years previously. This is so far the only study with such a long-term perspective. We planned to interview every single member of the inner family. The interview study ran between

²Schües (2013), Schües and Rehmann-Sutter (2013a, b, 2014, 2015, 2017), Rehmann-Sutter et al. (2013), Rehmann-Sutter and Schües (2015), Schües (2016), Moos et al. (2016), Raz et al. (2017), Busch (2015a), and Rieken (2020).

2016 and 2019 at the Institute for the History of Medicine and Science Studies, at the University of Lübeck. Field work and interpretation was mainly conducted by Martina Jürgensen and Madeleine Herzog.³ Christina Schües and Christoph Rehmann-Sutter regularly participated in discussing the findings against the backdrop of what was discovered during the first phase.

This book is based on the key findings of this long-term retrospective study. It presents these findings in four topical chapters, each followed by two discussion chapters, most of them written by guest authors. All the chapters emerged from an interdisciplinary workshop in February 2019 in Lübeck, where the authors had access to an extended and thematically organized selection of interview quotes, and presented the draft of their chapter. This selection of quotes has grown into the appendix of this book.

Stem cell transplantation is a practice that had its first successes about 50 years ago. Since the 1970s, increasing numbers of healthy children have served as allogeneic blood stem cell donors for their ill siblings.⁴ In 1968, a child diagnosed with lymphopenic immune deficiency syndrome received the first paediatric transplant (Yeşilipek 2014). Since then, different diseases of the blood building (haematopoietic) system, such as leukaemia or Fanconi anaemia, myelodysplasia, lymphoma and thalassaemia, have been treated using stem cell transplants. Stem cell transplantation is a risky but often successful and effective therapy for a number of serious, often fatal diseases, and for some of them, it has been the only possible curative treatment. Since the introduction of the immunosuppressive drug *cyclosporine* in 1980, the chances of success have improved significantly (Weil 1984). A survey article by the European Group for Blood and Marrow Transplantation (EBMT 2019) reports that an increasing number of stem cell transplants have been carried out since the mid-1970s, but it does not specify how many involved child donations. In 2000–2002, according to one census, there were more than 31,000 child transplants throughout Europe, some of them from sibling donors (Miano et al. 2007). Siblings are often chosen as stem cell donors because in approximately 25% of cases they have a matching HLA pattern. However, unrelated donors from growing lists of potential anonymous donors can be chosen as well, if somebody is HLA compatible.

³We are grateful to Sandra Matthäus for her contributions during the first year of the project.

⁴In Europe, the number of blood stem cell therapies increases every year. In 2010 more than 30,000 transplants were carried out for the first time (autologous and allogeneic added together), and this number increased by 6% between 2011 and 2012; 14,165 allogeneic transplants took place in 2012. Of these, 11% were in paediatrics: 2877 allogeneic transplants were performed with a recipient under 18 years of age. The overview took into account 661 of 680 centres in 48 countries (European Society of Blood and Marrow Transplantation EBMT, Annual Report 2013). See also Antin and Raley, *Manual of Stem Cell and Bone Marrow Transplantation*, 2013. In the US, the number of allogeneic blood stem cell transplants from HLA-identical siblings has remained more or less constant since 1995, ranging from about 2000 to 2500 per year, with a slight downwards tendency since around 2014, mainly due to higher numbers of haploidentical donor transplants from parents, which have increasingly been performed over the last 15 years (SIBMTR 2019).

It now seems amazing that during the first years of paediatric transplants, two opposing lines of thinking prevailed in the medical practice with children. First, up to the 1970s and still affected by the brutal medical experiments under the German National Socialist (Nazi) regime, children were explicitly excluded from medical practices that violated their fundamental right to physical and psychological integrity. Seen in this light, the twentieth century was not simply characterized by progress but also by a changing, sometimes cruel and inhuman history of medicine that also involved experiments on and the murder of many thousands of children. Yet it was also the epoch in which children's rights were explicitly formulated, which led to the child being given the moral and legal status of a subject. The years 1924 (Geneva Declaration of the Rights of the Child) and 1989 (United Nations Convention on the Rights of the Child) are particularly exemplary of these upheavals and milestones. Now, children are included in research and are allowed to donate body tissue for a sibling if it is of therapeutic use to that sibling in the event of a serious illness. Second, during the period during which transplantation practice was not yet consistently successful, when physicians still worried whether the intervention would have a healing effect on the sick child, ethical questions were rarely raised. At the forefront of the discussion were medical questions and problems such as graft-versus-host disease, which can occur after a paediatric bone marrow transplant.⁵ In the 1980s, the first short-term empirical studies were conducted, focusing on the medical and social experiences of the donors and recipients of paediatric stem cell transplants (Sanders et al. 1987). It is interesting to see that at the same time that the recipients' survival rate increased, ethical concerns about the practice also became increasingly visible in the literature. Around 1990, the first articles on the ethics of this practice appeared.⁶

The ethical debate gained momentum in early 2000s. Several, mostly short-term empirical studies were undertaken by medical social scientists (Packman et al. 1997, 2004; Pentz et al. 2004, 2008; Wiener et al. 2007). Morally, psychologically and legally, the conflictual structure of sibling donation became an issue of discussion. Stem cell transplantation had become a medically established practice, but it still raises doubts that could not be easily or adequately addressed by standard decision-making models within the Western ethical tradition. The subject matter also proved difficult for classical ethical concepts, such as Aristotelian virtue ethics, Kant's ethics of duty, utilitarianism or existentialist approaches, which were developed primarily for the regulation of relationships between adults. Stem cell transplantation between siblings does not involve symmetrical relationships between responsible citizens, or obligations to persons who are not of age or unable to give their consent. As elsewhere, medical practice can be unlike ordinary life. And free and informed consent cannot resolve the matter, since small children cannot meaningfully give or withhold consent. It has become common ethical and legal practice

⁵GvHD means a reaction of the donated stem cells ("graft") against body cells of the recipient ("host") because they are seen as foreign ("non-self"). Symptoms vary from mild to severe, and can lead to the death of the recipient (Eisner and August 1995).

⁶Forman and Ladd (1991); Kline (2006, ch. 13).

in therapeutic decisions that those who cannot give consent are given proxies who decide on their behalf and in their best interests. This applies to children who are unable to give consent, and to people with dementia. However, these procedures cannot resolve the issues connected to actions in the field of paediatric stem cell transplantation that involve healthy children who are to act as donors and be injured simply in order to donate. Acknowledging children as subjects with their own past and future biography means recognising their specific needs and rights. It also involves giving them a voice, giving consideration to their adequate involvement in decision-making, and focusing on aspects of care for the children that are relevant.

The ethical problems of blood stem cell transplantation from donor children arise against the background of the individual rights that form the fundamental normative constitution of modern societies. They are structurally based on the formal and material recognition of every person's human rights. This set of basic rights includes the principle that every human being has a right to be protected in her or his physical integrity. If this is taken seriously as a fundamentally defensive right, it cannot be overridden by the medical need of another individual. Only a therapeutic aim that benefits the child itself can justify an intervention into the body of a child who cannot give consent. Preventing or curing the disease of *another* child *per se* are not valid reasons to infringe one child's bodily integrity. Beyond a therapeutic justification, the right to bodily integrity can only be outweighed by the principle of voluntariness, which can be met if a mature person is able to give her or his informed consent to donation. However, the law and ethics see a young minor, perhaps 5 years old or less, as being unable to freely decide about her participation in donation. Ethically and legally, teenagers are given the possibility to dissent. The standard argument is that (i) the ill child needs adequate therapeutic help, which (ii) can be provided by the sibling's stem cells, and (iii) the parents bear the responsibility to care for the sick child who may need a stem cell transplant, as much as they are committed to protecting the potential donor child; however, (iv) harvesting the stem cells is a low-risk procedure and the donor's stem cells will regenerate. Thus, in this view, (v) care for the well-being of the recipient child and care for the donor child might require and justify (mildly) injuring the donor child. This line of argument, however, is simplistic on theoretical and practical grounds. For instance, it takes for granted that there is a tight causal connection between donation and survival: if the potential donor child does not donate, the sick child will die. This is often not the case. There might be an unrelated donor who could be found, or parents could donate bone marrow for a haploidentical transplant. And equally, a stem cell transplant from a sibling is not always successful. In principle, if a matching sibling will not donate and, hence, hypothetically speaking, the sick child dies, we could also say that she has died because of her illness and not because of the sibling's refusal to donate.

This situation can be better seen as a parental *moral conflict*: parents are obliged to care for all their children, but when a stem cell transplant is an indicated treatment, they might be asked by the medical professionals looking after their sick child to agree to injuring their other child, in order to help the sibling therapeutically. If we recognize and accept the intrinsically conflicting nature of this situation and

abstain from quickly resolving it by subordinating one concern under the other, in order to establish a formal justification, the moral (and legal) complexity of sibling donation can be understood in a much more nuanced way, which is also closer to the fine-tuned moral perception of the family members involved. To be specific, if blood stem cell therapy is suggested by doctors as the only therapy, and in consequence the parents are confronted with the demand to agree to the injury of their healthy child in order to fight for the life of the other, ill child, they are burdened with a decision that is conflictual at its core, even though it appears to be merely following a therapeutic imperative.

In order to better address this difficulty in the situation of decision-making, the 2010 policy statement of the American Academy of Pediatrics (AAP) states that a “donor advocate” should be appointed. This person should talk to the potential donor child, to see whether he or she understands the situation, and to help parents to see and consider the perspective of the potential donor child rather than seeing things mainly from the point of view of their sick child. According to the AAP, the donor advocate should be involved from the outset, starting with the decision about whether the minor should undergo HLA testing (American Academy of Pediatrics Committee on Bioethics 2010, 398). In Germany, the transplantation law was expanded in 1997 by a new paragraph §8a, which provides that it is permissible to extract bone marrow from the body of a minor to cure his or her sibling, if no adult donor can be found (TPG 1997, §8a) and the legal representative (i.e. the parents) have given their consent after being comprehensively informed. It does not call for a donor advocate. Before the introduction of this paragraph, stem cell transplantation from a minor donor was not mentioned in a legal document in Germany. The actual practice in Germany, however, clearly deviates from the legal provision to search for an unrelated donor first. Siblings have remained the preferred donors (Busch 2015b).

The *parental ethical conflict* of having to care for all the children and having to decide to harm the healthy in order to help the sick child, which lies at the heart of this practice, happens in a situation of extreme crisis when one child has a severe, life-threatening disease. Psychologically, the issue of stem cell transplantation between siblings concerns the whole family. Family members become involved and affected in different ways. The bioethical literature has clearly diagnosed and evaluated a conflictual situation for the parents, either on the level of the clash of norms and interests or from the perspective of proxy decision-making, the eligibility of a child as donor, and the participation of the donor child in this procedure.⁷ Less attention has been given to the moral conflicts of the other siblings who are also potential donors. Some of them need to decide whether to agree to be tested, and others would be willing but are unable to donate. Non-donating siblings may be sidelined for a certain time; they may need to put aside their own demands, and may be jealous.

⁷Bendorf and Kerridge (2011), Bitan et al. (2016), Schües and Rehmann-Sutter (2015); see further references in AAP (2010).

Qualitative research has demonstrated a much richer complexity of donors' and other family members' moral perceptions. Rather surprisingly, as Pentz et al. (2014) found, most family members did not view sibling typing and donation as a choice. This reflects our own earlier results as well (Rehmann-Sutter et al. 2013). Donors in Pentz's study were positive about the experience, and did not express regrets. The most important lack identified was in education and psychosocial support. However, this does not mean that donors' experiences were easy. There are psychological risks to donation, which begin when parents are approached about the possibility of having one child donate haematopoietic stem cells to another (AAP 2010). As Jennifer Hoag's group recently reported from a mixed methods study, while feeling influenced by family obligations, all donors wanted to make the final decision about whether to donate. The most important factor that guided decision-making for donors was an obligation to help. However, "[m]ost of the donors felt that the decision to donate was theirs to make" (Hoag et al. 2019, 378). The role given to the donors in decision-making influenced their perception of the outcome, and their feelings of responsibility for the health of the patient sibling. Findings such as these have been included in a proposal for an improved psychosocial care pathway (Kazak et al. 2019).

So far, only short term empirical studies have been published, covering months or 1–2 years after the transplant. Long-term assessment from the point of view of all family members involved is lacking. We consider this an important omission in terms of informing the ethical and legal discussions of the norms involved, which are in conflict within this practice, yet also have a long-term meaning in retrospect. To understand the conflict from different perspectives and at different times, the families need to be investigated more comprehensively. All family members, both parents and children, donating and non-donating siblings, can provide important views, which have not yet been studied in adequate length and depth. Do family members sense this ethical conflict? Do these considerations matter to them? How do parents actually decide? How do they see their decisions in retrospect, at different timepoints afterwards, and depending on the outcome of the transplant? Do they actually feel that they decide(d)? How does a family treat the many issues of responsibility? How do families interact? How do they see the body of the donating child in the context of the emerging needs? These are a few of the questions that seem to be relevant for understanding the issues philosophically and for the ethical discussion beyond regulation and clinical decision-making.

Our long-term retrospective qualitative study included 17 families who had lived through bone marrow transplantation between siblings who were children at the time. There were about equal numbers of families at 0–5 years, 6–10 years, and 11–20 years post-transplant. One family, which we included for comparison, was just before transplant (1 week). If possible we interviewed all members of a family, if they were old enough and agreed to participate. The interviews were conducted with individuals as well as with the family as a group, and recorded and transcribed verbatim. Interpretation was based on qualitative, hermeneutic-phenomenological research methodology. In most cases, we started with the family group interview, where interactions could be recorded. This gave us insights into the particular

family dynamics and the shared family narratives we heard. This was followed by a set of individual in-depth interviews with all family members. All the families that we interviewed live in Germany.⁸ Thus, the context of family life and of medical practice refers to this country. For the interpretation, however, we were inspired by and included analysis and discussion from other Western countries.⁹ The interview materials presented and discussed in this book cover reflections, narratives and memories of donors, recipients and other family members, as well as observations of family interactions.

We asked leading scholars from related fields such as bioethics, philosophy, and family sociology to discuss the findings from these interviews and our analysis from their perspectives. We asked them to reflect upon a broad sample of interview quotations, and gave brief introductions into our key findings. In an elaborated form, these introductions constitute the thematic introductions to the four main parts of this book. Additional quotes can be found in the appendix. For the sake of brevity we will call our own qualitative empirical study in this book the “Lübeck study”.

When we started the study we defined a series of main research questions. They included: (1) What are the short- and long-term psychosocial consequences of a blood stem cell transplant between minor children? (2) How are family relationships influenced by the period of illness, the transplant practice, and the time after it? (3) How do family members perceive each other in terms of their body and its involvement in the treatment? (4) How do individual family members see the ethical questions, but also the practical concerns and emotional density connected with bone marrow transplantation? These questions inspired the interview guides. As is common in qualitative research, we chose an iterative procedure. After collecting the first interviews, we started the analysis and interpretation, and reviewed the interview guide as well as our interview strategy, continuing similarly after the next series of interviews. The guide was repeatedly revised in this cyclical procedure. There were some challenges in a few family group interviews in situations of severe tension between family members.¹⁰ Using an inductive procedure based on systematic sentence-by-sentence coding of the interview transcripts, a series of overarching themes emerged. We have selected the main emergent themes as the topics of this book, and have organized it into four corresponding sections.

In order to introduce them, one chapter makes a link to the well-known novel and movie *My Sister's Keeper* by Jody Picoult. In this story, Anna is a young stem cell donor for her sister Kate; however, Anna has been specially conceived and selected in order to be a matching donor, using pre-implantation genetic diagnosis. Despite this obvious difference, Anna's story resonates in many ways with the stories we heard from our families. But in other respects, the fictional Anna gives a further dramatic aggravation of the family conflict. *Christoph Rehmann-Sutter and*

⁸We are not aware of any other qualitative study about stem cell transplantation between siblings in Germany.

⁹For further details on the stratification of the sample, the design of the interview study and the analytical methodology we used, see the introduction in the appendix.

¹⁰Some we discussed in Herzog et al. (2019).

Christina Schües analyse the film and make a series of comparisons between its narrative and the work of remembrance in the families. *Christina Schües* then offers a philosophical conceptual analysis of the child's well-being and the child's best interests. These ideas are central to the ethical evaluation of decision-making in paediatric medicine, and are related to the child's will and the family's well-being. How can a tragic problem be analysed and transformed so that the donor child, the recipient, and the whole family can be kept in communication with one another?

Each of the topical sections starts with a report of the relevant empirical findings, written by *Martina Jürgensen and Madeleine Herzog*.

I. *Mapping responsibilities*. How are responsibilities allocated, negotiated and understood in the complex relational network of patient, donor, other siblings, and parents, in relation to their physicians, the law and state authorities? The chapters in this section look at different types of responsibilities faced by the family members depending on their role as mother, father, donor, recipient, and other family members.

Families strongly believed that it was a shared responsibility to help the sick child and did not therefore consider donation a question to be decided, but rather a matter of course. Some even said it was a family duty. These moral understandings contributed to a dynamic differentiation of responsibilities among family members. Donors, for instance, acknowledged a responsibility for the success or failure of the transplant, and some said their duty extended over time and included more transplants later in life. In retrospect, it was also striking to see that most donors valued their donation positively.

Claudia Wiesemann comments on these findings from a medical ethics perspective. She asks how the decision to donate can be made freely and without coercion if the life of a child depends on it. She also examines whether sibling bone marrow donation can be reconciled with the moral ideal of family that is based on care. *Jutta Ecarius* introduces the perspective of education, and distinguishes a series of different dimensions of responsibility in education and family interaction within the structure of a family and with regard to the difficult situation of illness.

II. *Dealing with illness*. Which coping strategies do the families use? What does it mean for the families to be ill? Families had different attitudes, which reflected both their previous experiences and their basic attitudes toward the world.

Some families first responded by denial of the fatal diagnosis, hoping that it was a mistake. Many families suffered from a severe loss of control in several areas of their lives. The illness changed family roles. An important question is how long a child should be seen as "ill". Four different patterns of coping were identified: toughening up, resignation, ignoring, or acceptance. Families also found different things helpful in dealing with the situation and in making sense of the events around the illness: keeping or regaining control, maintaining routines, hoping that it will be all right, or making the best of bad things. In hindsight, many families felt that the

experience of the disease also had a positive impact on the family as a whole, and that individual family members could learn from it.

In her response, *Amy Mullin* discusses how philosophy can help us understand family responses and decision-making. She draws on interviews and explores how a relational understanding of autonomy might help map initial decision-making, how an ethics of care can contribute to understanding the balancing of personal needs against what is wanted for a seriously ill child, and how gratitude, rather than indebtedness, is the appropriate response to sacrifices aimed at saving a sibling. *Christoph Rehmann-Sutter* searches for connections between responsibility, memory and time, in order to explain the complex meanings of “retrospective responsibilities”. Story-telling within families and the emergence of family narratives is a place where responsibility is not just remembered, but also enacted. Families care about how things in the past are recounted in the present.

III. *Processes of decision-making.* How did different families and their individual members conceptualize and “make” a decision, and participate in decision-making? Do they feel they really have decided at some point? How do they evaluate the decision and the decision-making process in retrospect?

With one exception, all families said that the decision to conduct a bone marrow transplantation (BMT) was not experienced as an option but as another step in the therapeutic process, to which there was no alternative. They felt they had no other choice. The decision to have family members typed and, if they match, use them as donors, was not interpreted as a “decision” either, but was considered a matter of course for family members to do so. Families preferred a sibling donor over an unrelated one. Parents felt that they needed to talk to the (potential) donor about the donation. Most families said that the child was formally asked whether she or he agreed to the donation. However, everyone knew that a negative answer to this question was not possible.

Tim Henning takes an analytic philosophical point of view and investigates two moral pitfalls that emerge in the procedure of decision-making about stem cell donation by a child. There is a danger of violating what moral philosophers refer to as the separateness of persons, and of viewing the children as what he calls mere “value receptacles”. On the other hand, there is a special danger to the child’s autonomy – the danger of using the burdens of autonomy to undermine autonomy. *Lainie Friedman Ross* explores the limits of the best interest standard and the role of third-party oversight for some medical decisions even when the parents’ decision is not abusive or neglectful. She argues for including a living donor advocacy team to support the potential donor child.

IV. *Familial bodies.* Body parts (tissues, cells) can become a remedy for another family member. Whose body is that of the child? How does this affect the individual’s and the family’s ideas of being “whole” and “integral”? Can the family itself be seen in some respects as “a body”?

After a bone marrow transplant between siblings, another family member’s cells continue to live in the recipient’s body. This connects family members in a variety

of ways. Some families saw it as an essential change in the recipient's body and identity, while others saw it as a unification of two separate individuals. Some families described the donor's body as a "spare parts depot"; being seen as a life-saving resource then created a lasting responsibility in the donors. This relation was in fact seen by families as creating one system, one "familial body".

Margrit Shildrick explores stem cell transplantation with regard to questions of identity, of gifting, and of mortality. In looking at everything involved in the understanding of stem cell transplants – the biomedical procedure, the individual and collective experiences of the family, the data collected, the expertise and expectations of the researchers, and the varying analyses applied – what emerges, she argues, building on a Deleuzian framework, is a knowledge assemblage. *Christina Schües* investigates stem cell transplantation as a phenomenon of intercorporeality. This concept embraces the "family body" and a singular body, the sense of bodily belonging and bodily ownership, and a relationship that inheres within a transplant. She argues that even though the transplant is body material, it is always more than that: a ground for personal traits, symbols, and a particular bond between the siblings.

This interdisciplinary discussion is intended as a contribution to family research, to medical sociology, and to the understanding of ethics from the different lay perspectives involved. It also aims to be an inspiration for healthcare professionals and for bioethicists. In conclusion, perhaps two aspects elucidated in this book deserve to be especially highlighted: (1) *Family*. Today, family is predominantly seen as socially determined and fluid. In reality, however, biological kinship and parenthood still play a big role (blood relations), otherwise so much effort would not be expended in securing genetic relations to children by means of fertility treatments, in vitro fertilization, or searching for genetic parents after an adoption, or arguing for the right to know one's genetic origins. The question of a possible donorship of stem cells emphasizes the embodied similarity and dependency between members within a "family body". What do I signify for others based on my embodied existence? What is the meaning of my body features for these others? The closeness that is realized through a transplant of tissue creates a special form of closeness – and with this, of responsibility. A family body is what we share – in a very material sense. This is not only the case for parents, but also for siblings. If families feel the wish to solve a problem using their own means, from within the family, this should be seen not only as the capability to do something tremendously important together, but also as something that has a material basis. (2) *A child's body*. Parenthood has always been a very corporeal undertaking. It involves desire, passion, sex, conception, pregnancy, birth, breastfeeding and nourishment, care, protection, touch, punishment, and so forth. The parental approach to the child is very corporeal. At first, the parents' power with regard to their access to the child's body is nearly limitless: parents decide everything (or they think they do), they have unlimited right to know what the child is eating, when it is sleeping, what clothes it wears, which hairdo it has... Is this an unquestioned prerequisite that makes it easier to use the body of the child for another, higher purpose? Is this a reason why some parents do not even realize that a donation of stem cells infringes the bodily integrity of the child? Are they just accustomed to having access to the child's body?

These are not questions that we claim to settle. But both the family narratives and the academic texts in this book flesh them out and bring a substance to them that will hopefully broaden our knowledge about the practice of paediatric transplantation and its contexts.

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