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Citation for published version (APA):
Knibbe, M. E. (2009). 'Not a matter of choice': ethical perspectives on decision making about living parental liver donation. [S.n.].

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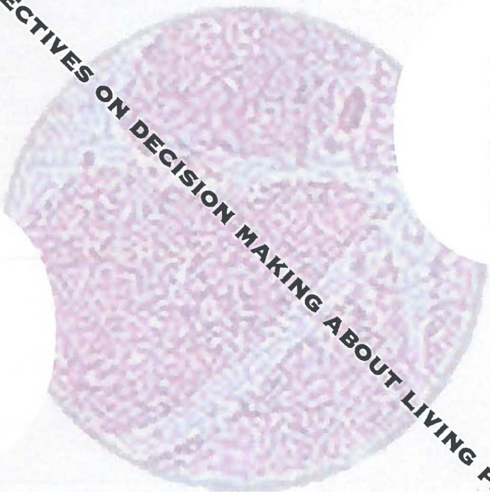
‘NOT A MATTER OF CHOICE’

ETHICAL PERSPECTIVES ON DECISION MAKING ABOUT LIVING PARENTAL LIVER DONATION

MARE KNIBBE



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STELLINGEN

Behorende bij het proefschrift

'Not a Matter of Choice.' Ethical Perspectives on Decision Making about Living Parental liver Donation — Mare Knibbe 6 mei 2006

1. De periode waarin ouders levende donor levertransplantatie voor hun kind overwegen is te kenschetsen als een overgangsperiode, waarin ze moeten leren leven met nieuwe onzekerheden en risico's. (dit proefschrift)

2. De aandacht van een ouder voor de risico's en voordelen van levende leverdonatie kan begrepen worden als onderdeel van de specifieke wijze waarop hij of zij hoopt op een goede uitkomst voor zijn of haar kind. (dit proefschrift)

3. Goede hoop kan omschreven worden als een evenwichtige investering van aandacht, inspanning, emoties en gedachten in een wenselijke en mogelijke toekomst. (dit proefschrift)

4. Autonomie en informed consent zijn niet de enige ingrediënten voor goede besluitvorming over levende donor levertransplantatie; goede hoop is ook van belang. (dit proefschrift)

5. Een moreel verplichtende relatie, niet de "inherent dwingende relatie" die Forsberg et al. beschrijven, vormt de achtergrond van de ervaring die veel ouders hebben dat levende leverdonatie voor hun kind "geen kwestie van kiezen" is. (dit proefschrift)

6. Om goede risicocommunicatie tussen ouders of ander familieleden te ondersteunen moeten professionals aandacht besteden aan gender gerelateerde rolpatronen in een familie. (dit proefschrift)

7. De invloed van professionals op de bereidheid van ouders om leverdonor te worden voor hun kind, is onvermijdelijk. Het is dus beter te streven naar goede invloed op de besluitvorming over donorschap dan te streven naar non-directieve voorlichting. (dit proefschrift)

8. "One's history as an agent is a web in which anything that is the product of the will is surrounded and held up and partly formed by things that are not [...]." (Bernard Williams 1981, Moral Luck)

9. "Dit is geen stelling," is een paradox.

10. Omdat werk dat geschreven is in vrije tijd vaak van betere kwaliteit is dan werk geschreven in kantooruren zouden onderzoekers meer vrije tijd moeten krijgen.

RIJKSUNIVERSITEIT GRONINGEN

'NOT A MATTER OF CHOICE'

ETHICAL PERSPECTIVES ON DECISION MAKING ABOUT LIVING PARENTAL LIVER DONATION

PROEFSCHRIFT

ter verkrijging van het doctoraat in de
Medische Wetenschappen
aan de Rijksuniversiteit Groningen
op gezag van de
Rector Magnificus, dr. F. Zwarts,
in het openbaar te verdedigen op
woensdag 6 mei 2009
om 13.15 uur

door

Mare Else Knibbe

geboren op 7 april 1978
te Riemst

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CONTENTS

GLOSSARY AND ABBREVIATIONS

DDLT
Deceased Donor Liver Transplantation

EEZ
Expertisecentrum Ethiek in de Zorg, Expert center for Ethics in Care

LRKT
Living Related Kidney Transplantation

LRLT
Living Related Liver Transplantation, in this thesis it refers to parent to child living donor liver transplantation

Domino Transplantation
If a post-mortem donor organ is transplanted to a patient whose primary disease allows the use of his/her therapeutically explanted organ for a consecutive second transplant, then this patient is called a domino donor. A domino donor can be considered a living donor if this is in accordance with current national laws on transplantation and/or guidelines. (Eurotransplant Manual)

A domino liver donation e.g. occurs in a patient who is suffering from a non-cirrhotic metabolic liver disorder, e.g. Familial Amyloid Polyneuropathy (FAP) or Oxalosis. This compromised liver can be used for a consecutive transplantation in a recipient who is chosen from the center's own waiting list. If no suitable recipient is available, then this organ is reported back to the ET duty desk for patient-specific allocation.

The genetic enzyme defect of the liver will only become clinically apparent in a second recipient long after the transplantation. Therefore, patients e.g. with a reduced life expectancy can be chosen as a recipient for such a liver, as the expected time until development of clinical signs resulting from the compromised liver organ might extend beyond the expected life expectancy of the recipient.

Extended criteria donors
The donor pool can be enlarged by accepting donors that do not meet the standard criteria for acceptance, e.g. donors with fatty livers.

Non-heart beating donors (NHB donors)

According to the Maastricht classification nonheartbeating donors can be grouped in five categories:

I Brought in dead
II Unsuccessful resuscitation
III Awaiting cardiac arrest
IV Cardiac arrest after brain-stem death
V Cardiac arrest in a hospital inpatient (new category, 2003)

Death in the setting of NHB III donation is based on the occurrence of irreversible circulatory arrest after ventilator switch-off. A subsequent period of at least 5 minutes is mandatory to ascertain brain death. During this 5-minute “no-touch” period, no preservation or procurement activities are allowed. This legal requirement follows the recommendations of the U.S. Institute of Medicine.

Opting in system for organ donation

People, who want to become donor upon death, have to register their will. This system is also referred to as an “informed consent system”.

Opting out system for organ donation

People are considered to be donor upon death unless they have registered their will not to be a donor. This system is also referred to as a “presumed consent” system.

Reduced size liver transplantation

In this procedure the liver volume of an adult donor-liver is reduced to a size that can be used for a pediatric recipient.

Size-matched donor liver

The liver-volume that a patient needs is dependent on the weight of the patient. Children therefore need a small liver graft for transplantation. Before the techniques of reduced size liver transplantation and split liver transplantation had been developed it was very difficult to get size-matched donor livers for children.

Split liver transplantation

The donor liver is split in two parts which are used to transplant two recipients.

CHAPTER 1

GENERAL INTRODUCTION

In 2004, when patients in the Netherlands with an indication for liver transplantation could first receive a partial liver graft from a living related donor, the transplant center in Groningen started a program for parent-to-child liver donation. In the first month of this program candidates for living donation were discussed in a weekly meeting with a selection of members of the liver transplant team: the physician who is responsible for the donor-screening; two pediatricians; and a surgeon. I also attended these meetings, since I participated in a research project into the ethical aspects of living related liver transplantation: LRLT*. In one of these meetings the physician told about the family of a boy who was waiting for a liver transplantation. This is the summary of the discussion in my notes:

> The father had wanted to donate. The mother had positioned herself as a stand-in, if the father turned out not to be a medically suitable donor, she would consider donation. Unfortunately, he had the wrong blood group, which made the situation very complex, as the physician indicates. But now things were going a bit too fast for her; now that his blood group appeared to be wrong, she was the only donor candidate left. The time pressure also increased because the boy's condition was rapidly deteriorating. Although the mother did not know yet how to think about donation, she enrolled in the donor screening, to find out if she was medically suitable. The physician and others present are hesitant to see her as a good donor-candidate; before accepting her they would want to have all the psychosocial aspects thoroughly examined. However, they decide to first examine the technical possibility. If there is a medico-technical contra-indication for her liver donation they don't have to turn this family inside out.

When this option of living liver donation was introduced, professionals and relatives around a patient faced new responsibilities. Parents of young patients or other relatives had to consider whether to donate or wait for a

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* See glossary & abbreviations for an overview of abbreviations and explanation of medical terms.

deceased donor liver graft, whether their family could cope with an extra patient, and if they were willing to accept the risk. Professionals also had to reconsider their responsibilities. Under which circumstances could they account for the involvement in risking the life and health of a healthy donor? How should they handle different views of colleagues on the subject? How could they inform and talk with parents or other relatives about the option of living donation without pressuring them? In the views that parents and professionals developed on such questions, understandings about professional and family relations formed an important background. The background of moral understandings about parenthood, about what it means to be a good doctor, about good patient-doctor relationships and the values involved surround the course of decisions about LRLT. This thesis aims to offer a reflective, critical, and normative analysis of these moral understandings.

AIMS AND QUESTIONS

The introduction of LRLT as an available form of transplantation involved changing understandings about relations in families of a patient, in the transplant team, and between professionals and family members. First, with the introduction of LRLT, professionals had to engage in new ways with the families of their patients. Second, professionals had to cooperate with each other in new ways. Furthermore, family relations often seemed to be challenged or confirmed in decision making about LRLT. The aim of this thesis is threefold: 1. To undertake a reflective analysis of moral understandings in decision making about LRLT. 2. To offer a critical reflection on the moral understandings that guide decision making and 3. To offer normative reflection on questions about good moral understandings. As will be explained more extensively below, these different forms of analysis and reflection are intertwined, and they are based on qualitative research.

To situate the Groningen LRLT program and this qualitative ethical research, I first have to delineate the backgrounds and contexts of the introduction of LRLT in this center. I will also situate my approach with the existing ways of framing ethical aspects of LRLT. Below I outline the backgrounds of LRLT as a medical practice and the ethical frameworks that have been developed for LRLT in order to position this research and indicate how it can add to the existing ethical perspectives. After a discussion of backgrounds, available ethical frames and remaining problems, I will come back to the aims and questions in this thesis.

BACKGROUNDS OF LRLT

International context

Though living related liver transplantation (LRLT) was new in the two centers offering this option in the Netherlands, in a global perspective LRLT was not so new. In other countries living donor liver transplantation had been practiced since 1988. For this form of liver transplantation, two surgical techniques that had been established before are used in combination. The donor operation is based on techniques used for many years in liver resections for tumors, and on techniques developed for reduced size and split-liver transplantation. Both techniques were also practiced for several years. The recipient operation also resembles the transplantation with a reduced size or split-liver graft; in which the volume of a deceased donor liver is adjusted to the weight of the recipient or is split for transplantation into two patients. The establishment of these techniques for adjusting liver volume made living donor liver transplantation possible (Broelsch et al. 1991).

Toward the end of the eighties, several liver transplant centers started exploring this option. In 1988 Silvano Raia performed the first living donor liver transplantation in Sao Paulo, Brazil. A 4-year-old patient with terminal liver failure received a partial liver graft from her mother. The child died six days after the transplantation, although the donor recovered from the operation (Raia et al. 1989). Shortly after this first attempt, a 17-month-old child from Japan was transplanted in Brisbane with a liver graft from the patient's mother. Both child and donor recovered (Strong et al. 1990). In Chicago the use of living donors had also been considered and discussed in the institutional review board since 1986. The intention to start an LRLT program in Chicago was announced with a discussion of ethical aspects in the *New England Journal of Medicine* (Singer et al. 1989). The Chicago protocol and its views on ethical aspects was a widely known and accepted example when other centers started LRLT programs in the nineties (Siegler & Lantos 1992; Singer et al. 1989; Broelsch et al. 1991).

In the nineties LRLT was offered by centers in Asia, Australia, Europe, and America. In Japan where, on widely held religious views, brain death criteria are not acceptable, it rapidly became a broadly practiced modality of liver transplantation. After the introduction of parent-to-child organ donation, Japanese centers also developed living liver donation for adult patients (Hashikura et al. 1994; Yamaoka et al. 1994). The donor risks in this procedure are higher compared to liver donation for pediatric recipients, because adult recipients need a higher volume liver graft for transplantation. Whereas children can be transplanted with the left or left lateral liver lobe; adult patients usually need the bigger right-lobe liver graft. Though parent-to-child liver donation found broad acceptance in many transplant centers worldwide, the offer of LRLT for adult patients remained more controversial, especially in countries with a system for postmortem donation (Cronin 2004). The Dutch Health Council also expressed greater reservations about LRLT for adult patients than for pediatric recipients (Gezondheidsraad 2003). Yet, increasing demand for donor livers and stagnating donation rates motivated many transplant centers to offer this option for adult patients with end-stage liver disease, or with irresectable malignant tumors of the liver.

When Groningen started with its LRLT program the risks of donor death after left lateral lobe donation were estimated to be between 0.1 and 0.2%. The incidence of major complications ranged from 5% to 20%, depending on a center's experience (Samstein & Emond 2001). For LRLT with adult recipients the estimated risks of donor death are 0.5 to 2%. Estimations of risks are difficult because there is no standardized assessment of donor morbidity. The reports of experiences in different centers are therefore difficult to compare. The statistics also show that donor morbidity has a strong correlation with center-experience (Broering 2007). Furthermore, there have been rumors about donor deaths that have not been officially reported (Strong 2000).

Local context of LRLT in Groningen

LRLT had been offered 'routinely' in many transplant centres world-wide since 1989, yet in 2004 it was adopted as a new procedure in Groningen. Though the novelty of LRLT was only local, its novelty was of central significance in the processes of decision making about LRLT. To a team that was never involved in living donor operations, the offer of living liver donation required a change of moral practice and perspectives. At first they had to find out if, how, and when involvement in harming a healthy donor was acceptable to them, and they had to deal with disagreements in the team on this topic. The experience with living donor liver transplantation elsewhere and the ethical views of peers were important context, but they did not take away the moral reservations that still existed in the team about LRLT.

These reservations have to be understood in the context of waiting list problems and measures that were taken or that failed to be taken to address these problems. In view of the maxim of *primum non nocere*, the use of healthy persons as a liver donor was only found acceptable when everything had been done to solve waiting list problems in other ways. The possible ways of expanding the donor pool, or of making optimal use of the existing donor pool, depended on steps taken in this transplant center, but also on other hospitals and national politics.

Although the Netherlands had postponed offering LRLT longer than many other countries, the Groningen liver transplant centre had participated in other international developments in the field of liver transplantation. The liver transplant program started in March 1979 with the transplantation of the first adult patient. On the basis of its subsequent successes, the Groningen center was invited with three other pioneering centers (Cambridge, Hannover, and Pittsburgh) to participate in the NIH Consensus Development Conference on liver transplantation in 1981 in Washington DC USA. During this meeting the consensus formed was that liver transplantation had exceeded its experimental phase and was an accepted treatment modality for patients with end stage liver diseases (National Institutes of Health Consensus Development 1983).

In 1982 the program was extended with a pediatric branch, and to date, the Groningen Pediatric liver transplant program is the only center in the Netherlands performing such operations. During the first years of this pediatric program, transplantations were performed exclusively with whole pediatric donor livers. However, such size-matched pediatric donor livers were scarce. This lead to an increase of waiting list mortality, especially in children. It also led to a deterioration of the condition of the children on the waiting list, leading to inferior outcomes. In a Dutch journal for healthcare two years before the LRLT program started, the chief surgeon sketched the history and context of the liver transplant program in Groningen to explain why they had to consider offering LRLT (Slooff 2001). In order to alleviate the shortage of grafts for children, the technique of reduced-size liver transplantation was adopted in 1984. Adult donor livers, often the very best ones, were reduced to left or left lateral grafts, discarding the right part of the liver. The use of this technique was a disadvantage for adult patients on the waiting list. Later, split-liver transplantation was introduced, a technique in which both parts of the donor liver were used; the left side for a child and the right side for an adult patient. The introduction of both techniques resulted in a decline of waiting list mortality for children. However the problem of organ shortage was never completely resolved. Expanding the donor pool remained an important challenge for this centre as well as for liver transplant programs in the rest of the world. Non heart beating donation was revitalized and domino transplantations were done, yet, to no major effects on the shortage of grafts. Looking at living donation therefore was a logical action. In Groningen, however, some team members were reluctant towards the development of living donation programs because it was felt that the potential of postmortem donation was not exploited fully (Kranenburg 1998). Some surgeons reasoned that before harming healthy persons with as risky an operation as living partial liver donation, all possible measures should be taken to fully exploit the existing postmortem donor pool.

In addition to the strategies for expanding the donor pool, another approach to waiting list problems, restricting indications for liver transplantation, was often discussed, but never adopted. In reaction to the death of two children who in the same month received a liver transplantation while in a very bad condition, the intensive care physician asked in the weekly team meeting if the transplant team should make a stricter selection of patients:

> 'Now patients only receive a liver transplant when they are in a very bad condition. Other patients patiently wait for their turn, which only comes after their condition has worsened as well. Of course the idea is that everybody should get a chance but now everybody is victimized by this policy, including us.'

The question arose whether the scarce resource of donor livers should be given to patients with poor chances of survival. If liver grafts were given only to patients in reasonable condition, with better chances of survival, those on the waiting list would get optimal survival benefit of the available liver grafts. In addition to this argument from utility, there was also political pressure to restrict indications for liver transplantation in order to get better results for the program. Such results were important for the public image of the program and for obtaining funds and skilled personnel. Nonetheless it was difficult to give such considerations a place in decision making about indication for transplantation. In a discussion that was organized around this topic one of the pediatricians explained; *'When holding a consultation with a patient, you can't have the interests of other patients in the back of your head.'* In the words of another pediatrician: *"should we have other statistical patients in the consult room, in addition to the concrete patient?"* Pediatricians felt bound by their responsibility to individual patients; they could not consider the interests of others in the treatment of this patient. In this meeting it was concluded that if considerations of maximizing utility were to play a role in the indications for liver transplantation, they would have to be enacted by some kind of external conscience, to retain clarity about responsibility to individual patients. Although doubts were expressed about patients with complex diseases and complications, the decision to deny liver transplantation to a patient was only taken if there were strict contra-indications for liver transplantation, as formulated in the literature. Not only was it difficult to decide on the team level that some patients would not get a chance of a life-saving treatment, to be effective such a restriction in indications for liver transplantation also required a change of policy on a national level.

Thus, among the different strategies to address and cope with waiting list problems, the option of restricting indications was not adopted. Another much-discussed nationwide strategy for expanding the donor pool was a change of the opting-in system for organ donation into an opting out system. In sum, the team itself had adopted a set of measures to expand the donor pool; however on a national level some potential ways of addressing waiting list problems were not realized.

The waiting list problems and the discussions about these problems formed the context in which LRLT was introduced. According to part of the team, waiting-list problems justified the offer of LRLT; however, some surgeons still questioned if the problems should be addressed with an offer of LRLT. They suggested using stricter criteria for indication and they argued that more political efforts should be made to change the opting-in system for post mortem organ donation, in order to increase national donation rates.*

Thus LRLT was introduced in spite of different views on the ethical acceptability of offering this procedure in this center.

Change

When the LRLT program started, the team had to find a way of dealing with such an innovation involving moral reservations. In a discussion of transplant medicine and therapeutic innovations in the eighties, the surgeon F.D. Moore stated that the ethics of therapeutic innovation depends on three conditions: 1) the strength of scientific background; 2) 'field-strength': the required experience and technical skills of a team performing a new procedure; and 3) the ethical climate in an institution (Moore 1988). In this transplant centre the first two conditions were not an issue: the required technical skills had been practiced before in partial liver transplantation and conventional liver resection. As for the third condition, the introduction of LRLT required changes in attitudes,

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* With the current Dutch Law for Organ donation (WOD) people have to take active steps to register their will to be donor upon death. Since many Dutch do not register their will, patient and medical organizations argue for an opting-out system; a system that is also known in Spain and Belgium; you are considered to be organ donor unless you have opted out.

relations, and moral views; it required an ethical climate that could go through these changes. This could involve many things like room for exchanging views, rearticulating professional roles and relations, mutual understanding and tolerance between different perspectives involved; and openness to revision of moral views. At the start of the LRLT program it was not clear how such a transition in ethical climate would go. The liver transplant team had to find a way to offer LRLT in the specific circumstances in this team, with its inherited moral views and its Dutch political and juridical context.

Because of moral reservations and the changes in ethical climate that introducing LRLT required, the Expert Center for Ethics in Care (EEZ) was involved in the first years of the LRLT program. Together with Els Maeckelberghe, a member of the EEZ (and my copromotor) we facilitated several discussions on ethical questions in the team, and my qualitative ethical research was conducted from within the EEZ. The research took a focus on the new forms of engagement between professionals and families that the introduction of LRLT brought about.

New forms of engagement

When LRLT was introduced (in spite of different interpretations of context and remaining moral reservations) the transplant team and the families of patients became engaged with each other in new ways. The institutions of healthcare and family have always interacted with a certain amount of friction, as Hilde and James Lindeman Nelson describe (Lindemann Nelson 1995). However, in the combination of pediatric medicine and living donation, doctors and nurses become even more intricately involved in family patterns. The willingness of the transplant team to undertake LRLT depended in part on the willingness of parents or other potential donors to donate. In the course of the explorations of this option, the motives for donation and the context in which they arose were examined and tested by professionals. Professionals from diverse disciplines, with different relations to donor, patient, and family, reviewed a donors' motives, attitudes, social network, and the families economic and employment situation. A very thorough donor screening, including medical and psychosocial aspects, was considered important; however, the motivational or attitudinal aspects in situations of parents with a very ill child were difficult to judge. The interactions and relations between parents, child, and professional caregivers had to be reinterpreted in the light of living donation; however, it was not always clear how to do this. It was not easy to tell if a potential donor really wanted to donate, or whether she simply could not refuse when the team offered this option.

In short, LRLT was introduced in spite of moral reservations, under pressure of scarcity of donor livers and in a liver transplant team with different views on how this shortage should be solved. This was the context in which professionals and parents had to find out if LRLT was a good and realistic option for their child. The interactions and relations around patient and potential donor were very important in the exploration of the option of living donation; however, they too were difficult to grasp and evaluate. Below I outline the existing ethical framework for LRLT. While this normative framework shaped moral understandings of professionals about LRLT, it does not support critical reflection on these understandings and their significance in LRLT-practice. It guides the application of generally accepted principles of medical ethics, without exploring their relation to other moral concerns that are not backed up by the principles of medical ethics.

BROADLY SHARED ETHICAL FRAMEWORKS OF PARENT-TO-CHILD LIVING RELATED LIVER TRANSPLANTATION

The most widely known and extensive discussion of ethical aspects of LRLT comes from ethicists and physicians involved in the LRLT program in Chicago (Broelsch et al. 1991; Siegler 1992; Siegler & Lantos 1992; Singer et al. 1989; Singer et al. 1990; Whitington et al. 1991; Whitington 1996). The terms in which they identify ethical aspects of this procedure, in particular concerns of nonmaleficence and autonomy, were also used by professionals in the transplant center I studied to express their reserves.

The views developed in Chicago can be summarized as a scheme of mutually related bioethical principles that should be balanced in specific relations and circumstances. I first summarize the principles and their relations very roughly and subsequently indicate how their application is discussed in the context of LRLT:

- *When donor-risks are very low and recipients have great potential benefit from living donor liver transplantation, the principle of 'do no harm' can be overruled by the principle of beneficence.*
- *The autonomy of a donor's decision to donate is a necessary but not sufficient condition for the ethical acceptability of LRLT.*
- *Donor autonomy should be constrained by the medical obligation to do no harm, which can only be overruled by considerations of beneficence.*

In the application of bioethical principles to LRLT, professional responsibilities in relation to patient, donor and family form an important context. To indicate how donor risks can be weighed against recipient benefits, Whitington states that ethical acceptability is not solely a matter of the quality of the individual doctor-patient relationship; medical professionals should consider their responsibility to the whole family (Whitington 1991). Health professionals have a responsibility for the welfare of a patient as well as a patient's family. LRLT is justified when the health benefit for a recipient is expected to be of psycho-social benefit for the whole family, including the donor. In reaction to this view, Spital stated that it is *only* the psycho-social donor-benefit that justifies LRLT. The psychosocial benefit that a donor has from the continued relation with a loved one should be the justification for accepting a living liver donor (Spital 2004).

Considerations of autonomy too take on greater complexity in the context of LRLT. The Chicago physicians Mark Siegler and John Lantos give their views on donor-autonomy and informed consent in reaction to a decision of the ethics-committee in Sao Paulo to accept an unrelated volunteer as a liver donor (Segre 1992; Siegler & Lantos 1992). In a Sao Paulo case, Silvano Raia et al. could not find a suitable donor in the family, so they accepted a healthy unrelated volunteer as a liver donor for a 19-month year old girl (Raia et al. 1989). The ethics committee had formed a positive opinion about this procedure, on the basis of considerations of autonomy (Segre 1992). They stated that the individual considering living donation should have the controlling decision. According to the committee, the views of third parties about the reasons for donation (gratitude, financial interests or strong family bonds) should be of secondary moral importance. Siegler and Lantos, however, write that the ethics committee had based their approval of the procedure on an 'extreme and inappropriate reliance on donor autonomy' (Siegler & Lantos 1992). Repeating their earlier argument, they stated that the central ethical question is whether the doctor is right to allow donation in light of the fact that there is no such thing as a right to donate (Singer et al. 1989). Doctors should balance donor risks and recipient benefits and they should only agree if the donor risks are extremely low when weighed against recipient benefits. Siegler and Lantos also disagree that motives for donation are irrelevant. As opposed to Segre et al., who claim that judgments of third parties about donor-motives have less relevance, the Chicago physicians recommend psychiatric or psychological evaluation of donors and their motives, to determine if an informed consent is truly voluntary.

According to Siegler and Lantos the potential for coercion should be a key element in the evaluation of informed consent. They distinguish three possible forms of coercion: First, a donor's feeling of guilt when faced with the possible death of the patient can be a form of internal psychological coercion, although these motives can often hardly be distinguished from laudable motivations such as love and loyalty. They consider such internal coercion acceptable because in their view, 'the need to balance selfishness and altruism is a universal feature of an individual's relationship with his or her family' (Siegler & Lantos 1992). A greater threat to a donor's autonomy is thought to come from a second possible source of pressures, namely family pressures or pressures from the transplant team. Transplant teams should try to minimize these external forms of coercion. Third, according to Siegler and Lantos, the legalization of financial incentives to donate could coerce people to become donor and ought to be opposed.

RELATIONS IN THE CHICAGO FRAMEWORK

Relations and interactions involved in LRLT are understood and placed in specific schemes in the above-described ethical framework. In this framework, the family relations around donor and recipient are a potential source of coercion as well as a motivating factor. Furthermore relations between donor and professionals are potentially coercive; however, these relations can also serve to protect donors from pressuring or coercive factors. Relations are thus captured in a scheme of factors that are either undermining or supportive of donor autonomy. In this scheme, it is difficult to examine the ambiguities surrounding questions about donor autonomy. Why, for example, is guilt placed on the coercive side of the spectrum in spite of its closeness to "laudable motives" for donation? And what is the relation between internal and external coercion?

Perhaps the so-called gift-exchange which has been employed since the 1970s is in a better position to grasp the complex relational webs and the ambiguities of freedom, generosity and obligation. Renée Fox and Judith Swazey, the most prominent proponents of this view, write that although giving and receiving have a "voluntary disguise," they are often binding (Fox & Swazey 1974). The mere existence of transplantation as a life-saving treatment puts people who are close to a transplant patient in the position to save someone by donating. The offer of LRLT to parents underscores the normative expectations toward parents that they make sacrifices for their children. In these positions donation can only be refused at high costs. When the opportunity for giving occurs, a refusal to give, receive or repay can generate open or hidden conflicts, feelings of guilt or of being rejected. On the other side, acceptance of this irreciprocable gift can also cause serious tensions. Nevertheless, many donors and recipients managed to transcend these potential tensions and conflicts. In this gift-exchange view the crucial question is not whether a decision is free; it is rather how to enter carefully into the exchange, through interpretation and mediation of the relations involved.

In most ethical discussions about LRLT, there is no mention of gift exchange, its relational webs and social dynamics. In the above-outlined ethical reflections on LRLT relations are mainly treated as a given context of application, not something needing interpretation and mediation. Yet the ethical principles of nonmaleficence, beneficence and respect for autonomy are not applied to "bare facts" of the reality of doctors, potential donors and families, they are applied to narratively constructed understandings about the practice of LRLT and its participants. (Chambers 1999) Moral understandings about LRLT are made up of intertwined narratives of identities (of parenthood or what it means to be a doctor), relations (family relations or doctor patient relations) and values (autonomy, hope, or trust). This thesis examines the moral understandings about LRLT.

Autonomy and informed consent about liver donation remain complex issues because they seem to have a difficult fit with the relational context. There is a fissure between the informed consent norms for LRLT and experiences in practice. Several empirical studies about donor decision making indicate that donation is not seen as a matter of choice, and that many kidney and liver donors hardly think about the risk information that was given (Fellner & Marshall 1968; Fellner & Marshall 1970; Franklin & Crombie 2003; Crowly-Matoka 2004; Forsberg et al. 2004). Some ethicists try to bridge this gap by examining and reformulating conceptions of agency that are implicit in common models of autonomy and informed and voluntary consent (Crouch & Elliot 1999; Spital 2005). Crouch and Elliot propose a relational notion of moral agency to come to a more realistic understanding of donor autonomy and informed consent. They point out that the idea that intimate family relations and conscience can be coercive is inspired by an over-individualistic notion of moral agency. They give a general revaluation of relations in donor autonomy; however, they do not examine the specific character of family or transplant relations to understand which kind of relations are supportive of autonomous agency and which aren't.

THEORETICAL APPROACH

In this sketch of the introduction of LRLT in the international and the Dutch context, I identified two problems. The first is that the move to LRLT required a transition in ethical climate that could enable processes of collaborative decision making with diverging and sometimes conflicting moral perspectives. The second is that it was difficult to understand and evaluate the morally relevant features of the new kind of relations and involvement between family members and professionals that the offer of LRLT brings about.

The answer to the problem of the team – an ethical climate that enables collaborative decision making – is not formed in this thesis but emerged in practice. To assist the team in addressing this problem, several discussion meetings were organized and facilitated together with my co-promoter Els Maeckelberghe. This problem and the way it was addressed in the team formed the context of my research. It is also described in chapter two.

The aim of this thesis is to offer a reflective, critical, and normative analysis of the moral understandings that surround the practice of LRLT. These moral understandings present themselves as narrative understandings. This view on morality and narratively constructed moral understandings is very much inspired by the theoretical views of Margaret Urban Walker. In her book *Moral Understandings* Margaret Walker presents a view on morality as a 'socially embodied medium of mutual understanding and negotiation between people of their responsibility for things open to human care and response' (M.U.Walker 1998). In that sense, the practice of LRLT itself should be seen as a moral practice. In LRLT as a socially embedded moral practice, people show what they value by making and holding each other responsible for certain things. Interactions, in which we make and hold each other or ourselves responsible, are guided by implicit or explicit moral, narratively constructed, understandings about who we and others are, about our relations, and values. To function, for example, as the parent of a patient in a transplant center, one has to have some understandings about one's own roles and those of others involved. Ideally these understandings are shared and endorsed by those involved in collaboratively formed patient care; however different positions and perspectives in a practice also produce divergent or even conflicting views of what happens in this practice and why it happens.

To avoid confusion about notions of responsibility, I do have to specify how I followed the processes in which responsibilities with regard to LRLT crystallized. In philosophy, the concept of responsibility is often understood in relation to metaphysical questions about freedom and determinism, or in reflections on the human condition or moral agency. In this thesis, by contrast, responsibilities are seen as the outcome of collaborative and interpretive processes.

Starting from a specific understanding of their commitments and concerns parents and professionals explore whether, given the circumstances, possible developments, and opportunities, LRLT is part of their responsibility. Parents and professionals have specific historically developed but not always clearly outlined areas of responsibility. Parents are commonly expected to educate and care for their children, but this implies a number of different practices; making a safe home, preparing food, giving emotional support, teaching discipline or tolerance, seeking medical support etc. Pediatricians, surgeons, and other supporting professionals are expected to offer the best available treatments for children with a chronic or life-threatening disease, and to support the family in caring for these children.

In the processes I followed, parents and professionals tried to find out whether living liver donation, or operating living liver donors fell in these areas of responsibility or whether they were in conflict with them. In my research I was not so much interested in the outcome of these processes as in the processes themselves; how circumstances and people's place in them were understood or changed; how parents and professionals came to their understandings of these circumstances, how they conceived of and invited possible and desirable outcomes. These processes had interpretive and collaborative dimensions. The interactions and division of labor between parents and professionals in the care for their child can be seen as a collaborative dimension of these processes. The interpretive processes, in which the collaborations were negotiated, were steered by narratives about parenthood, doctors, relationships, and values like autonomy, trust, or hope.

Having defined morality as a family of practices in which people hold them selves and each other responsible for certain things, Walker distinguishes three tasks of ethics and moral philosophy: reflective analysis, critical reflection and fully normative reflection. Reflective analysis aims at mapping what people do and how they understand what they are doing, in terms of their identity, relations and values. Critical reflection takes a step further, it asks to what extend the understandings of different parties about interactions are shared, if people really understand what is going on or whether their perspective is based on deception, or confusion. Critical reflection also aims at examining the authority of different values, like autonomy or considerations about parent-child relations. Do they hold up to critical examination? Reflective analysis and critical reflection in this thesis are based on a qualitative empirical study, the methods of which will be described below. A third level of reflection distinguished by Walker is fully normative reflection. Normative reflection aims to find out whether the moral understandings in a practice are really good, compared to other understandings one can imagine. Below I outline the design of the qualitative study, subsequently I'll indicate how different levels of analysis and reflection were used in this thesis.

METHODS

To give the interpersonal aspects of LRLT practices a central place in the study-design, respondents were asked to participate not individually but together. Parents who had been donors or potential donors were asked to participate together. In addition, observations at team meetings provided the opportunity to follow what happened among professionals involved, while observations in the outpatient pediatric clinic followed interactions among parents, children, and professionals.

Interviews

At a minimum of four months after the transplantation of their child, parents who had been screened for liver donation and their partners were asked whether they were interested in participating in this study. Twelve families were included, involving 22 parents, 2 uncles, and one aunt opting for donation. In four children LRLT was performed and a further eight children were transplanted with a deceased donor liver (DDLT). Two families had been referred to Hamburg for LRLT after an initial screening, because they came to the liver transplant center in Groningen before the LRLT program had started.

To explore the significance of living related donation in families, a rather open, semi-structured interview style was adopted.* Respondents were asked to tell in their own words about the time leading up to transplantation, and their thoughts, feelings, attitudes, and decisions about living donation. The structure was given by the introduction and a few interview topics that had to be covered: experiences of hospital encounters; dealing with different sources of information; decision making about LRLT; risk perceptions; (changing) perceptions of the patient's condition; (changing) attitudes toward living donation;

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* Semi-structured interviews can be any form of interview between completely open-ended and completely structured. My interviews were closer to the open-ended side of the spectrum.

and responding to others' views about donation. The introduction to the interviews was important to create an understanding of the social setting of the interview. As interviewer, I emphasized to respondents (mostly two per interview) that I wanted to learn from their story and perspectives because LRLT was new in this country, and I told them that their names would not appear in publications about this research. Furthermore, in the interviews with parents of patients I made it clear that although the study was about living donation, I wanted to hear the whole story from the moment that parents noticed their child was ill. The idea was that this would give parents more space to situate the topic of living donation in a context as they experienced it. During the interview most questions were oriented at understanding the internal (in-)coherences in stories. With these questions I aimed to stimulate respondents to give and clarify their account in their own terms. At some moments I introduced concerns of the transplant team about living donation and informed consent to get a better picture of how respondents related to these concerns.

The interviews were designed to generate narrative material that could be used to form a better understanding of the moral practice of LRLT. By means of the combined-interview format as well as the topics I invited respondents to tell about their experiences in relation to others. Asking direct questions about relations seemed out of place in an interview in which threats to their child and the efforts to avert these threats were vividly recalled. However, the topics in the interview scheme mentioned above encouraged parents to situate their story in different relationships. When recalling conversations about the disease of their child or about living donation parents explained their attitudes, thoughts, and feelings in relation to others involved.

The interview material gathered was constructed in the small social setting of parents (donors or donor candidates and partners) and interviewer. The color of what was told should be interpreted in this social setting; the interviews did not yield highly personal but interpersonal stories. Since the character of the social setting in different interviews varied, the narrative forms used by respondents were also very different. Depending on their understanding about me and my research some respondents took on the role of co-researchers; examining their own experiences for me, others tried rather to convince me, and through me a broader public, of the complexity of LRLT or of the value that LRLT had for them. Stories also had different 'levels of organization'. Some respondents had clearly spoken or written about their experiences before: their accounts were more polished and had probably been formed in relation with different audiences. For others it was the first time they sat down to recall events and talk about the time before transplantation. Their stories were more structured by the memories evoked in the course of the interview. This diversity in interviews would pose a problem if the aim of the study were to get a general picture of experiences, motives, or relations as they really were. However, as I will explain more extensively in the section on reflective analysis, the interviews were designed to explore different ways of interpreting and framing participants' reflections on what happens in LRLT.

The fact that interviews were held retrospectively makes them liable to a specific bias. Respondents might uphold a certain positive or critical image of the decision-making process. The reason to make use of retrospective interviews was primarily a moral one; we did not want the interviews to interfere in the decision-making process. In order to enhance a careful interpretation of interview material, interviews were designed to come to replication and triangulation. Triangulation usually indicates the use of different procedures of data collection (like interviews and observations) to get a picture of a specific topic. However triangulation can also be used in the scope of one interview, if the interviewer chooses different entries to introduce a subject matter (Wester & Peters 2004). For example: I asked explicit questions about attitudes toward donation in different stages of decision-making, but I also asked questions about conversations with professionals and family in which attitudes were more implicitly pictured. This form of triangulation made it possible to take biases into account in the interpretation of material.

Observations

Observations were used in addition to interviews. Observations were done for a period of three months in the pediatric outpatient clinic and for a longer period of one and a half years in the weekly meetings of the transplant team. In the first months there was a weekly LRLT meeting with a small group of two pediatricians, one surgeon and the gastroenterologist who did the donor screening. After these first months it was decided that LRLT cases would be discussed in the general team meetings.

In the outpatient clinic I followed how patients and parents were introduced to the practice of liver transplantation, and to the working of the waiting list. Here I also observed how nurses, pediatricians, and parents fine-tuned their information, questions, attitudes, and resolves to each other. Furthermore I saw how the topic of living donation was carefully introduced, suspended, and reintroduced in conversations. Although my presence may have had influence, the social setting of the clinical encounter was not significantly changed by the presence of observers, since there are often observers, students, and junior doctors in a university hospital.

With observations in the weekly team meeting I tried to gain insight in the team perspectives on LRLT and the context of scarcity of donor livers in which it was introduced. In these meetings I followed a number of discussions about indications for liver transplantation and how to deal with scarcity of organs. Because the surgeons often had to operate on patients in an advanced stage of their disease, the question repeatedly arose whether they should be more critical about which patients should get a chance for transplantation. Given this lively culture of discussion it was remarkable that there was very little said about cases of living donation. When cases of LRLT were introduced, information about the progress of the screening was given, but there was hardly any conversation about it. Perhaps discussions on this topic were avoided, because it was a charged topic to some, not something that could be handled in a weekly meeting. There had been more discussion in the small LRLT meetings in the first months of the program, and in other occasional meetings I attended or conversations outside the weekly team meetings, perspectives on LRLT were expressed. Team perspectives were visible between the lines of observations and interviews. To obtain more explicitly voiced views on the subject, a focus meeting was organized with Marian Verkerk, the supervisor of the project (Kitzinger 1994). Focus meetings can take many different forms and can be used for diverse purposes in a research project as a whole. In general they can be characterized as a kind of group interview, in which a multiplicity of views, attitudes, and feelings are elicited in a group context. In this research the focus meeting was used as a form of triangulation. In the meeting the team was asked to react on the picture of their approach to LRLT, a picture we had developed on the basis of interviews and observations.

Analysis

The analytic process consisted in ordering and organizing material in such a way as to make it speak about the research questions. This process started with the interview structure, the actual interview, and the focus of the observations at team meetings. Interviews were transcribed and observations were written down immediately after the observed occasions. Content analysis was used to identify recurring themes. After this first processing of material, further ordering of the material did not follow a fixed set of procedures. This does not mean that the material can be made to say anything; the process of ordering requires attending to the interpretive structures and organization that are already there. Such structures resist certain forms of ordering while complying more smoothly within others. In the interviews, parents create order in the things that happened. Their own ways of ordering things were partly build up around the organization and understandings about LRLT in the hospital. Thus analysis involved identifying different layers of interpretation and organization in the collected material.

Ideally one would use multiple coding to minimize bias. Because this requires a lot of time, I did the coding and interpreting myself. However, in the process checks were build in for input and questions form others. The first content-analysis of interviews was discussed extensively with my promoter and copromotor. Furthermore the focus-meeting with the transplant team served not only as a form of triangulation (collecting different data about and perspectives on the same subject) it was also a member-check, did team-members recognize the analyses we presented of there approach to LRLT. The participants in the focus meeting indicated they recognized the description that was given of the teams approach to LRLT.

Reflective analysis

The analysis of interpretive structures in the stories of parents or in team-discussions also involved what Walker terms as 'reflective analysis'. In reflective analysis the understandings about LRLT were mapped against a background of intertwined narratives of identity, relations, and values. Different participants in the LRLT practice had their own narratively constructed moral understandings about living liver donation. For example some parents indicated that as parent they should become liver donor because they thought that as a good parent one should always be ready to do anything necessary and possible for the life of their child, without reservations or even in spite of other compelling considerations. The moral understandings of doctors about LRLT were formed in the context of specific disciplines: ideas about good pediatricians, good donor advocates or good surgeons differently shaped attitudes toward LRLT. Professional concerns about donor autonomy also surrounded decision making about LRLT. Medical professionals of different disciplines were worried about the consequences of the above mentioned convictions about good parenthood that seemed to make it difficult for parents to come to free decisions. As doctors they wanted to help parents help their child but they were also concerned about doing harm, and they valued donor-autonomy. Although they presented the option to parents, they avoided picturing LRLT as clearly falling in the sphere of parental responsibilities.

Critical reflection

Critical reflection aims at examining the authority of different understandings about living donation. Are understandings about LRLT shared? Do common ways of framing interactions deserve their authority? Which perspectives are endorsed by dominant understandings about donation and which are made incomprehensible or less effective? Where reflective analysis explores how participants in the practice of LRLT make sense of their responsibilities; critical reflection will examine if moral understandings really support an adequate understanding of what people do in this practice. For example, dominant interpretations about decision making, framed by informed consent, are confronted with parents' interpretations about the hospital encounters in the time leading up to liver transplantation. Do informed consent models help doctors to make sense of attitudes toward living donation and the relations involved, or are they rather confusing or obscuring the significance of attitudes and relations?

In critical reflection, a resistance to one of my structuring interview topics offered general guidance in my attention and questions. One of the things I asked about was decision making. This made some parents respond that they had little to tell me: there had been little to decide about. In many interviews, points or moments of decision making cannot be indicated. Decisions about whether or not a (probably) suitable donor would donate often seem to be something that *happens* in the course of ongoing adjustment to the progressing disease of the child. The time leading up to transplantation with a living donor or deceased donor liver graft can be characterized as a process of considering and fine-tuning responsibilities. Whereas decisions are often thought to be taken deliberately, by individuals, at fixed, organized moments in time, like choices (Mol 1997; Mol 1996), this characterization emphasizes that courses of transplantation often receive direction in constant adjustment to new situations and in mutual attunement between parents and professionals. The widespread understanding about medical decision making as an issue confined to informed choice is inadequate and confusing. Informed consent is part of the process, but decision making is also guided by other less articulate understandings of relations and values. In critical reflection I draw attention to these less articulate understandings about donor decision making, guided by values like hope or trust or by different views on autonomy or voluntary consent. Furthermore I develop some of the less articulate understandings in LRLT practice. Hope, for example was an important but not very articulate theme in the stories of parents. By developing a better understanding of hope in decision making I also propose a better moral understanding of interactions in LRLT-practice, an understanding that can complement the more common moral understandings that are mediated by ideals of free choice.

Normative reflection

Normative reflection according to Walker asks if the moral understandings in a practice are really good or better than others that might be imagined. I offer normative reflection on good hope, and on the question how good risk-communication about living liver donation can be better understood. In relation to questions about the collaborative character of team decision making, voluntary consent, and trust, this thesis offers some groundwork for normative reflection. I point out in which direction these themes need further development and propose orienting questions in order to come to better moral understandings about LRLT.

These different levels of analysis and reflection were used alternately in the course of my research. In the following chapters the different levels of reflection are not always clearly distinct. Chapters two and three are mainly the offspring of reflective analysis and critical reflection. The chapters four till seven present more normative reflection.

OUTLINE OF THE THESIS

Chapters two and three offer reflective analysis and critical reflection on different contexts and processes in which responsibilities with regard to LRLT crystallize. Chapter two explores the moral understandings about living liver donation in the liver transplant team. It describes the practical answer formed by the team to the problem posed by the introduction of LRLT; that is an approach to LRLT that enables collaborative decision making in spite of conflicting moral perspectives in the team. The team's approach also formed a practical answer to moral questions about the freedom of parents to decide about liver donation. This approach to LRLT shaped the ways parents were introduced to the option of LRLT. Chapter three explores how moral understandings of parents about LRLT are shaped in interactions with the team. This chapter is an (early) explorative paper that identifies themes that need further development in order to understand the dual roles of parents in LRLT. The themes that are proposed are: the process character of decision making, trust between parents and professionals, and emotions about living liver donation. Chapter four places LRLT in another context: that of the parents of children with liver failure. In their stories, hope is a central theme. Interviews testify to diverse hoping patterns in which parents have different styles of orienting themselves towards the future and involving professionals in their hopes. They depend on professionals in diverse ways, each according to his or her own “economy of hope”, and create different conditions for agency in medical decision making. Thoughts and attitudes towards the option of LRLT are embedded in these economies of hope. Responsibilities with regard to LRLT shape up in these mutually interfering processes of team and parents. This chapter concludes with a normative reflection on good hope.

Chapters five and six deal in different ways with the engagements between the transplant team and families, while taking two different focal points, voluntary consent and donor risk communication. The interactions between potential donors and professionals are officially regulated by these informed consent requirements. However, the informed consent norms and goals are difficult to interpret when medical decisions are also family decisions. In diverse studies, donors reported that donation was not a matter of choice; that they donated in spite of great fears; or that they had not considered the donor risks in their decision to donate. These experiences and attitudes raise questions about informed and voluntary consent. These chapters (five and six) propose ways of contemplating such attitudes and experiences in the complex collaborative settings of family and team. Chapter seven offers a general summary and conclusions. At the end of this thesis English and Dutch summaries are provided.

For reasons of anonymity the names of respondents have been changed into fictitious names.

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CHAPTER 2

INTRODUCING PARENT TO CHILD LIVING LIVER DONATION; DOCTORS' CONCERNS ABOUT RISKS AND PRESSURES

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ABSTRACT

This paper explores how processes of considering living parental liver donation are structured by the Groningen liver transplant team in the first years of its LRLT program. LRLT was introduced in this center in spite of moral reservations about this procedure that still existed in the team. Team members held different views on the acceptability of donor-risks and on the political context in which LRLT was introduced. In interactions with parents, pediatricians propose specific understandings about LRLT as a safety-net. With this understanding about LRLT they created room for synchronization and collaborative decision making in spite of different views.

Submitted

INTRODUCTION

The liver transplant team in Groningen started a program for LRLT in 2004. The introduction of the program was paralleled by research into different aspects of this procedure. The ethical aspects were studied within a qualitative-ethical research. Descriptions we gave on the basis of qualitative research of the explorative character of interactions in this starting practice elicited many critiques, both from inside the team, and from outsiders (anonymous reviewers, or a public of ethicists in a conference). Team members themselves were critical about the lack of clear decision making procedures. Ethicists sometimes remarked that the team had misunderstood the principle of primum non nocere or that there should be more clarity about what risks parents ought to take on behalf of their child. In this paper we want to describe and defend the approach that was taken to LRLT in the first years of the program. Even though there are good reasons for criticism, the approach did form a practical answer to two central moral concerns about LRLT.

One of the concerns about LRLT is that the offer can put parents in a difficult position. As several studies have pointed out; organ donation for a child or even another family member is rarely seen as a matter of choice. (Forsberg et al. 2004; Knibbe et al. 2007). Most parents will feel that a good parent cannot refuse to become a donor. In some reactions bioethicists stated that we should maybe consider that the offer of LRLT involves an appropriate form of moral pressure on parents. According to these bioethicists we should therefore try to answer the more general question what risks a parent can be expected to take for a child. We think however that there is no general answer to this question, it should rather be considered in concrete cases, with potential donors and other caregivers involved. When a child becomes critically ill and in need of liver transplantation, its parents and other caregivers must redefine their responsibilities. Parents must figure out whether they should donate or wait for a postmortem donor graft, and whether the family is in a position to cope with an extra patient, namely the donor. These processes of considering donation are structured by the parents' encounters with members of the transplant team. We argue that with its approach, the transplant team created time and space for reflection, even if this time and space was difficult to find. Thus the team offers an example of how decision-making can be structured when decisions are not seen as choices.

Another concern about LRLT is the fact that a healthy person is subjected to a major and risky operation. The usual justifications for overriding the principle of primum non nocere do not work here; the operation is not for the health-benefit of the donor. This makes it more difficult for surgeons to account for their involvement in harming the donor. Again, one could postulate a general principle that could account for all cases in which harm may be done to a parent on behalf of a child. Such general views on the guiding principles were developed in the liver transplant center of Chicago. The Chicago group of Siegler and Broelsch has served as a worldwide accepted example with regard to medical as well as ethical aspects*. Nonetheless some of the medical professionals that would be involved in the start of a program for LRLT were not convinced that it was acceptable to harm a healthy donor**. Though many arguments and examples have been given to support the acceptability of LRLT as well as arguments against offering LRLT in the Dutch context, it seems that responsibility for the harm and risks could not be taken on the basis of arguments and deliberative processes alone. The locally innovative character appeared to have a central moral significance in the modus operandi of the team. In these first years they had to find out if, how, and when involvement in harming a healthy donor could be acceptable, and they had to deal with disagreements on this topic. In a discussion of transplant medicine

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* When the feasibility of living liver donation had been established in 1989, the transplant-team in Chicago did a clinical trial, before and during which close attention was given to ethical aspects as well (Singer et al. 1989; Broelsch et al. 1991; Siegler and Lantos 1992). In the years after the Chicago-protocol was developed experiences in different centers have improved operation-procedures; reducing the risks of the procedure for donor as well as recipient. Other centers have thus provided important landmarks, experiences, viewpoints and guidelines with regard to LRLT. These experiences were reason for the Dutch Health Council to conclude that it was acceptable to start offering LRLT in the Netherlands (Gezondheidsraad 2003).

** The practice of harming a healthy person who wants to donate an organ was and is widespread and considered acceptable in kidney transplant centers in the Netherlands. However, to this team it was new, and liver donation seemed incomparable to kidney-donation mainly because of differences in donor-risk. The liver transplant team did not perform kidney transplantations and was therefore not used to operating living donors, kidney or liver.

and therapeutic innovations in the eighties, the surgeon F.D. Moore stated that the ethics of therapeutic innovation depends on three conditions: (1) the strength of scientific background; (2) “field-strength” – the experience and technical skills of a team required for performing a new procedure; and (3) the ethical climate in an institution (Moore 1988). We focus on the last condition, as the first two were not at issue: the required technical skills had been practiced before in split-liver transplantation and partial liver resection. As for the third condition, Moore warns especially against ulterior motives for innovation, such as reputation and capital gain. However, innovative procedures can demand more of an “ethical climate” than the absence of hidden agendas. They require changes in attitudes, relations, or moral views. These alterations in the local moral landscape of the liver transplant center are also affected by national politics and legislation or lack thereof. The team’s approach is only fully morally intelligible within these broader contexts, as we shall explain.

We take a view on accountability for harm and risks that involves more than deliberative processes; it does not only involve reference to shared principles or norms; it also depends on collaboratively formed interpretations of concrete shared experiences and relations. We argue that in the first years of the LRLT program in Groningen experiences and relations were carefully formed, in order to explore moral views on living donation and possible changes of moral perspectives from within very specific situations.

The theoretical background of this paper is formed by a practice-driven naturalized approach to bioethics. Because LRLT is a social practice the moral responsibilities of the parents, the treatment team, and other involved parties must be articulated and negotiated within the context of the specific culture in which it takes place (Walker 1998). In our observations about how these responsibilities crystallize in the local moral landscapes of a Dutch transplant center; aspects of LRLT-practices that may be taken very much for granted elsewhere take on a different meaning.

This paper takes a focus on one transplant team and its political context. Nevertheless, this focus on the local can be of interest in international discussions to grasp something of the way in which broadly shared ethical precepts and concerns can gain significance in the context of locally shared understandings, assumptions, sensitivities and circumstances. Other centers in other countries have inherited their own moral understandings and sensitivities; however concerns about donor-autonomy, maximizing outcomes, and handling risks in a responsible manner are common concerns in liver transplant centers. The approach to LRLT that the team took in the first years of its program, offers an interesting way of addressing concerns about donor-autonomy, an issue that has kept drawing attention of doctors, ethicists and social researchers worldwide. As has been observed many times; an offer of the option of living donation, kidney or liver, can bring potential donors in a difficult position, in which it is hard to refuse donating. With its approach to the subject of LRLT the team had specific ways of reducing pressures on parents to donate.

This study was approved by an accredited Medical Review Ethics Committee (aMREC).

METHODS

Subjects

Observations and interviews were part of a research project entitled *Living Related Donation, a Qualitative Ethical Study*, which was carried out at the University Medical Center Groningen at the start of a Living Related Liver Transplantation program. Parents who came to the liver transplant center to have their children screened for liver transplantation were informed about all their options. Subsequently the child was screened and put on the national waiting list for a post-mortem donor liver. Parents who underwent a donor screening were asked, along with their partners, whether they were interested in participating in this study after their child had been transplanted. Twenty two parents, 2 donor (candidate) uncles and one aunt of 12 families were included. In four of the twelve families LRLT was performed. The children in eight families were transplanted with a deceased donor liver (DDLT). The inclusion in the study of families whose experiences went both ways kept the focus on the process of decision making. Central to this study is not the experience of donating but the decision making processes that took place beforehand.

Other subjects under investigation were professionals of different disciplines in the liver transplantation team. They were not asked to participate individually; rather as our aim was to get a view of the collaborative processes of decision-making, we observed the collective team discussions.

Study Design

Semi-structured interviews were done with parents after the liver transplantation of their child (LRLT or DDLT) (Bernhard 1995). Respondents were asked to tell in their own words about their thoughts and experiences, starting from the moment they noticed that their child was ill. The advantage of open or semi-structured interviews is that respondents, not the researchers, indicate what is relevant in their story and in what terms it should be told. To enable comparisons among the stories of parents, the interviewer used a list of topics. The topics covered were: experience of encounters in the hospital with different professionals or other patients and their parents; dealing with different sources of information; perceptions of risk; perceptions of the child's condition; (changing) attitudes toward living donation; and dealing with views of others about donation.

In order to explore the perspectives of professionals in the transplant team (the other subjects under investigation), we attended the weekly team-meetings (Marshall and Rossman 1989). Further observations were done in the outpatient pediatric clinic to explore the ways children and their parents were introduced into this medical practice. Finally a focus meeting was organized in which the team was asked to comment on our findings concerning how the risks and benefits of LRLT were handled and communicated.

Data analysis and theoretical background

Interviews were recorded and transcribed, and observations were written down immediately after the occasion at which they were gathered. Content analysis was used to identify recurrent themes (Bernard 1995). Further analysis of themes was guided by the research focus on the processes in which responsibilities of parents and professionals to the child and family crystallized. For this paper we examine one of the structuring contexts of these processes: the attitudes and decisions of the transplant team. Without careful attention to what the team was doing, the parental processes of reflection cannot be fully explained. Qualitative research methods yield strong internal validity; they allow for variations in different general and local characteristics of organ transplantation practices that, together, shape processes of assigning, deflecting, and taking responsibility. The external validity; the degree to which results apply to parental liver donation in other centers, can be traced with comparative analysis of similarities and differences between those centers and the one in this study (Marshall & Rossman 1989). Conclusions of a study like this one cannot be generally applied; however, they can raise questions not only about how widely shared certain moral understandings actually are, but also *which* understandings are driving the assignment of responsibilities.

Managing Pressures

The risks to the health and life of a healthy person involved in living liver donation have long been reason for the transplant team in Groningen to refrain from offering this option and invest in other ways of tackling wait-list problems. Part of the team had been in favor of offering living donation for some time; however, some of the surgeons had more reservations about living donation. *'We prefer DDLTx and we are very conscientious about that, we first try other options before agreeing with LRLT.'* To address wait-list problems, ways of expanding the donor pool without resorting to living donors had been tried first; several publicity campaigns and political discussions about how best to increase donor registration took place. In addition, to provide organs more suitable for children, split-liver transplantation and reduced-size liver transplantation were offered. In 2003, however, the Health Council observed that it was acceptable to offer LRLT for children in the Netherlands, taking into consideration the ample experience with LRLT in children in different centers worldwide and the better chances of survival for children on the liver transplant waiting list when LRLT is offered alongside DDLT (Gezondheidsraad 2003). Groningen is the only Dutch liver transplant center transplanting children, so the team in Groningen was the only one in the position to put this into practice and offer LRLT for children. It was under these pressing circumstances that the team started offering LRLT, in spite of the moral concerns of part of the team about subjecting healthy individuals to a major operation. Under pressure of wait-list problems, peers (who offered LRLT routinely in other countries), and parents who wanted to pursue this option, the team started offering LRLT. *'Since we were the only center in the country that could offer LRLT for children, we had to start, partly under external pressure. It did not come completely from inside.'*

In the first years of its LRLT program the team approached the subject of living donation very carefully. Guided by the maxim of *primum non nocere,* part of the team retained its reservations about the moral acceptability of operating on living donors. One part of the surgical team in particular viewed this maxim as having strong normative force. As the chief surgeon explained: *'We have a license to kill. Every surgeon has to live with his own graveyard of patients who died as a result of his actions.'* When the patient is actually a healthy person, it is even more difficult to live with involvement in harm and to account for risking life and health. Surgeons' concerns about the risks involved in living donation induced them to adopt a cautious approach to LRLT in the first years of the program.

The broader cultural and political landscape, in which this transplant team operates, sheds light on the hesitations of these surgeons about a procedure that is considered acceptable in many other transplant centers worldwide. In the Netherlands, the organ donation system works on an opt-in basis: Dutch people must take active steps if they want their organs to be transplanted after they have died. By contrast, in Spain, for example, organ donation works on an opt-out basis: the rule is that when one no longer needs one's organs, one has a responsibility to give them to others that can be deflected only by taking active steps to opt out of the system. Because in the Netherlands, the donation rate is one of the lowest in Europe, professionals felt that first a major effort should be made to increase national donation rates, and only then embark on an LRLT program. A backdrop of surgeons' thoughts about LRLT is thus formed by the attitudes of Dutch citizens, many of which do not decide or talk about organ donation after death, combined with the political opt-in approach to organ donation.

Though part of the team had reservations about LRLT, other team members saw more of the benefits of LRLT; when LRLT was of potential benefit to child and family it seemed a good treatment option to them. How were these different views about LRLT handled by team members in the collaborative processes of consultation and treatment decisions? From observations in weekly team meetings, outpatient clinic, and parents' reports, we can infer that in practice, the more conservative attitude was adopted by others in the team as well, in spite of the difference in views. In the first years of its LRLT program, the team was more inclined to offer LRLT as a backup option, treating it neither as preferable to waiting for a liver graft from a deceased donor, nor as a way to extend the donor pool. In the donor screening process attention was paid not only to medical risks but also psychosocial and financial risks to donor and family, as a study of the legal framework surrounding living donation had exposed several serious gaps in healthcare legislation and in donors' insurance coverage (Hubben 2005), which could result in considerable financial risk for some donors. The legal setting was thus another reason for the team to offer LRLT with caution. In the consultation-process, the gastroenterologist responsible for the donor screening offered potential donors a medical out: on request, he could say they found a medical contraindication that, although it was not worrisome, made a candidate unsuitable as a donor. No one in our study reported having used this option but it was offered nonetheless.

In the teams' consultations with parents the risks of donation were heavily emphasized, while the advantages were somewhat underplayed. According to parents who had been in other transplant centers, they too emphasized the risks of live donation, but to nothing like the same extent that Groningen did. In a focus meeting with the team in which we asked for comments on our observations, one of the pediatricians explained why they took the reservations of surgeons as point of departure, in spite of different views: *'I'm not sure if it matters what we [pediatricians] think. We can have our opinions, but the surgeons are the ones who have to do it. We have to respect their position on living liver donation, in order to reach the end line together.'* Another pediatrician explained how they took the different views of colleagues into account in consults with parents:

> 'You are also very careful about how you talk about the advantages of LRLT because you want to come to joint decision making. You don't want to make things difficult for others [colleagues with reservations] in advance. That is why you bring up LRLT very carefully, to keep open the space to come to synchronization. [...] If you tell people that it is the best treatment option then colleagues will have a difficult time in confrontation with very enthusiastic people.'

A hepatic care nurse added that there was another reason to deemphasize the advantages of living donation: *'Also we don't say that LRLT is the best treatment-option because that would hardly leave parents a choice.'* In addition to the donor-risks, this was another concern of professionals about LRLT: Professionals in the transplantation team had some worries about how much room parents had to come to free decisions about donation. They were aware of the experience described by many parents, that donation for ones child is not a matter of free choice (Forsberg et al. 2004). At the start of the LRLT program several professionals from different disciplines expressed their concern that parents would feel cornered if they were offered the option of living donation. These concerns, in combination with concerns about risks to donors, impelled the team to adopt a very careful approach to the subject of living donation.

How was the course of LRLT decision making structured over time? When a pediatric patient was screened for the liver transplant wait-list, doctors and nurses informed parents about the option of living donation, but avoided asking them directly whether they were interested in living donation: *'We mention the possibility of LRLT in passing and after that we leave it hanging in the air a little.'* The patient was then put on the wait-list, and living liver donation was only pursued as a parallel trajectory if parents showed sufficient interest in this option. As was indicated in the protocol, the initiative had to come from donor candidates themselves. Pediatricians informed parents that the team preferred transplantation with a liver graft from a deceased donor. In the outpatient clinic, some parents had to raise the topic repeatedly before doctors or nurses considered their initiative as a real wish to explore the option of donation. By organizing the information and initiatives in this way, doctors and nurses avoided placing parents on the horns of a dilemma. Even where there was no choice in the matter and living donation was the only viable option, it was not something that parents could passively enroll in. Parents had to take active steps to pursue this option.

When parents put the topic of living donation on the table for discussion, pediatricians explained the advantage of living liver donation with an emphasis on time-frame. With a living donor it is possible to choose the best moment for the surgeries, when the child is still in good condition for the transplantation. One pediatrician pictured the optimal moment as an intersection in time of growth and the development of the disease; if the child was still very small it was better to wait and let it grow some more before operating; however, it was best to transplant the child before its condition worsened. Because both growth and the progress of liver disease are difficult to predict, the best timing for transplantation of children is usually not clear cut, and can be reconsidered from moment to moment. This was a consideration with which pediatricians created space for synchronization in the decision-making process. When a living donor trajectory was initiated, the point about timing gave all parties involved – both professionals and parents – the time to consider and discuss from moment to moment how they felt about living donation in view of the child's condition and position on the waiting list.

Although pediatricians were careful about the communication of advantages, this way of discussing them was in line with generally held medical views on living donor liver transplantation with infant recipients. Nevertheless one can ask whether the team had good ways of structuring and influencing decisions about LRLT.

A NEW FORM OF TRANSPLANTATION

Before reflecting critically on that question, it is useful to consider how to address it. We follow Margaret Urban Walker, who proposes that the evaluative standard be whether practices can account for themselves in their own moral terms: 'Critical reflection asks whether what is going on in actual moral orders makes the right kind of sense to the participants in those ways of life'

(Walker 1998). Reflection in this paper will be confined to team perspectives, for although they are not the only participants in the decision-making process regarding LRLT, we have explained elsewhere what kind of senses the teams' approach to LRLT made to the participating parents (Knibbe & Verkerk 2008). Here we can only give a rough summary of parents perspectives. How parents made sense of the teams approach to LRLT was related to the diverse ways they had nourished their hopes and managed to live with the uncertainties and threats to their child. Parents who had relied mainly on professionals to form their interpretations of their situation and options had seen the professional concerns and reservations as an expression of their medical responsibility. Parents who had thoroughly informed themselves; using internet and contacts with other parents of liver-transplant patients had asked more critical questions about the team's approach.

What kind of sense did the approach to LRLT make to the professionals involved? Their attitudes were shaped by concerns about their own involvement, both as individual doctors and nurses and as a team, in this newly evolving practice of living liver donation: Under which circumstances was the teams' involvement in LRLT justified? How could they offer LRLT in a way that put the least pressure on parents? And how could the team come to joint decision making in spite of disagreements? These were primary concerns in the team with regard to the introduction of LRLT.

The approach to LRLT we described formed an answer to these concerns. The team's ways of organizing information and discussing risks and advantages was aimed at reducing several kinds of pressures and creating space for mutual attunement in decisions about LRLT. With its approach the team tried to reduce pressure on surgeons as well as on parents, so that all parties could live up to their responsibilities as they themselves could endorse. Although the team had embarked on a LRLT program as a response to the pressure of wait-list problems, the changes in moral understanding that such a program required had to move at their own pace. The principle of nonmaleficence, which was especially felt by surgeons, could not be made to bow to the pressures of the wait-list. It was not clear from the start how such changes in moral understanding should go, but there was concern that they should not be forced.

To some extent, the team also managed to reduce pressures on parents to donate. An offer of LRLT for children makes parents responsible for donation. However, as was also indicated above, in their conversations about LRLT physicians and nurses prevented parents from accepting this responsibility too quickly. They tried to show acceptable routes around it. Pediatricians emphasized the option of waiting for a DDLT and the gastroenterologist responsible for the donor screening was willing to say that a candidate who wanted to withdraw but could not openly refuse donation, was medically unsuitable as a donor.

In some cases the team's approach to LRLT tended to have a paradoxical effect. The efforts to create time and space for synchronization and to reduce pressure on parents sometimes ended in situations that backfired on both professionals and parents. When the child's condition deteriorated quickly, decisions about LRLT also needed to speed up. LRLT then became a matter of higher urgency, with relatively high risk, and higher pressure all around. This effect undermined the idea of a careful start of the LRLT program. Although the team tried, often successfully, to reduce pressures on parents as well as surgeons, the child's condition sometimes put limits to the time and space they could create.

In short, the team's approach formed a fine-grained though limited practical response to central concerns about the introduction of LRLT in the Netherlands. However, the approach was less supportive of other central concerns in healthcare that were not directly connected LRLT, namely the more general aim of offering best care for the patient. Many parents wanted to become donors because they wanted the best possible treatment for their child, and LRLT offers the advantage of flexibility so that it can be done when the child is in optimal condition. When LRLT is treated as a backup choice or even as a last resort it is less likely to maximize results for the patient, because the optimal time for transplantation has already passed.

To some readers this approach may seem very exceptional or typically Dutch, reflecting the famous Dutch polder-model (a consensus-model for decision-making) and notions of tolerance and solidarity. Without comparable studies in other countries, however, it is difficult to tell how exceptional it is, and to which extend the team's approach reflects Dutch culture. It is also possible that this approach only seems exceptional because such processes of mutual fine-tuning in a medical team are rarely described. Representations of decision-making processes in medical or ethical literature are often more schematic.

Now we can return to the question whether the team's approach is a good one, given the team members' diverse inherited moral views and circumstances. Possible improvements could be aimed at offering the best possible medical care. Should the team structure its decision making about LRLT in a way that is more supportive of the best possible treatment for the patient, as this is also what motivates most donor candidates? It would be a good aim toward which to aspire in the future; however, we think that the efforts to reduce pressures in the first phases of the LRLT program were very important even if they were not aimed at creating optimal outcomes for the patient. We agree with Carl Elliott, who claims, 'First, as a moral agent, the doctor must ask not simply whether a change in a given state of affairs would be morally better, as a detached observer might ask, but whether or not he should become the agent of that change' (Elliott 1995). To be able to address the question of agent-relative responsibility: whether this specific transplant team and its surgeons with their commitments and views should become an agent in a living liver donation, the above-described efforts to create time and space, were needed. In the care for children with a life-threatening disease, pressures on all the caregivers can be very strong. Parents can feel pressured to donate, but the team can also be subject to pressures of the progressing disease; of parents and of their own consciences concerning surgery on a healthy person. The careful tentative introduction of LRLT enabled the team and its members to consider their involvement as agents in living donation from case to case and from moment to moment.

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CHAPTER 3

THE FAMILY AS PATIENT AND CAREGIVER: ADJUSTMENT OF THE ETHICAL AGENDA ABOUT PARENTAL ORGAN-DONATION

Mare Knibbe
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ABSTRACT

The family of a child in need of a transplant has a double role. It has a role of patient on the one hand, receiving professional care, and of caregiver on the other hand, sharing responsibility with the medical caregivers. In order to reflect on the complex intertwining of responsibilities connected to this double-role, we propose a change of the agenda of moral questions about living parental organ donation. The moral discussions about living donation usually focus on informed consent, risk-benefit ratio and voluntary choice. We do not deny the importance of these issues, but we shift the attention to three other, related moral concerns: process, trust, and emotions. These issues were derived from a qualitative study consisting of observations in a liver transplantation team and semi-structured interviews with parents who donated or considered liver-donation to their child.

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INTRODUCTION

The family of a child in need of a transplant has a double role. It has a role of patient on the one hand, receiving professional care, and of caregiver on the other, sharing the responsibility of care with health professionals. When offering treatment for children, transplantation teams strive to offer not only what is best for the child, but also what is best for the family. In that sense the family is their patient as well. Parents, however, also carry responsibilities for the family of which they are part.

In order to do justice to this double role and the complex intertwining of responsibilities, we propose an adjustment of the ethical agenda concerning family transplantation. In most ethical guidelines and discussions, the central moral issues are information-disclosure, voluntary consent, and risk-benefit ratio. We do not deny the importance of these issues, but we shift the attention to three other moral concerns: process, trust, and emotions. We derived these issues from the stories of parents about caring for a child in need of a transplant. We will argue that transplant teams need to pay attention to the way they create and restrict moral space for parents in the process leading to transplantation if they are to do justice to the double-role of parents. In this process, parents tune their resolves about donation to attitudes in the transplant team. Trust relationships, and dealing with emotions about donation are of central import to the quality of this process.

This paper is based on a qualitative analysis of the observations in a liver transplantation team and interviews conducted over a one and a half year period with parents who donated, or had considered liver donation to their child. The observations and interviews were part of a research project entitled *'Living Related Donation, a Qualitative-ethical study'* which was carried out at the University Medical Centre Groningen simultaneous to the start of a 'Living Related Liver Transplantation (LRLT) program'. In our study we included 22 parents, 2 uncles (opting for donation) and one aunt of 12 families in which the possibility of LRLT was examined and considered, irrespective of the outcome of screening and considerations. In four of the twelve families LRLT was performed. The children in eight families were transplanted with a post-mortal donor liver (henceforth abbreviated as PMLT). The inclusion of families in which the decision-making trajectory had different outcomes (e.g. LRLT or

PMLT) allows for an emphasis on the moral perspectives of parents confronted with the question about donation. It was not the experience of donating that was central in our study, but rather the processes of decision-making leading to different outcomes.

PROCESS

The process leading to transplantation should be an issue on the ethical agenda, because, as the stories of parents make clear, it is a process in which parental responsibilities are reconsidered and redefined. When a child becomes critically ill, and in need of special care and transplantation, its parents (and sometimes other family-members) have to redefine their responsibilities. Parents have to figure out whether they should donate or wait, whether the family can cope with an extra patient, and how they personally feel about donation. In this process parents' perceptions of themselves and of what, and who is important in their life can be subject to change. We first outline the points of reference that parents found in the hospital, for their own considerations regarding LRLT; the views of professionals and other parents. We then offer a sketch of the considerations parents made about LRLT during this process. Having discussed this process we will shortly introduce two other issues about family transplantation for the ethical agenda; themes that are central to the quality of this process: trust and emotions.

The hospital as a moral landscape

The process of reconsidering parental responsibilities is governed to a great extent by the responses of healthcare teams to the disease of the child, their attitudes toward living donation, and the ways in which they discuss risk. We offer a short sketch of medical attitudes toward LRLT, to describe the moral contexts of the hospital in which parents must make choices.

There may be several aims in mind when a transplant-team offers the option of living donation. These aims may diverge, depending on the availability of post mortal donor-organs. In some countries LRLT is the only practically feasible form of liver transplantation. In other countries LRLT-programs are launched to tackle waiting list problems. Some transplant-centers see LRLT as providing a potentially significant contribution to the supply of donor livers. For individual families in these centers the advantage of LRLT is the possibility of elective transplantation: the operation can be planned when the patient is still in good condition.

In the transplant center where we conducted our study a LRLT program had recently been started. Part of the team still had grave concerns about operating living liver-donors, because of potential risks for the donor. Other team members saw more of the benefits of LRLT. In spite of the different ideas of team members, the team generally adopted a reserved attitude toward LRLT. One of the surgeons said: *'We prefer transplantation with a post-mortal donor liver and we are very conscientious about that, we first try other options before agreeing with LRLT.'* Thus the team is more inclined to offer LRLT as a safety-net, not as a way to electively transplant the child. With this cautious approach to the introduction of LRLT the team also avoids exerting pressure on parents to donate.

The attitude of the team shapes the process in which parents form their views about donation. Many parents in our study had expressed their will to donate when they first heard about this option. If the team had responded to the willingness of parents by taking initial steps to organize an elective transplantation, the stories of parents would presumably have been different. Parents who became liver donor might then have said retrospectively that they took a split-second decision to donate. This is the way donor-decisions were characterized in other studies about living donation. In the (still) often cited study published in 1968, Fellner and Marshall reported that the majority of the kidney-donors in their study had made a split-second decision to donate when the subject of donation was first mentioned (Fellner & Marshall 1968). In a more recent qualitative study about living liver donation, by Crowley-Matoka et al., similar findings are presented; 'agreeing to donate was an "automatic leap" they made on first hearing of the possibility' (Crowly-Matoka 2004). However, in our study this spontaneous "readiness" to donate was not yet a decision, it was rather a starting point for the development of more specific resolves about donation, and about the circumstances in which this was to be done. In the stories of parents we interviewed we can recognize the way the liver transplant team structured the process of decision-making. In our transplant center the donor screening usually starts as a careful exploration of this option, while stressing the possibility of waiting as long as the child is in a reasonable condition. When parents were found eligible as donors, the decision about LRLT was not yet taken. Many parents eventually decided they would donate (only) once waiting became problematic. The team thus molded the dynamics of the process in which parents considered their responsibilities.

The attitudes of professionals were also points of reference in the content of parents' considerations. The percentages mentioned in the information about donor-risks are not dependent on the attitudes of professionals. However the team's reservations about LRLT do find expression in the intonation, emphasis and earnestness with which risks are discussed. Some parents adopted the same weighty perception of risks in their considerations. In some cases this was of influence in their views about the circumstances in which they wanted to donate: did they want to donate in circumstances when the child was still in good condition or in more critical circumstances, when waiting became problematic? To some parents the perception of risks as considerable was also a source of fear about the operation, and about the consequences of LRLT for the family. Other parents found the donor-risks small and acceptable, in spite of the emphasis of the team. They understood that it was important for the team to handle risks in a careful manner, but in their own considerations the risks were less weighty.

The attitudes of professionals form part of the moral landscape in which parents redefine their own responsibilities. However the internet and the stories of parents with experiences in other transplant centers could become points of reference to parents as well. Learning about the experiences of parents with LRLT can be helpful as well as confusing. For some parents it was a way to become more familiar with the practice of LRLT. Familiarity made it easier to deal with the risks and burdens. Some of the stories from other families were upsetting, but other stories were reassuring, and thus helped parents to deal with their fears.

The stories of parents from other transplant centers also helped to put professional attitudes in perspective. Parents who sought contact with other parents found out that other transplant centers have different attitudes and lighter ways of discussing risks. Some parents exaggerated the contrasts: *'in other countries LRLT is peanuts, a plumber's job!'* Other parents found it more difficult to judge which view is most appropriate: *'and I find it hard to judge what is more realistic; the lighthearted tone of that center or the severe tone in our center.'*

Parents' formation of perspectives on LRLT: Dynamics

In the transplant center in which we conducted our study, parents (not professionals) usually had to take the first step if they want to be screened for living donation. They had been informed about the possibility of donation before their child had been screened for transplantation. After their child was accepted on the waiting list parents could be screened if they clearly indicated their intention to take this step. The team did not usually ask parents if they wanted to donate.

Most parents stated that they spontaneously wished to donate if circumstances made donation necessary and possible: Matthew: *'we saw this as a chance; we wanted to use all the options we got.'* However, this spontaneous 'readiness' was not yet a concrete decision, ideas about living donation and good reasons and circumstances to choose this option changed in the course of time: Lisa: *'At first I thought, "yes I want this", but then you get information and you hear what consequences donation has, and can have.'* In this respect the spontaneity observed in our study differs from the spontaneous 'split-second decisions' described in other studies. In the course of the parallel trajectories of waiting and preparing for possible living donor transplantation, many parents continued to adjust their views about living donation. The process of considering responsibilities differs greatly between parents. They may adjust their views to the condition of their child, family circumstances, professional views, views of their partners, new information, and stories about LRLT.

Notwithstanding the differences between the narratives of parents, many stories converged on the same issue: most parents eventually saw living liver donation as a safety-net. They did not see refusing donation as an acceptable option. However waiting for a post mortal donor liver and postponement of living donation as long as their child was not in danger, was acceptable. This safety-net-knowing that they were not completely dependent on the supply of donor livers- made waiting bearable.

Parents' formation of perspectives on LRLT: Issues

In the formation of perspectives, several issues were involved. In the process of redefining their responsibilities, parents considered the risks of donation in the light of their commitments, and of their coping resources. The evaluation of risk in this light differed enormously, ranging from irrelevant to very serious. The words of William's mother offer an insight into the connections between different issues in this process:

> 'For me and my husband, the risks were a weighty factor. I for myself thought, well, we have another son as well. He was four at the time. And I'm just as much his mother as I am mother to William [the sick child]. And I realized that even if things would be going for the best, I would have to be fit enough to deal with a worrisome child. I need to be there for William 200%, to put him back on the rails, with medicines, school and everything. There are so many issues connected to living donation. If I would have been only half functioning because of the operation, we would not have pulled through. My husband also

> said, “if something happens to you, I will be very sad, and left on my own with a worrisome child”’.

Other parents told completely different stories about their thoughts regarding LRLT. However, this example serves to show the relationship between perception of risk (weighty), ideals of parenthood (being there 200%), resources for coping with problems (no-one, she seemed to suggest, was present and capable to take over when she needed to recover), and redefining responsibilities in face of a child needing a transplant. William’s mother seemed to load all responsibility for the wellbeing of her family on her own shoulders. Her ideal of attentivity – being there 200% – and the concomitant parental role divisions, determined partly her perception of the risk and cost of donation: the risks involved more than health complications: the whole family would suffer the implications of the intervention. Other parents had other ways of considering risks, articulating their commitments and circumscribing their responsibilities. However, in the processes they described, the perception of risk, normative ideas about motherhood and fatherhood, and coping-resources were interdependent in similar ways.

TRUST

If we understand the period leading up to transplantation as a process in which responsibilities are reconsidered, we can see the challenge of forming and maintaining trust-relationships.

In this process, families cannot merely rely on a continuity of roles and shared habits. The sociologist Adam Seligman describes trust as a form of reliance on others that is situated between two extremes; confidence on the one hand, based on some measures of certainty; and faith on the other hand, which can be completely blind, without a cognizable basis (Seligman 1997). Trust is involved when relying on a person or institution involves uncertainty and risk, but has some basis as well.

For parents the process leading up to transplantation, was a period of transition which involved many and great uncertainties. While caring for the child, parents and professionals had to re-assess the situation constantly: How long will the child be able to live on his or her old liver? How long will she stay in a condition in which she can endure the operation? Can the family cope with a family-liver-transplantation? What are the chances of receiving a post-mortal donor liver? When is the time to donate? Under which circumstances is it better to abandon donation? In dealing with these uncertainties, parents had to rely on the team, on its skilled estimations of risk and opportunity and on the team-specific 'norms' in handling these.

When trusting a transplant team to guide the process leading to transplantation of their child, several issues were at stake for parents. As can be expected the life of their child, their own wellbeing and that of the family emerged, but their integrity as parents was also an important issue. As becomes clear from our interviews and observations, parents (had to) rely on the judgments of professionals when considering their own responsibilities. Trust-relations in a hospital are usually based on the assumption that doctors intend to enhance the health and wellbeing of their patients. However, in the process of considering family-transplantation, trust-relationships are not only based on the protection of health-interests; the relationship with professionals should somehow encompass the commitments of parents as well. If parents can trust that the team will include in its judgments not only their interests, but also their commitments, this trust-relationship can enable them to respond to the rigorous changes in their life.

EMOTIONS

The prospect of living donor liver transplantation often incited strong emotions. Emotions found their way into the process of considering donation in many different vehicles. Some parents gave free voice to their emotions with each other and health care professionals while others integrated them in their risk assessment or in religious considerations. Parents, who consciously paid attention to emotions and spent a lot of time talking, reported that they felt it important to bring their emotions out into the open. A mother explained; *'you want to look each other straight in the eye, whatever comes out of it.'* But for some parents emotions were mostly confusing, and it could be hard to give them a place in the decision- making process. Some parents reported that fear about the risks of donation made it hard to stand firm on their resolves about donation. In one case, the fear of a mother was confusing to professionals as well, raising questions about her intention to donate.

In the above described process in which parental responsibilities are reconsidered, emotions can be seen as signals which draw attention to problems that parents face. Emotions usually indicate that something important is at stake. However the background to an emotion is rarely transparent. Careful interpretation of emotions can contribute to the quality of the decision-making process.

CONCLUSION

The moral concerns about LRLT that we wish to add to the ethical agenda (process, trust, and emotions) cannot be isolated from the general process of care and decision making. The start of the first LRLT-program in Chicago in 1989 was accompanied by a debate about medical responsibilities. Now that LRLT is an accepted practice in many countries we can shift attention to the ways in which particular practices of LRLT appeal to parental responsibilities. For families, the period of waiting for a PMLT and/or considering LRLT is a time of transition. Parents have to reconsider their responsibilities. The moral perspective in which a transplantation team conceives of its own responsibilities forms part of the moral landscape in which parents find their ways.

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ECONOMIES OF HOPE IN A PERIOD OF TRANSITION. PARENTS IN THE TIME LEADING UP TO THEIR CHILD'S LIVER TRANSPLANTATION*

CHAPTER 4

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* We thank the participants in the Naturalizing Bioethics workshop that was held in Groningen, May 2007, for their very useful comments on a first draft of this article.

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ABSTRACT

In which ways can the future that parents of liver transplant patient's hope for be present in hoping? And how are professionals involved in the hopes of parents? In our empirical-ethical study about liver transplantation of children and living parental liver donation, the various answers to these questions were mutually related: Ways of attending to the future were geared to the way parents entered relations with professional caregivers and vice versa; relations were geared to specific patterns of hope and inviting a future.

In interviews with parents about the liver transplantation of their child, the time leading up to transplantation is depicted as a period of transition. The illness of their child and the uncertain prospects of transplantation had abruptly interrupted their lives. In this period they had to learn how to live with the child' disease and threats to its future and they had to find their way in a complex medical practice that was new to them. Parents testified to different ways of carving a route through this period of transition. In this process, hope seems to be a central quality.

A focus on the futurity and social character of hoping in our study sheds light on some interesting variations in 'economies of hope'; the investments of thought, attention, imagination and feeling, and in divisions of 'hoping labor' between patients, parents, professionals, or other caregivers. Our respondents had different ways of involving others in their hopes. We think that recognition of these variations in economies of hope is important if we want to estimate the value and vulnerabilities of specific hoping patterns.

'Naturalized Bioethics; Toward Responsible Knowing and Practice',
Lindemann, H., Verkerk, M. A., Walker, M.U. (eds.) Cambridge,
Cambridge University Press. 2008, p162-181

> “I wonder how many miles I’ve fallen by this time?” she said aloud. “I must be getting somewhere near the centre of the earth. Let me see: that would be four thousand miles down, I think –” (for, you see, Alice had learnt several things of this sort in her lessons in the school-room, and though this was not a very good opportunity for showing off her knowledge, as there was no one to listen to her, still it was good practice to say it over).
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> Lewis Carroll, *Alice’s Adventures in Wonderland*

INTRODUCTION

When infant patients and their parents tumble into the world of liver transplantation, they are not as lighthearted and curious as Alice – the hospital is not a Wonderland. However, they do discover, as she does, that they are leaving the ordinary life they shared behind. The geography lessons that Alice learned in school have become somewhat pointless; they do not seem to tell her where she is. The same happens with family habits and self-understandings when a child is threatened by disease and the need for liver transplantation. In retrospective interviews with parents about their child’s liver transplantation, the time leading up to the transplantation is depicted as a period of transition. Their child’s threatening disease has abruptly interrupted their lives, and indeed, many parents indicate that somehow their life stopped in this period: *‘Your life comes to a halt’*, as one of our respondents put it. In this period of transition, parents must reconsider their responsibilities, making up their minds about living-donor liver transplantation. How should they care for their child and family? Should they donate or wait for a donor liver? Can they accept their partner’s decision to donate? Can they afford to wait? Can the family cope with an extra patient?

In our interviews, as parents testify to different ways of carving a route through this period of transition, hope seems to be a central quality. With Margaret Urban Walker, (Walker 2006) we understand hoping to be as basic to human life as breathing. Hope is therefore not a state of mind that distinguishes this period of transition from other phases of life. Like breath, however, hope comes most forcefully to one’s attention when it is in short supply: when an imagined future vanishes, or when *‘Your life comes to a halt’*. It is the threat to hope, and the response of protection and nourishment that re-create "hoping space," that makes hope a central theme in this period of transition.

Hope also is closely connected to agency. The connection goes both ways; hope cannot be understood without agency, but agency is not possible without hope, whether big or ordinary*. The lives of our respondents came to a halt when the (ordinary) hopes that they used to have for their child and family seemed to be closed off. To start picking up their lives again, they had to find new hoping space. In many ways, parents actively regulated their attitudes and activities to nourish and protect what hopes they had, thereby creating the conditions for agency. In short, hope seems to be necessary for threading or carving a way into the new moral landscape that parents face after their child has fallen ill.

In this chapter, we first outline the period of transition in which hopes were lost and new hopes needed to be found and protected. Then we offer a conceptual analysis of hope, rejecting several models in favor of a dynamic conception that allows us to make sense of what the parents in our study were going through. Finally, we offer suggestions for what can contribute to good hoping in the period leading up to transplantation. Throughout, we use our observations of a liver transplantation team and the semi structured interviews we conducted over a one-and-a-half-year period with parents who donated or had considered donating a liver to their child. The observations and interviews are part of an ongoing research project entitled "Living Related Donation: A Qualitative Ethical Study," which is carried out at the University Medical Centre Groningen**.

PERIOD OF TRANSITION

With something like amazement, many parents recall their ways of thinking and acting in the period leading up to transplantation. *'I lived through these*

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* For a more extensive discussion of the connections between hope and agency see for example Victoria McGeer (McGeer, 2004).

** In this study were included; 22 parents, 2 uncles (opting for donation) and one aunt of 12 families in which the possibility of LRLT was examined and considered. In four of the twelve families LRLT was performed. The children in eight families were transplanted with a deceased donor liver (DDLT). In this article we will focus on the theme of hope in the interviews with parents, and leave the topic of living donation aside.

two years in a daze', one mother told us. As parents try to reconstruct their experiences in an interview, they make clear that the illness of their child was unsettling but that it resettled them as well. Parents recollect having a different state of mind and functioning in a way that was unlike their usual ways. Although there is a great variety in the stories that parents tell about this period of transition, all parents had to deal in some way with the progression of the disease in their child, the uncertainty of the waiting list for donor livers, and the uncertain prospect of possible donation.

To give an impression of this transitional period, we present a fragment of a conversation observed in the outpatient clinic. Most of the children who need a liver transplant are born with biliary atresia, a condition in which the ducts that carry bile from the liver to the gall bladder are blocked or absent, leading to liver damage and cirrhosis of the liver. David is such a child. At six month of age, he had just been referred to the Groningen transplant center because the doctors at his former hospital thought that he would not be able to live much longer on his old liver. The pediatrician explained to the parents how he saw the stage they were in at that moment, and he looked backward and forward with them at the possible developments:

> 'When biliary atresia is discovered, the liver has already been damaged by the bile that is obstructed. A kasai operation can restore the bile flow; however, this solution is only temporary*. This morning we saw a twenty-year-old boy who lived with the kasai for a long time before he needed a liver transplant. Usually, though, it doesn't last that long. You are here now because the bile flow seems to be hampered in spite of the kasai operation. This can change; we don't know. To prevent more damage, diet is very important. But the changes are difficult to predict. And while we don't know how long things will go well, we do know that at a certain moment, David will need a transplant. To prepare for that moment, we want to screen him now for liver transplantation. Ultimately, we only do liver transplantation when there are no other treatment options, but to be ready when the time comes, David has to be on the waiting list.'

In the time leading up to transplantation, the condition of the child and family was constantly viewed as something that could develop in different ways; it might be getting better or it might be getting worse. Generally, the expectation was that in the short term the condition would get worse without transplanta-

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* In a kasai-operation a piece of bowel is used as a bile-duct.

tion. It was a period in which patients and their parents were constantly betwixt and between. Hope, with its ways of "dealing with temporalities," was a condition of carving a route through this period and meeting its challenges.

The challenges that parents face in this transitional period can be summarized as being of two kinds. First, parents had to adjust and often readjust to the progression of the disease in their child, and to the prospects of transplantation and possible donation. Second, parents had to accustom themselves to a medical practice that was new to them. Within this practice, they had to come to shared understandings of their situation, of the disease, and of the treatment options for their child.

CONCEPTIONS OF HOPE

Hope is discussed in different ways in health care contexts. In a first way, the discussion about hope is connected to the giving of information and to the way patients handle information. Here, hope (A hopes that P) is defined in terms of two components: desire and subjective probability (Day 1970; 1998). A desires P and believes that P is to higher or lower degrees probable but not certain. To hope well in this view means that the beliefs are well informed and realistic. Especially in situations of terminal care, this gives rise to moral dilemmas. Should we inform the patient about the fact that she is dying and thereby take away all hope for survival, or should we give her hope and therefore not inform her about the actual state she is in? (Ruddick 1999).

Adopting this belief-and-desire conception of hope in health care has practical implications. The emphasis on beliefs and information in discussions about hope often underpins a certain role division in handling hope. The focus is mostly on beliefs of patients or their parents and on the actions of professionals who might be able to do something about these beliefs. This focus gives the impression of an active party, influencing hope, and a passive party, the object of influences. This picture cannot do justice to the hope-related activity we found in the stories of parents about the time leading up to liver transplantation of their child. Parents actively regulated their information-intake, attention, and thoughts regarding outcomes.

In a second approach, hope is incorporated as part of the treatment or counseling of patients. On this approach, hope is connected not only to belief and desire but also to well-being and agency. In an example of this second conception developed by the oncologist Jerome Groopman (2005, xii), hope generates a kind of chain reaction in patients, in which each link of the chain improves the chances of healing: 'For all my patients hope, true hope, has proved as important as any medication I might prescribe or any procedure I might perform.' Groopman does, however, distinguish real hope and giving real hope from false hope that is based on manipulative information giving. The insight about the importance of hope leads Groopman on a quest to discover how to handle the hopes of patients and family, how to guide or support them in hoping well. Other authors have adopted a similar approach, seeing hope as part of the treatment of patients: 'Along with medical treatment, health care professionals have identified hope as a deterrent to illness and death, and a necessary component of healing' (Westburg and Guindon 2004, 1). Hope is also seen as something that can help patients cope with the course of a disease. Furthermore, patients with strong hopes are usually more cooperative about treatment regimens than patients with weaker hopes.

At first sight, this conception of hope seems to be broader than the conception that is based on desire and belief. It connects hope to well-being but also to the agency of patients and health professionals. Hope is presented as a state of mind that causes or stimulates certain (more responsible) behavior. Professionals strive to inspire hope, in order to invite patients to act in specific ways. If we look at the practical use of this conception of hope, though, the patient still seems to be the more passive party in interactions regarding hope. In that respect, this conception does not differ from the first. The professional, being the active party, is still in the position of giving hope or taking it away. Because hope is good for fostering patients' involvement in their treatments, and because hope can make patients vulnerable, health professionals have to handle hopes in a careful manner. The second conception seems to suggest a cause-and-effect chain of connections: actions of professionals influence hope, and hope in its turn influences the well-being and agency of patients. It is acknowledged that hope often results in a more active involvement of patients (or parents), but the activity involved in hope itself is still opaque.

In a third conception of hope, the clinical psychologist C. R. Snyder (1995; also Snyder et al. 2002) gives a more explicit account of the connection between hope and agency, defining hope as a process of thinking about one's goals. This process embraces two components: agency (the motivation and energy to move toward the goal) and pathways (the ways to achieve that goal). According to Snyder, hope can be seen as a cognitive appraisal of one's goal-related capabilities. As an example of "agentic thinking" (Snyder et al. 2002) cite phrases that people with high hopes tend to say to themselves: "I can do this" and "I am not going to be stopped." Thoughts about pathways are about planning, how to reach a goal, and what to take into account. This definition gives a more clear-cut place to the activity involved in hoping; it consists of two kinds of goal-directed thinking: agency thinking and pathway thinking.

The third conception, however, also has its problems when it comes to understanding the hopes of our respondents. The conception is too goal directed to come to an understanding of either the hope-related activity in the stories of our respondents or the significance of hope in the period of transition that is our focus. In Snyder's conception, agency is strongly linked to gaining control and to chosen goals. One can wonder whether having a goal is a necessary condition for hope. Often hope is less ambitious and searches more for desired outcomes than for chosen goals. Parents in our study hoped that their child would come out of the transplantation in the best possible way or that life would be less filled with anxieties. Hoped-for outcomes are not always very articulate. In the transitional period, the outcomes were often reimagined and adjusted; they were not clearly defined from the start. As we argue later, this activity of reimagination itself can be understood as part of what it is to hope.

The three conceptions of hope we discuss here do not help us to come to a satisfactory understanding of the hope-related activity in the stories of parents we interviewed. To enable an understanding of hope in those stories, we need a more dynamic conception of hope, one that allows for less ambition about reaching chosen goals while maintaining a sense of the involvement of agency in hoping.

To develop a more dynamic notion of hope, Margaret Urban Walker (Walker 2006, 48) proposes to describe hope as an emotional stance or a patterned syndrome that is 'characterized by certain desires and perceptions, but also by certain forms of attention, expression, feeling, and activity.' One can recognize hope in oneself or in others not in single mental features but in patterns of these "phenomena of hope"*. As Walker writes, there is no single "recipe" of specific ingredients in precise proportions that constitute hope, but there are patterns of ingredient perceptions, expressions, feelings, and dispositions to think, feel, and act that are part of the repertory of hopefulness.

In developing this conception of hope, Walker discussed four features of hope that make up hopes of people in different constellations and interplay. One feature of hope is its futurity: hope is directed at a state of affairs that has

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* Walker borrows the attention to 'phenomena of hope' from Wittgensteins Philosophical Investigations.

not yet come to pass. Hope can be oriented at a near future or a far-away future, but it is always forward looking. Even if I hope that things (in the past) went well, it will be something I will find out in the future. A second feature is the desirability of what is hoped for: the state of affairs that is hoped for has to have some value for the hoping agent. One cannot hope for an outcome that one does not value at all. The desirability is a feature that can give hope in a health care setting a specific dynamic. In health care, patients, their parents, or other family members often need time to learn to value the best possible outcomes of a treatment. Third, there has to be a "nonzero" possibility of what is hoped for. The hoping agent has to believe that the state of affairs she hopes for is at least possible. If one considers a desired future to be impossible, one will lose hope for that future, however desirable it may still be (although hope can still be directed at possible futures with a very low probability). Finally, Walker mentions with special emphasis the efficacy of hope: the dynamic tendencies of hope to steer thought, feelings, attention, speech, and actions. We dwell on Walker's explanations of the efficacy of hope in somewhat greater detail to come to an understanding of the agency involved in hoping.

To understand what we are doing when we hope, we should look at the 'dynamic tendencies to attend to, or be attuned to what is hoped for in a way that tilts or propels us toward making it so' (Walker 2006, 47). The agency involved in hoping consists of several exercises of thought, activity, expression, and attention. Walker (2006, 45) outlines these aspects of hoping as the "efficacy" of hope and states that hope's 'nature is to engage our desire and agency, so that in hoping, the world is, in some respect that one cares about, construed as open to the outcome one favors.' This characterization fits the diverse reports of our respondents about the ways they managed to live through the time leading up to transplantation. In this formulation, interpretations of the world and acting in the world are pictured as two locations on a continuum; beliefs about the world are actively formed and continuously adjusted interpretations of one's situation and its openness to a certain possible and desirable future. Interpreting one's situation is an activity that is sustained by other activities as well. Activities of our respondents could involve seeking or avoiding contact with other parents of liver transplant patients; asking for second opinions; and surfing the Internet or staying far from it. With regard to regulating information, attention, and contact with others, some of our respondents tried to feed their imagination with hopeful scenarios, whereas others tried mainly to keep their imagination from straying to frightening scenarios. With these diverging activities and interpretations, parents had different ways of construing a health care environment, open to good outcomes for their child.

EVALUATING HOPE

How can we recognize good hoping? And how can professionals form a supportive environment for the good hope of parents? In Walker's account of good or misplaced hope, correct beliefs are less important than the activity, imagination, feeling, expression, or other forms of agency that are engaged in hoping. Walker states that hope can be false or mistaken only if one believes there is a possibility where there is none. One can rarely be certain that there is zero possibility of attaining a desired object, however, so that leaves room for hope. Even if there is only the slightest possibility of realizing what one is hoping for, hope cannot be false. And even if hope were based on a mistaken belief that the impossible can happen, one should be careful about advising against such hope because people have a need not only of what they hope for but also for hope itself. Hope, we repeat, is a condition for agency. Without any hope, ordinary or grand, people are left with only inertness, terror, and despair. One could advise against certain imprudent actions inspired by hope but not against hope itself.

To recognize hope that is good, given the abilities and inabilities of parents in this transitional period, we can evaluate the "economy of hope" – that is, the investment and engagement of energy, thought, attention, feeling, and activity made in hoping*. We can try to assess whether the energy engaged in hoping is well spent. We can examine, for example, how the future is imagined and invited in one's actions, attention, and thoughts. We can evaluate its desirability: is the future that one hopes for and invests in really desirable and valuable, or is one investing in something of little value? We can check the assumed possibility of a desirable future or we can evaluate hope's dynamic tendencies – the exercises of thought, attention, and activity made in hoping. Does this hope elicit a good kind of activity and state of mind? Does it not lead to neglect of things that deserve attention? Our respondents invested their energy and

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* Victoria McGeer coined the term 'economy of hope' to refer to approaches to hope in which hoping well is understood as 'having the right quantity of hope'. We use the 'economy of hope' to refer to the (quality of) engagement and investment of energy, attention, thought and activity.

attention in different ways in their hope for good outcomes. In some cases, one can question the wisdom of the investments of hope they were ready to make.

To outline the kinds of questions that can be posed about the economy of hope, we discuss the investments of hope Jonathan's parents made. Jonathan's parents had three children together, were divorced, and had both found new partners. After Jonathan was put on the waiting list for liver transplantation, his parents developed different views on his illness and on living liver donation. When Jonathan was three, he was diagnosed with biliary stenosis; his bile was slowly poisoning his liver. He coped reasonably with his health problems until he had an esophageal bleeding at the age of eight. He was then put on the waiting list for a liver transplantation to avoid a second bleeding of the esophagus or stomach, because the doctors thought that he might not survive a second time. One pediatrician had pictured the risk of another bleeding as a time bomb; without a liver transplant, it would eventually happen again, but it was hard to tell when it would happen. In the interview, Jonathan's father reported that the heavy metaphor had alarmed him. He had asked for further explanation; how critical was the situation? The pediatricians had reassured him that Jonathan was still doing well and that he had some time to wait for a liver transplantation. The father agreed to wait for a deceased donor liver and to become a liver donor in case of emergency; he thought that not risking his health unless it was really necessary would be better for the sake of his wife and three children.

> 'You keep balancing, but you continue to ask yourself, is it still responsible to wait? That is what you want to know, but they can give you no guarantees, but as long as they gave me the impression that we were not in an emergency situation, we stuck to this scenario [of waiting].'

Jonathan's mother saw her son's situation as more urgent. She thought the situation could rightly be called a time bomb and reported having been on tenterhooks for quite a while. If the doctors had not refused her as a donor, she would have donated instantly.

> 'Since I am forty and I have a dangerously ill child who has his whole life still lying before him, I would be very happy to donate, and if I would die for him, well it might be less simple than it sounds but I don't think I have a problem with that. ... The children will manage, they still have a father, and others, they will be okay.'

Jonathan's parents invested their attention, energy, actions, and thoughts differently; they had different economies of hope. Jonathan's mother was ready to invest her life in her son to give him the best chance. She was unconditionally committed to her son's well-being and could not be sidetracked by considerations regarding her other children, who were doing well, or by other aspects of family life. She had no second thoughts about liver donation; it would be worthwhile if her son could have a future, with or without her. By contrast, Jonathan's father imagined a future that included the whole family. With every change in their situation, he considered what would be best for Jonathan as well as others involved; he talked with others about donation and relied on the estimates of the pediatricians about Jonathan's condition. After accepting the reassurance of the pediatricians, he felt less pressed by the danger to his son.

Questions about good hope are connected to other values in life; answers depend on the kind of futures we value, on ideas about a good state of mind, and on involvement in situations with specific risks and uncertainties. How should one live with this risk and the uncertainty about its magnitude? Is it better to accept this uncertainty as a new and ongoing part of life, as Jonathan's father did, or is it better to realize that normal life has stopped, and sort out what is most important in the future, as Jonathan's mother did? These are the kinds of questions that have to be discussed by those involved when evaluating economies of hope.

The features of hope that Walker describes can help us think about good hope; however, they cannot be isolated when evaluating hope. When evaluating, we have to connect specific features of hope to a broader view of the economy of hope. A broad view of economies of hope, with variously patterned features, can generate insights that are more useful in practice than general judgments about good and false hopes or "high and low hopes" (Snyder's words). Instead of judging hope to be altogether good or bad in virtue of one characteristic, a focus on the economy of hope can help to identify and respond to good and vulnerable aspects of specific hopes.

TWO FEATURES OF HOPE

To think further about good hoping in the period of transition that is our focus, we discuss different shapes of hope in our interviews and observations with parents of patients requiring liver transplants. We focus on two features of hope and good hope in particular: the futurity of hope and the social character of hoping*. These features deserve special attention because they are related to the specific characteristics and challenges that constitute this transitional period. Remember that we sketched this period as the time in which parents had to learn how to live with the progression of the disease in their child and the uncertain prospects of transplantation, and in which parents had to accustom themselves to a medical practice that was new to them.

A focus on the futurity and social character of hoping sheds light on three variations in patterns of hope. First, different temporalities can be involved in hoping. Some parents oriented their actions and attention toward short-term problems of that moment; they tried not to look further than one step ahead. Others tried to vividly imagine good long-term outcomes of transplantation. Second, hopes can be directed at goals but also at vague and indeterminate outcomes. Third, there can be different divisions of hoping labor between patients, parents, professionals, or other caregivers. Our respondents had different ways of involving others in their hopes. We think it is important to properly recognize these differences in patterns of hope before judging specific economies of hope.

Futurity

In which ways can the future of what is hoped for be part of hoping? In many discussion of hope, the futurity of what is hoped for is conceptualized as the desired goal that lies in the future. Snyder, for example, started his research on hope by asking people to tell about their goal-directed thoughts. We think that goal-directed thought and action is only one way of hoping. A hoped-for future is not necessarily clearly outlined to a hoping agent. In our interviews we can roughly distinguish three ways of attending to the future, each of them part of a different economy of hope. We outline two ways of attending to the future and discuss a third way more extensively.

In a first way of attending to the future, parents tried to imagine vividly what they hoped for. They sought contact with other parents to learn about the recovery of other children after transplantation and about the well-being of other families. They listened to stories and information selectively. As Barbara explained, *'No, I had little need for information; I did feel a need to talk to other parents, because you want to hear a lot of stories. But you just want to hear many many positive stories. You only want to see the positive situations.'*

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* Walker does not treat its social character as one of the features of hope; however she does endorse its social character in her discussion of other features.

In this way of attending to the future, parents paid less attention to information about risks of transplantation and donation, or to stories about patients who died. Parents who told about this way of dealing with information reported being aware of the risks, but their attention was grasped by stories, gestures, or expressions that could sustain their imagination of a hoped-for outcome. Some parents explained that it made no sense to think a lot about complications and problems of transplantation and living donation, when that was the only lifesaving treatment option for their child. As there was no choice to make, there was no reason to consider the risks carefully.

In a second way of attending to the future, parents prepared for all possible scenarios to realize the best possible outcome. In this mode, parents tried to gather all the information they could find about disease and treatment of their child, in order to gain more control. Margaret reported, *'You absorb anything that might have something to do with it. In order not to miss anything, to avoid being taken by surprise. So you know what is going wrong, what you can expect, what is the situation at hand, and what can happen.'*

This general openness to stories and information was emotionally stressful. Parents who thoroughly informed themselves often stumbled upon stories about patients who died and about medical mistakes. However, they developed a thorough understanding of the child's disease and the transplantation options. As they encountered different perspectives and found information about other transplant centers as well, these parents were in a position to compare and evaluate the team's attitudes and policy regarding transplantation and living donation. In this critical position, there was more they could do themselves to realize a hoped-for outcome.

A third way of attending to the future, "living day by day," is exemplified by David's mother Selma: *'I did not want; I could not look too far ahead. I was living only day by day, and how David was that day, and more than that I could not, I couldn't use.'* Our interpretation of living day by day as a way of attending to the future needs explanation. We interpret the way Selma lived through the time leading up to transplantation at greater length. To understand her way of attending to the future, however, we need to look at others surrounding her as well.

In our discussion of the transitional period leading up to transplantation, we presented the pediatrician's explanation of David's disease and treatment, given in the first conversation that David's parents had in the transplant center. In his explanations, the pediatrician considered different possible future scenarios. He focused on a timeline that in his eyes seemed practical to consider. David's father, however, tried to look further ahead. He asked the pediatrician to offer a picture of the future: *'We are also trying to get a picture of the future, like how will things go after transplantation, what can we expect? ... How long can you live with a liver transplant? Or is that still unknown?'* The pediatrician expanded his comments, citing a few statistics:

> 'No, we don't know exactly how long someone can live with a liver transplant that he received as a child. Somebody [with a liver transplant] recently turned twenty-five. But it remains uncertain how things will go. Of all the transplanted children, 80 to 85 percent can lead a normal life and go to school. They all have to use medicines against rejection for the rest of their lives, but with that, they can do all the normal things.'

At the moment of that first conversation in the transplant center, these uncertain prospects of an 80 to 85 percent chance of a normal school-life with medicines for the rest of their lives could seem both unbearable and hopeful. David's father tried to picture the best possible scenario he could hope for. To David's mother, it seemed impossible to look at this uncertain future. In her questions, Selma focused on a smaller time frame; she tried not to look further than one step ahead. Her questions to the pediatrician were mainly about diet, where to ask questions when problems would arise, and about the pain her son had to bear that day. Living day by day was the only way Selma could get through the time of waiting for her son's transplantation.

Can we say that Selma had hope for good outcomes, if she did not try to picture them? The timeline that she had in mind was not that in which an ultimate outcome of her hope (if she had hope) would be realized. Using Snyder's conception of hope, one could conclude that she did not really have hope, or that she only had small goals. We will not endorse these conclusions. With her care and practical questions, she invited outcomes that she knew would be better than the outcomes invited by neglect or mistakes. She knew this, even though she could not bear imagining what these uncertain outcomes would look like. With her small timeline, practical questions, and involvement, it seems that for Selma hope started with acting toward an uncertain but preferable future of all possible futures, not with setting a goal or imagining the outlines of a future. In this she was supported by the pediatrician, who did imagine the possible outcomes and could advise her on ways to invite a future life for her son. Her hope thus rested on her trust in the pediatrician and the team he represented.

We stated that for Selma hope started with acting toward a favored outcome, imagined by others, not with imagining it herself. One can ask, however, whether it is possible to hope and continue hoping without somehow imagining a hoped-for outcome. If we accept that hoping involves inviting a future state of affairs, some form of imagination of a hoped for future is a vital feature of hope. Maybe Selma was not forming mental pictures of the outcome of transplantation but imagining outcomes in other ways. Imaginations involved in hope can take many forms – detailed, fragmented, vague, visualized, or otherwise. An example Walker uses is that of people clutching and pulling the railing at the racetrack as horses enter the home stretch. She suggests that this gesture can be seen as embodied imagination. In the period leading up to transplantation, there can be imagination of a hoped-for future in the ways parents care for their child, perceive the child's condition, listen to doctors and to stories of other parents, or follow the recovery of other patients.

One can ask if the hope of David's mother would be better or stronger if she did imagine the future more clearly. In answering this question, we have to keep in mind that in reimagining a desirable and possible future for their child after transplantation, parents have to confront the loss of certain possible futures as well. The process of reimagining an uncertain future often requires recognizing the loss of some hoped-for futures one had, and the risk of losing new hopes as well. This loss can make reimagining the future painful, as it was to David's father, or unbearable as it was to his mother. For Selma, relying on the imagination of others allowed her some time to accept this loss and to learn to value another possible future for her child.

These three ways of attending to the future, exemplified by Barbara, Margaret, and Selma, contribute to different economies of hope. With their different approaches of the future, parents spent their energy on other aspects of their situation. Parents who, like Margaret, prepared for all possible scenarios, invested energy in developing a critical stance in the process of care for their child, in order to get the best possible care. With their broad orientation via Internet, they tried to reduce their dependence on the transplant team. They also had to spend a lot of energy on handling the emotions inspired by the upsetting information they often found. In the approaches exemplified by Barbara and Selma, parents depended more on the steps the doctors proposed, spending most of their own energy on keeping a positive frame of mind and on daily care. We saw that "living day by day" contributed to an economy of hope in which emotions about uncertain outcomes, and the loss of a future once hoped for, were regulated. This regulation of her emotions allowed David's mother to devote full attention and energy to the problems and necessary care of that moment.

What can we say about good or vulnerable aspects in these different economies of hope? At some moments in the interview, parents explained their own ways of dealing with uncertain prospects as a necessity; something they could not have done otherwise, and at other moments as an approach that in their eyes was most sensible. Both Barbara and Margaret characterized their own attitudes as more level-headed, compared to attitudes of other parents they had met. Their specific ways of inviting a good future for their child fitted in with values they held in life. Margaret emphasized her autonomy, whereas Barbara spoke about being (emotionally) strong and positive toward her daughter. Apart from these connections to values, there are vulnerabilities as well in these different patterns of hoping. Parents who confined their attention to positive aspects or to short-term problems were more vulnerable to disappointment, problems they did not prepare for, or abuse of trust. Parents who tried to control the care process and stay informed of everything that could be relevant to their situation were more vulnerable to exhaustion and friction with professionals. Ways of attending to the future were geared to the way parents entered relations with professional caregivers and vice-versa; relations were geared to specific patterns of hope.

The Social Character of Hoping

For a complete picture of economies of hope, we have to look at social contexts as well. The words, expressions, and attitudes of professionals in the transplant team were often described in detail by our respondents. They seemed to be important to the ways parents managed to construe their situation as open to good outcomes. In what follows, we outline the relational dimension of the three ways of attending to the future we have described.

Like Barbara, Melle's parents both indicated that their attention to risks was limited. However, they also indicated that the decision-making process took place in a constellation with professionals, one of whom was perceived as remarkably open and concerned about risk. Melle's father recalled:

> 'This doctor was really considerate and open and also harsh and clear about the risks [of liver-donation]. All the same, however, as a parent you are in a certain flow with your child and you shut certain things out. [That is, you don't consider risks] Because you're the parent.'

The impression that risks were handled and communicated with special care was meaningful to Melle's parents, although they distinguished their own concerns in this respect from those of the team. Not risk itself, but the belief that the risks were handled by trustworthy professionals, was deemed relevant by

Melle's parents. While hearing the information related by the doctor, they observed the way the doctor (and with him the team) dealt with their situation. They tried to get a view of the moral landscapes in the medical practice they had entered.

Margaret had other ways of involving professionals in her hope. In the long periods she had spent with her son in different hospitals, she had seen many professional mistakes. Her trust in professionals was placed more carefully, and she made a routine of checking different sources of information and stories. In this way she tried to control what happened to her son. The involvement of others was conditional. Some professionals found this a very difficult kind of involvement. In two reflective meetings with pediatric nurses in which their relations to parents of patients were discussed, nurses reported they felt very uncertain and less capable under her controlling eyes*. From their perspective, according to their economy of hope, the investment of energy and attention was not working well with the conditional way Margaret entered relations. From Margaret's perspective, however, with the experiences she had, it was the best way of realizing a future for her son.

In discussing the way David's mother invited the best possible future for her son, we already mentioned her reliance on professionals. Her hope and its investments depended completely on the relations with professionals. She not only relied on their interventions but also depended on health professionals to start imagining and valuing a possible future for her child.

This short overview shows how parents involved professionals in their specific patterns of hope. What can professionals in a transplant team do with this involvement to support a good economy of hope? We think there is not one specific way of communicating information or of counseling that works to inspire a good kind of hope in all parents. Health professionals are not the gatekeepers of hope; they cannot regulate the hopes of parents. However, they can critically assess and adjust their own involvement in the hopes of parents. To support the hopes of parents, professionals need to clarify whether they can agree with and live up to the involvement that parents assign them in their hopes. Compared to views in which professionals are pictured as gatekeepers of hope, this is a more modest professional approach. The critical reflection in this approach encompasses more, however, because

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* The reflection in these meetings was facilitated by the ethicists Els Maeckelberghe and Enne Feenstra. We thank them, and the pediatric nurses for the opportunity to observe in these meetings.

it requires sensitivity toward the hoping patterns of parents, as well as self-reflection and team discussions.

Assessing or adjusting professional involvement in hopes of parents entails negotiating mutual expectations. Professionals must be clear about their professional norms and procedures, but they also need to be sensitive to the diverging ways parents involve them in their hopes. For critical reflection on their involvements in the hopes of parents, it is important to recognize the values and vulnerabilities that are present in different economies of hope, as we have pointed out. However, assessing their involvements in hopes of parents also requires self-reflection. In the hopes of parents, professional values and vulnerabilities are addressed as well. David's mother tapped the support and comfort-giving that for many professionals is a valuable part of their work. The way Barbara or Melle's parents involved professionals was flattering, underscoring their medical authority and resulting in a smooth and (in health care, highly valued) efficient cooperation. Margaret, however, made clear that some of the involvements professionals get to have in the hopes of parents are more difficult to deal with. Many nurses felt less capable in her critical presence. It can be tempting to see ways of hoping that build on professional values as better than the hopes that address professional limits or vulnerabilities as well. However, the more difficult involvements of professionals in hopes of patients, parents, or family can be seen as a good opportunity for critical self-reflection and discussion of professional and team values.

The time leading up to liver transplantation of a child is a period of transition, in which parents enter a new moral landscape with unfamiliar risks and uncertainties. Hope is a central quality when it comes to facing the challenges in this period. We discussed the usefulness of different conceptions of hope to come to an understanding of our research material. In the interpretation of interviews about this period, hope can only be understood and appreciated if its dynamic tendencies are taken into account. Margaret Walker explains this tendency as the tendency 'to attend to or be attuned to what is hoped for in a way that tilts us or propels us toward making it so.' (Walker 2006, 47) While adjusting and readjusting to the condition of their child and the new practice they entered, parents actively regulated their intake of information and the awareness of information given. They guarded and re-created their hoping space in different ways, attended to the future in different ways, and, accordingly, entered into relations with professionals in different ways. The stories of parents showed that professionals cannot be the gatekeepers of their hope, as is suggested in some accounts of hope in health care. The information, behavior, and attitudes of professionals were important to parents to inspire trust; however, professionals did not control the risk awareness of parents or determine their hopes. Professionals can support the hopes of parents by caring about their own involvement in these hopes.

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CONFOUNDERS IN VOLUNTARY CONSENT ABOUT LIVING PARENTAL LIVER DONATION: NO CHOICE AND EMOTIONS

CHAPTER 5

Mare Knibbe
Els Maeckelberghe
Marian Verkerk

ABSTRACT

Parents' perception of having no choice and strong emotions like fear about the prospect of living liver donation can lead professionals to question the voluntariness of their decision. We discuss the relation of these experiences (no choice and emotions), as they are communicated by parents in our study, to the requirement of voluntariness. The perceived lack of choice, and emotions are two themes we found in the interviews conducted within the "Living Related Donation; a Qualitative-Ethical Study" research program. As a framework for the interpretation of these themes we discuss views of moral agency. We adopt a view in which relations are seen as constitutive of moral agency. Judging from this view, the perceived lack of choice can best be understood as a sign of commitment. We argue in this article that neither seeing no choice, nor emotions in themselves should be seen as compromises of a voluntary consent. However both experiences draw attention to aspects that are important to come to an evaluation of consent to donation. We discuss the story of one mother as an exemplary case to show how both themes can intertwine.

Medicine, Health Care and Philosophy, 2007, vol. 10, afl. 4, pp. 433-440.

INTRODUCTION

When parents do not perceive living donation for their child as a matter of free choice and strong emotions play a role in their decision, this might lead professionals to question the voluntary consent of parents (Crowly-Matoka et al. 2004; Forsberg et al. 2004). Fear about donation for example might be seen as an indication that a donor-candidate does not really back her own decision to donate. We will argue that seeing no choice and emotions like fear should not, in themselves, be seen as compromises of voluntariness.

In the literature on Living Related Liver Transplantation (LRLT) the decision-making process is generally examined and evaluated as concerns the rules of informed and voluntary consent and the principle of respect for autonomy. Informed consent and the allied right to self-determination are considered very important in healthcare. Parents sign up to be a donor for their child based on relevant information. When parents see no choice, however, and strong emotions play a role, it can be difficult to tell whether a decision is voluntary.

> 'At a certain point in time, Casper took a turn for the worse and I felt pressured to think about Living Related ... well, we'd better give it a try ... And then, knees shaking, we finally decided to enter the donor screening program. We said to each other, 'We hope that the doctors will tell us, "You cannot enter the Living Related program for medical reasons." ... But I was very angry for a time. It's a fine thing that medical science has come so far, but to put me in a position in which I had to decide whether my child lives or dies ...'

Is Casper's mother acting voluntarily when she signs up to be screened for donation? Both the experience of having no choice and strong emotions about donation can give rise to questions about voluntariness. We will discuss the relation of these experiences, as they are communicated by parents in our study, to the requirement of voluntariness.

Interviews were conducted within the 'Living Related Donation; a Qualitative-Ethical Study' research program. These consisted of semi-structured retrospective interviews, regarding living related liver donation with twenty-five respondents in twelve families: twenty-two parents, two uncles and one aunt.

In all families one parent or both parents had been screened for liver donation, in two families an uncle opted for donation. In four of the 12 families a LRLT was performed, in eight families the child had received a post mortal donor liver before living donation was planned.

The material collected contains many themes. In this article we do not intend to give an overview of our findings, we will focus on the interpretation of two themes in relation to questions about voluntariness.* After a short overview of the perception of choice/no choice in our study-sample we discuss pictures of moral agency as frameworks for interpreting this perceived lack of choice. We only discuss moral agency insofar as it is relevant to come to an interpretation of 'no choice'. We leave other themes related to moral agency, consideration of risk and dealing with information aside. Subsequently, we will use the story of one of our respondents as an exemplary case in which the themes 'no choice' and strong emotions are central.

The fact that interviews were held retrospectively makes them liable to a specific bias. Respondents might uphold a certain positive or critical image of the decision-making process. The reason to make use of retrospective interviews was primarily a moral one; we did not want the interviews to interfere in the decision-making process. In order to enhance a careful interpretation of interview material, interviews were designed to come to replication and triangulation**. The interviewer chose different entries to introduce a subject matter. For example: she asked direct questions about attitudes toward donation in different stages of decision-making, but she also asked questions about conversations with professionals and family in which attitudes are more implicitly pictured. This form of triangulation made it possible to take biases into account in the interpretation of material.

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* Our focus on the interpretation of these two findings impels us to leave aside the important but more general question about when professionals have enough certainty regarding the consent of parents, whether it is well informed and free.

** Although triangulation usually indicates the combination of different observation-procedures, it can also be used and is very important in the scope of one interview, as is indicated by Fred Wester and Vincent Peters p193-194 (Wester, F. et al. 2004).

VOLUNTARINESS IN DECISIONS REGARDING A FAMILY MATTER

It is generally accepted that the informed consent procedure contributes to a decision-making process that is acceptable in view of the principle of respect for autonomy. Autonomy in this case is understood as the right to self-determination. The guidelines for informed consent serve as a filter. If these guidelines are not met the right to self-determination is insufficiently guaranteed and the proposed treatment may not (yet) be carried out. Informed consent can be valid or invalid. The informed consent procedure is designed to prevent coerced or misinformed decisions.

In order to know what is needed for informed consent about LRLT, professionals have to distinguish voluntary from coerced decisions in a family-context. Clarity regarding this criterion when dealing with LRLT is not a simple matter, for it is an event in the life of a family which is usually characterized by strong involvement of all concerned. The child's dependence and the parent's duty to care for their child may at certain moments seem at odds with the conditions for voluntary decision-making.

Many parents in our interviews state that living donation for their child was not a matter of choice. Because of their intimate relation with the child who was in danger, they simply *had* to donate, if possible. Other authors have concluded from similar findings in other studies that there is an aspect of coercion in the decision of parents to donate (Forsberg et al. 2004). We however will contend that these findings indicate that intimate family-relations are a strong motivating factor, not a coercive factor.

In the figure on page 88 we present an overview of the degree to which respondents considered living organ donation a choice. After giving an explanation about parents' perception of choice we explore interpretations of the relational context of seeing no choice.

Having a choice implies there is more than one option to choose. If there is only one option, there is no choice. The *perception* of having choice or having chosen depends on the *acceptability* of the options presented. Strictly spoken, all parents have the option to refuse living donation, but for many parents refusing was not acceptable. Twelve parents did not consider refusing as an acceptable option. They did not consider living donation a choice, for as parents they felt compelled to do any and everything they could for their child. Nine parents spoke about living donation as a chance and a good choice. In their stories, being unable to refuse was not a theme. Four of the twenty respondents spoke about refusing living donation as an acceptable (but in the

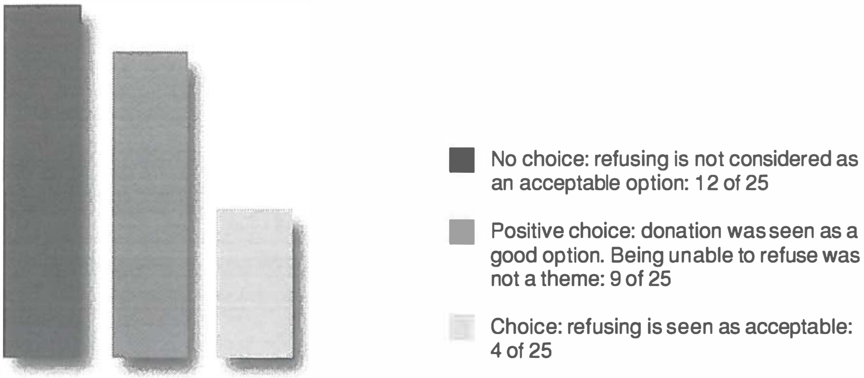

Figure: Perception of LRLT as a choice/ no choice

end not favored) option. How can the perceived lack of choice be related to questions about voluntariness in decisions about family liver transplantation?

Some authors see a danger of coercion in the parent-child bond. Parents force themselves to donate a liver based on love or sense of duty (Siegler et al. 1992; Singer et al. 1989). One possible form of coercion is psychological or internal coercion created by the donor's own feelings of guilt because the patient might die without donor participation (Siegler et al. 1992). This internal coercion is difficult to distinguish from laudable, altruistic parental motives. The feeling as if there were no choice in the matter is seen as an example of internal coercion or coercion stemming from the parent-child relationship. Forsberg et al. concluded from their interviews in which this experience was described that, 'a more useful approach might be to confirm that the parent-infant relationship is inherently coercive' (Forsberg et al. 2004).

In their critical reviews of the literature on intra-family transplants, Crouch & Elliott and Spital demonstrate that this interpretation is inspired by a specific image of the moral agent, namely that of an independent and self-interested person. They argue for a relational concept of moral agency in the family and consequently give family ties a different place in the interpretation of "having no choice" and voluntary consent.

Spital puts forward that parents make decisions regarding liver donation based on their love for their sick child and the desire to keep him or her alive (Spital 2005). Such decisions are made within intimate family settings. These family relations should not be seen as coercive. He explains the feeling of having no choice by making a distinction between coercion and coercive situations. Potential donors often find themselves in stressful or *coercive situations*, but this does not mean that coercion is involved: '…there is an important difference between coercion, and coercive situation. Both conditions limit freedom, but only coercion eliminates autonomy' (Spital 2005). A donor is only coerced if someone imposes her will upon him. According to Spital, informed consent given in a difficult or coercive situation is not per se invalid.

Crouch and Elliott dismiss entirely the association between parental decisions about donation and coercive elements. When addressing the issue of good comprehension of the transplant decision-making process within the family, Crouch and Elliott believe that moral philosophy got us off on the wrong foot (Crouch et al. 1999). In moral philosophy the idea of a moral agent as being self-interested, independent and free from emotional bonds, commitment and duties is central. As long as voluntariness is linked to this notion of moral agency we will not understand how parents experience deciding whether to donate.

> 'If we are ever to get straight about the nature of voluntariness, we must recognize that moral and emotional commitments are not exceptional, are not constraints on freedom, but are rather a part of ordinary human life. More specifically, they are part of ordinary family life that we must take seriously if we want to understand how family members make free choices about organ donation' (Crouch et al. 1999).

Family members not only have shared interests and values, the sharing itself is important to them. Sharing with one another and the feeling of community are important. In this the interests of family members are tightly interwoven and it is not always possible to differentiate them. This also means that we do things for family members we would not do for others. Love, duty and conscience are thus not curtailments of freedom, but rather expressions of who someone is. 'Neither love nor conscience constrain the mother's autonomy; rather, they give voice to her autonomy and say something about the kind of agent she is and the kind of family of which she is a member' (Crouch et al. 1999).

We think that parents' perception of having no choice should be understood as a result of commitment to their child. The findings about perceived lack of choice should neither be seen as signs of internal coercion as Siegler (et al) point out, nor as a result of the inherent coerciveness of the parent-infant relationship as Forsberg et al. conclude. Both of these interpretations seem to imply that we should generally accept or reject some forms of coercion as part of family- transplantation practices, leaving no room for a critical evaluation in specific cases. If however we understand the often perceived lack of choice as signs of commitment, we can start identifying the questions that seem crucial in evaluating voluntariness in family-decisions. Before assessing these questions, we have to add a critical remark to the picture of moral agency in the family drawn by Spital, Crouch and Elliot.

We agree with Crouch and Elliot that commitments are part of family life, and are not *necessarily* constraints on the autonomy. This however does not rule out the possibility of constraining relationships in a family. As Marilyn Friedman points out in a feminist discussion about relational autonomy: some relations are supportive of autonomy, other relations are not (Friedman 2003). In order to judge freedom of consent to donation, a decision in which family relations are central, professionals need to get some idea of the quality of these family relations.

Another aspect of a relational view of moral agency is in need of some specification as well. What kind of connections between relations and moral agency do we want to endorse if we adopt a relational view of moral agency? Following Friedman we can make a distinction between the more traditional philosophical views in which relations are seen in a causal connection to moral agents, and views in which relations are understood as constitutive of moral agency*. A causal connection between relations and moral agents is a connection most philosophers agree on. Moral agents have come to be what they are in relations to their parents or educators. This view however leaves the picture of moral agency that Crouch and Elliott criticize unquestioned. The "relational history" of moral agents is still compatible with pictures in which moral agency is abstracted from specific social roles and commitments. We adopt a view in which relations are seen as *constitutive* of moral agency. Relations are the background against which moral agents define their responsibilities, and they are part of what is reestablished; damaged, repaired or negated by the way responsibilities are taken. There is no way of understanding moral agency of donor-candidates without some knowledge of relations to the child and to significant others in the process of care for the child in need of transplantation.

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* c.f. Marilyn Friedman (2003) for the distinction of these two theoretical connections; causal and constitutive. She discusses the connections between relations and autonomy.

A more practical question generated by a relational view of moral agency is, what exactly professionals should look for in these relations. An evaluation of relations in the judgment about consent to donation can be highly impractical and intrusive. For example, healthcare professionals could look at family-relations to find out about "who the donor-candidate really is", and whether donation is coherent with the life story of the donor-candidate. The next thing professionals might want to know is whether the role in which donation seems to fit coherently is accepted freely by a parent or not. These questions might seem relevant if we want to understand to what extent parental liver donation can be free, but they are alienating in a situation in which a child's life and the families wellbeing are at stake.

Judgment about the relational aspects of moral agency and freedom of consent should keep a focus that is limited to the situation and decisions at hand. When a child becomes critically ill and in need of special care and transplantation, its parents and sometimes other family-members have to redefine their responsibilities. In this process parents' perceptions of themselves and their relations to family and friends can change dramatically. This process of parents, responding to the special caring needs of their child is the process in which professionals can evaluate the significance of relations for the moral agency of donor candidates. Does the moral agency of a donor candidate find articulation in her relations to significant others, or does she seem to disappear in these relations?

Spital and Crouch & Elliott thus have introduced two important premises in the discussion on donors' voluntary consent: people are relational moral agents and LRLT is a family matter in which some form of involvement of other family members in the decision-making processes is important. Crouch and Elliott warn that this involvement must not be misunderstood as signifying a lack of freedom and that transplant teams must take this into account in the requirements of informed consent. We adopt this relational view of moral agency with the addition that relations can be both, enhancing and restrictive of autonomy. In order to contribute to the donor decision-making process the interpretation of living donor voluntary consent must be based on a relational view of the moral agent. When parents state that they have no choice, they point out that their options are restricted by what is most important to them. These perceptions of parents should guide questions about autonomy and voluntary decision-making to questions about the quality of commitments and relations involved in the decision about parental liver donation.

Close family-involvement and the experience of having no choice, is not the only issue that poses questions about voluntariness. As parents in our interviews show, the prospect of living liver donation often incites strong emotions. We will argue that the interpretation of these emotions is a complex but important component of evaluating a voluntary consent to donation.

EMOTIONS POSING QUESTIONS ABOUT VOLUNTARINESS

Emotions of parents can put professionals on different tracks when evaluating the voluntariness of consent. Voluntary consent requires a state of mind that in some way endorses the proposed living donor procedure. When parents show strong emotions about the decision to donate, professionals can interpret this as resistance to donation and thus see reason to probe deeper into the voluntariness of a decision. Emotions are important landmarks in a decision-making process. However, we will point out that these landmarks are not unequivocal. Emotions can be given different interpretations and consequently guide the steps in the decision making process in diverging directions. Emotions can pose questions about voluntariness, but we should beware of deducing direct answers from emotions about voluntariness.

We will further explore these two experiences, having no choice and strong emotions, in the story of Margaret. Her story makes clear that emotions can be interpreted in different ways during the decision-making process.

Margaret is the mother of two children. Her daughter is eight and her son a year and a half. Her son had a liver transplant a few months ago. During the interview he was home playing on a rug on the floor, but before the transplant he was in hospital for several months. His condition was so critical that he could not go home. Although his was an urgent case on the organ donor waiting list, it took a long time before a suitable donor liver was available for him. In this waiting period, during which her son could have died at any time, Margaret was screened for living liver donation. Her husband had offered to do this first, but his blood type did not match so Margaret had herself examined to see whether she might be able to donate a piece of her liver to her son. This screening process was complicated, however, by her fear of the donor operation. This fear made her decision-making more difficult and interfered with her contact with medical professionals.

> Margaret: 'It also didn't feel right because my stomach hurt when the man [the screening physician] showed up. That was of course because I'd registered and I thought I had to go through with it, but I really wasn't convinced.'
> Interviewer: 'Hmm.'
> Margaret: 'I was frightened. I was terribly scared.'
> Interviewer: 'You didn't agree on an emotional level?'
> Margaret: 'Yes, that's it! When I saw that man – brr, there he is again, I thought.'

The internist responsible for donor screening noted that she was having a lot of trouble with the prospect of the donor operation. He asked her whether she really wanted to donate and did not get a clear answer. Her choice of words in the interview also raises doubts as to her will to donate a piece of her liver: *'... but I really wasn't convinced.'* As the interview continued, however, it became clear that although her fear did indeed get in the way, she did not want that to stop her. She reported that she wanted to do everything she could to save her child's life and that it would be awful if they were to refuse her as a donor on account of her fear.

Margaret indicated that as a mother she had no choice, that this was something she *had* to do:

> Margaret: If you look at it rationally then of course you eventually realize: there is no choice.
> Interviewer: Yes, other people say the same ...
> Margaret: It's not about people, but as a parent I think that ... I think that as a person there's a choice, but not as a parent. It's just a shame that things have got to be this way.

Margaret here endorses what Crouch and Elliot explained, that feelings of obligation are part of "the moral agent in the family." When the interviewer uses the general denominator "people," she emphasizes the relational basis of having no choice, by specifying that it is parents who are bound to opt for donation. The fact that she wants to become a donor in spite of her fear is an expression of who she is as a mother and of what is most important to her. Still the fear makes it hard to back her own decision.

Margaret has herself screened for liver donation in spite of her fear. The explanation she gives resembles that of the other parents interviewed: *'as a parent you have to, you want to, you have no choice.'* The decision is connected to who she is and wants to be, as a mother of her child. In that sense, she is autonomous. But when the screening proceeds Margaret looses her grip on herself. Her fear interferes in her relation with the gastro-enterologist, raises questions about her voluntariness and makes the burdensome time with her sick child even more stressful.

Fear of donating is an emotion which professionals can handle in different manners. The ways in which emotions guide the process of deciding depend partly on the questions they ask about these emotions.

When framed in the informed consent procedure, fear will prompt questions about the voluntary nature of donor candidature. Margaret was frightened and the signals she gave off raised doubts as to how prepared she really was to donate. From the interview, however, we might infer that her decision making process was probably helped more by extra attention and support than by skepticism about the decision itself. For Margaret, fear was not a reason to abandon living liver donation. In the other interviews in which fear played a role, and in two other studies on LRLT donor decision-making, these findings are confirmed (Crowly-Matoka et al. 2004; Forsberg et al. 2004). The perception of the screening experience is often marked by this fear, but it does not always limit willingness to donate.

Professionals can thus see fear as a reason to question the voluntariness of the decision or as an occasion to give the donor candidate extra support.

What indications can we get from emotions about voluntariness? The question about voluntariness is a very important one to address when emotions show that someone is struggling with the prospect of donation. Emotions can have a signaling function. Nevertheless emotions by themselves don't answer these questions. There is no direct unmediated relation between emotion and the will to do something. If we want to address questions about voluntariness we have to ask more generally what emotions refer to.

In the interview Margaret admitted that her fear had to do with her responsibility to her other child, a daughter also in need of special care: Margaret**:** *'Yes, that [the risk of dying] is the reason why I initially didn't want to do it because we also have a daughter who needs special attention. I thought then, "ok great, he needs a piece of liver, but my other child also needs a living mother.."'*

Regarding the question as to whether the chance of complications put her off she reported:

> Margaret: 'But the worst part of dying was far, far worse – not that I'm scared of it, but for her [daughter]. Then he [husband] would be left behind with a child saved by a piece of my liver. He'll have lost his wife and friend and the children would then no longer have a mother ...'

We have indicated above that the decision to donate is strongly motivated by who the donor is and wants to be for the child as a mother or father. The interview extracts conform to the view in which relations are seen as constitutive of a moral agent. Margaret here shows that this disturbing emotion, her fear, was also tied up with who she is for her other child and husband.

This fear also expresses what she means and wants to mean to others. Once this comes to the surface, fear makes clear that not only her son, but also her daughter and husband are important to her. When fear is interpreted, the involvement of others concerned in her decision is acknowledged.

However, as we argued before, the importance of others involved should not preclude a critical evaluation of relations. These relations are the context in which she articulates her responsibilities in the process of dealing with the disease of her son. The quality of these relations should be involved in the evaluation of consent to donation.

This interpretation of fear does not answer questions about voluntariness, but it creates conditions for addressing them. When fear is given an explicit place and meaning, the personal significance of Margaret's decision can become clearer for all concerned.

We argued that emotions should be taken seriously in questions about voluntariness. Emotions are important landmarks in the decision making process. They can be difficult to understand, and they do not lead to direct conclusions about voluntariness, but nevertheless their relevance in the decision should be assessed.

CONCLUSION

Parents presented with the option of LRLT must make a decision which can have dramatic consequences for themselves, their child and their family. Because their child is seriously sick, parents often do not see donation as a choice for they want to and must be ready to do this for their child. Yet some parents struggle with their emotions about living donation which make it difficult for them to be completely convinced of the decision. We have attempted to outline how the experience of 1. having no choice and 2. those emotions that seem to dispose against living donation, can be interpreted in relation to questions about voluntary consent.

When interpreting voluntariness in cases of parent-child liver donation, it is important to come to a proper understanding of the family engagement. In traditional interpretations of informed consent a strong commitment seems to be at odds with the requirement of voluntariness. However, when voluntariness is linked with independence we can do no justice to parents' decision-making. By contrast, when we interpret voluntary consent from the perspective of a relational view on moral agency, justice can be done to the strong bonds between donor, recipient and other closely involved persons. The experience of many parents of not having a choice should guide the attention of professionals to the family commitments and relations that are central in the process of caring for their child. Relations can open as well as restrict ways for parents to redefine themselves and their responsibilities in response to the illness of their child. Whether relations are supportive of autonomy in the decision about donation depends on the quality of these relations.

In addition to the feeling of having no choice, the emotions of donors about the prospect of donation can also raise questions about voluntariness. Some parents who consent to the donor screening have emotions like fear or anger about donation. Such emotions can disrupt decision-making. These emotions seem to contradict what parents do and want when they agree to be screened for liver donation.

Emotions are relevant to questions about voluntariness, but they are not unequivocal. The emotion of fear can put conversations with professionals on different tracks in the decision making process.

Margaret's interview made clear that her fear of donating was bound up with concern for herself and her family. If parents, professionals and others concerned make space for these emotions and if they interpret them, they can clarify what living organ donation means to the donor candidate. Although not all emotions back up the decision to donate, they do point out what is important and of value to a donor candidate. The interpretation of emotions creates an understanding of the decision making process with which questions about voluntary consent can be addressed.

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Donor-risk Communication in families considering living related liver transplantation

CHAPTER 6

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ABSTRACT

In the process of decision making about LRLT, the donor-risks are regarded differently by different participants; family members and professionals. This paper explores communication about the donor-risks in family-processes. Risk-communication is commonly framed as an informed consent issue; however, some of the problems or qualities of risk-communication in families are difficult to grasp in the terms of informed consent. Risk-communication plays an important role in the transitions a family is going through, and in giving significance to changes. We propose that besides adhering to informed consent norms, good donor-risk communication should also be supportive of the changes that a family is going through when LRLT is considered.

Submitted

When healthy individuals consent to undergo an operation solely to benefit another, the communication of the risks of that operation bears a special weight and significance. Risk communication can change processes of decision making and shape the moral significance of decisions to donate or not to donate, supporting but also disturbing the complex collaborative endeavors of care and decision-making within which this communication takes place. It can be difficult to tell what constitutes good risk communication. This paper addresses the question of what good risk communication, in the family context of living related liver transplantation with pediatric recipients, might be.

In the bioethics literature, risk communication has been most discussed as part of informed consent procedures. Without denying the importance of informed consent, we direct attention to other interactions and processes in which risk communication gives and gains significance. To address our question we explore the significance of risk communication in the processes of change going on when a family is considering the option of living related liver transplantation (LRLT).

Risk-communication gains and gives significance in family-processes that overlap with decision making. Good risk communication, we argue, should be understood in the context of giving significance to transitions in the family, not only as an unhampered exchange of information between potential donor and professionals. Because families in which LRLT is considered are going through a time of great turbulence, we believe good risk communication must be supportive of the transitions that families are going through.

This discussion of donor-risk communication is based on a study that is part of the research project entitled "Living Related Donation: A Qualitative Ethical Study," carried out at the University Medical Centre Groningen. For this study we conducted semi-structured interviews with 22 parents, two uncles, and one aunt of 12 families who had considered liver donation for an infant transplant patient. A short conversation was held with a second aunt in the course of the interview with her husband. This conversation is also used in this paper. In four families LRLT had been done, in the other eight families LRLT had been postponed or abandoned for various medical or psychosocial reasons. If LRLT was postponed it was often kept as a safety net; the family would wait for a post-mortem donor liver, but before waiting became too dangerous for the patient, they would do LRLT. In these eight families the patient had been transplanted with a post-mortem graft. In addition, we observed the weekly meetings of the liver transplant team and in the outpatient pediatric clinic.

The views in this paper are developed on the basis of observations and interviews in one liver transplant center with its own ways of handling donor risks. Yet, we think that our proposed ways of framing and evaluating risk communication can be of broader use to other centers and ethicists as well.

We first sketch the processes in two families considering LRLT. When framed by informed consent norms as they are commonly understood, it is difficult to make sense of some of the problems with risk communication in the two families. To make sense of familial attitudes toward risk and to identify relevant criteria for assessing good risk communication, we situate our discussion within the collaborative family processes we observed in our study.

We write about risk communication as different forms of verbal and nonverbal communication, not only between professionals and potential donors but also between parents or among other family members. In our view, good risk communication does not only depend on the professionals who disclose risk information; it also depends on family interactions that are beyond the control of professionals. However, professionals can play an important role in what goes on in the family. Although professionals cannot lay down the terms for risk communication in the family, they can adjust their own 'share' in these conversations to family processes.

COMPLICATIONS IN FAMILY PROCESSES

We first sketch two complicated family processes. In our study they are exceptions rather than exemplary cases, but they can help us draw attention to aspects of risk communication in families that often go unnoticed when they go well.

When Baber needed a liver graft from his uncle Jamal, his transplantation became a contentious event. This uncle had a special bond with his nephew, since he had always joined Baber's family, of Asian origin, in the hospital as an interpreter. He was the best Dutch-speaking member in the family. When both parents were deemed medically unsuitable as donors, Jamal volunteered to donate. Jamal's wife reports that she had been very scared: *'I was very scared when he was going to donate; I didn't know what would happen. I tried to stop him, ... but he didn't listen to anybody, he only saw the baby* [Baber]. ...

He told me there was a small risk only, but even then I was scared.' In this short account of fear about what could happen, she recalls her husband's disregard of risk: he thought the risks were small and he listened to nobody: *'he only saw the baby.'* Professionals seemed to have a more remote and mediated presence in her account. When her husband told her that there was a small risk only, he summarized the general message he had picked up from professional risk communication. However she was neither impressed nor reassured by this communication. Jamal indicates that she and other family members had heard other, more frightening stories about living donation. Jamal found the risks small and acceptable, but the rest of his family had very different ideas about the magnitude of the donor risks.

Since nobody could stop Jamal, Baber's parents were pressured by other family members to refuse the offer to donate. Baber's mother reported, *'We didn't want him to donate, (me and my husband) because if something would happen to him, we would feel very guilty and ashamed before the family; we were very scared.'* However, they were also pressured by Baber's uncle to accept his offer. He first tried to persuade the whole family by explaining how thorough the screening procedures for donor candidates were. When the parents, fearing the reproach of other family-members, later continued to oppose LRLT, Jamal put them under more pressure. Uncle: *'I told them; you heard what the professor said; he has no more than four weeks to live if we do not operate him now. What do you want? ... If you give up on your child, please give him to me.'* This way of framing their decision put Baber's parents in an even more difficult position. They kept wavering, agreeing one moment, withdrawing their consent in the next moment. Finally, after the mediation of a generally respected great-uncle, Jamal managed to get their consent to his giving Baber a piece of his liver. After the transplantation, both Baber and Jamal recovered. Jamal was a family hero; however, Baber's parents still had a difficult relationship with the rest of the family.

In another family, Elske, mother of a liver transplant patient and one of the potential donors, was overwhelmed by the information about donor risks: she kept fretting about them, unable to make up her mind. The aunt of the patient connected doubts about Elske's possible donor status to specific expectations she had of mothers: *'because I thought, being a woman, she is the one who keeps the family rolling, what happens if she is in the hospital?'* In the interview with Elske and her husband, the differences in the way they discuss living donation and its risk is striking. To Elske it was a practical and religious issue, brought home to her by other family members:

> ‘I was also more sensitive to comments of others ... like how will things go with the family if you have medical complications, such things ... or are we not going too far? [from a spiritual viewpoint] ... I’ve never faced such difficult things’

To Elske’s husband, who was also screened, living donation and its risk had been a more intellectual and religious issue. In the interview he never mentioned practical concerns about family care and positioned himself as a more independent thinker, less sensitive to comments of family members. He had studied Bible fragments that could have a bearing on the question, and he had thoroughly considered all the risk information given by professionals. Moved by the suffering of his son, he became convinced that he should pursue living donation. Elske’s concerns did not seem to have any salience to her husband; according to him, she was under the influence of the more traditional side of the family, where such things were difficult to discuss. Elske herself, keeping the family rolling, seemed to lack space and peace of mind to determine her position about living donation or to consider its risks. She felt very frightened, but she also felt unable to refuse to donate. *‘You don’t know what you’re at ..., what will happen to the family if something happens to me, these things. They were the most difficult things I ever encountered.’* This made it difficult to give the risks and risk-related fears a place in the decision-making process. She entered the donor trajectory, although thoughts about worst-case scenarios kept haunting her. Risk awareness seemed to be paralyzing to the degree that refusal as well as consent to donation was extremely difficult.

DONOR-RISK COMMUNICATION; GIVING SIGNIFICANCE TO CHANGES

Elske’s fretting response to considerations of risk and the familial tensions in Baber’s family point to problems with donor-risk communication that have rarely been discussed. These problems can only be understood if we pay closer attention to the family setting in which living liver donation is considered. Up till now the communication of donor risks has been discussed mainly as an issue of informed consent. Those discussions are primarily concerned with donors’ frequent disregard of the risk to themselves. Such disregard of risk has been observed in other studies and was also reported by different respondents in our study (Fellner & Marshall 1968; Fellner & Marshall 1970; Crowly-Matoka et al. 2004; Knibbe & Verkerk 2008). Several ethicists point out that these donor attitudes call for a rethinking of common models of informed consent and autonomous agency (Sauder & Parker 2001; Spital 2004; Crouch & Elliot 1999). The fretting response to risk communication poses fewer problems in view of informed consent norms as they are commonly understood, because this response seems to testify of awareness of the donor risks involved: the information about the possibility of death or of compromised recovery after donation has clearly been picked up by those fretting about risks. Yet this risk awareness can be disturbing or troublesome in the experience of parents as potential donors.

The problems we sketched above can be viewed as problems of adjusting and giving significance to the turbulent changes in family life brought about by the infant's life-threatening illness. We propose to see informed consent – and the medical accountability for harm and risks that depends on a valid informed consent – as only one of the normative contexts for risk communication. The communication of donor risks also serves another goal: to be supportive of the changes a family is going through. Jody Halpern and Margaret Little point out that risk communication should take into account that people can only do something with the information given if they are able to maintain a sense of themselves and a sense of meaningful connections to a world that is relatively safe and familiar (Halpern & Little 2008). In the context of living related liver transplantation this task of maintaining or finding a new sense of self and (life-) world is a collaborative family process. Risk communication has an important place in this family process; however, its role should not be overestimated. It cannot solve all problems that may arise in the stressful time leading up to transplantation. It can make adjustments in a family go better or worse; however risk communication itself also depends on these processes. This two-way connection makes good risk communication in family settings a complex issue. To understand what went wrong in the above described cases, and how such things can go better, we use other examples from our study. With these examples we explore how risk communication was situated in different family practices.

FAMILY PRACTICES

We here discuss two related practices in which the donor-risks were placed. The first is the practice of family-care, which involved responding to changes and needs of the sick child as well as providing continuity in spite of the child's life-threatening disease. The second practice concerns the maintenance or re-articulation of family relations that were sometimes challenged by different attitudes toward LRLT and the risks it involved. By how they attended to risk, respondents positioned themselves differently in relation to the potential recipient, other family members, and professionals. In our exploration of the ways risks were communicated in these processes, we also propose an understanding of what went wrong in Baber's and Elske's families.

Family care: change and continuity

When a child needs a liver transplant, its parents can consider living liver donation (and its risk), but they also must find a way of living with their child's disease, the extra burdens of care and uncertainty about their child's future. The family life they had lived before can not continue in the same way; their world changed when their child fell ill. However, for the sake of their other children and work, parents often try to retain continuity in some respects: they try to maintain a presence, pay attention, engage in caring activities, or cultivate a stable state of mind. The threats to the child and the sometimes extraordinarily high demands of extra medical care can make it difficult to provide this continuity. To cope with this highly demanding situation, parents regulate activities, attention, and emotions in specific ways. Role divisions between parents and professionals help to distribute burdens of care, including emotional burdens. In families with more children, it is often mothers who stay in the hospital during hospitalization of the sick child, while fathers stay more at home with the other children. To some fathers this has been reason to prefer themselves as liver donor, above their partner; it would be fair because she already has so much to deal with. Attention to the risks of donation can also become one of the 'burdens' that are distributed.

If we follow how attention to donor risks is distributed among family-members and professionals, good risk communication can be viewed with the kind of critical perspective on gender or other inequalities with which divisions of labor or distributions of burdens in care are often viewed. Gendered divisions in care for the sick child and family can make things easier; however, as is often the case with role divisions, they are not always well balanced. In some families, it seems that mothers carried the heaviest burdens of care. Elske's fretting responses to risk communication can be placed in this context. It is difficult to sketch role divisions on the basis of interviews. The frayed edges of role divisions often become more visible in what people do than in what people say about them. Yet, some differences in the stories of Elske and her husband can help to lay out the precarious position Elske found herself in. In the interviews in Elske's family, it seemed that the continuity of family care was particularly dependent on her. In this precarious role she could not find the peace of mind to give attention to donor risk a place in her decision; she did not consider the risks; instead, she was haunted by worst-case scenarios. Rather than making up her mind, she postponed the decision and hoped that the doctors would decide she was not a suitable donor.

Although Elske did not become donor in the end, her reception of donor-risk communication seems similar to donor experiences described by Forsberg et al. They write: *"Decisions were arrived at and preparations were made, often with the donor in a state of mental stress and traumatized by the whole situation"* (Forsberg et al. 2004). Instead of enabling potential donors to decide and prepare, risk awareness undermined their capacity to respond to the problems of their situation.

For a further exploration of role divisions in attending to donor risks, we draw two other examples, in which risk communication seemed to be more supportive of the changes families were going through. In these examples respondents make clear that their attitudes to donor risks were responsive to the attitudes of others.

Hans, a donor candidate, indicates that although the risks didn't matter to him personally, he knew that his wife, Barbara, was worried that something would happen to him, and he cared about how she felt: *'For myself I wasn't bothered by the risks, but for my wife I was. She would have to bring two to the operating room, and for her that was very difficult.'* Barbara confirms that she had been more worried about risks, although she tried to focus on positive expectations. The risks had a place in their decisions through Hans's considerations of his wife's worries.

Parents also adjusted their attitudes toward risk to the impression they had of professional ways of handling risks to donors. Melle's parents for example said that they had paid little attention to these risks. His mother asserted: *'The risks didn't play a role,' and the father reported: 'We knew there were risks, but we did it for our child, end of discussion. We did not consider the risks.'* However, they also reported that they knew that the transplant team was very concerned about donor risks. The parents didn't try to get a thorough understanding of the risks, but they understood that the professionals had this thorough understanding and concern, and the professionals' concern was meaningful in their own considerations.

These examples show that parents had diverse ways of lending salience to the attitudes of others in their own thoughts and feelings about donor risks. By their consideration or disregard of risks to themselves, they positioned themselves differently with regard to family care as well as decision making. When a potential donor had seemed very determined to pursue donation, her partner often gave more attention to the possible drawbacks of living donation. The example of Hans and Barbara shows that in these collaborative processes, the risks could sometimes be weighed without potential donors' themselves giving direct and explicit attention to risks. Attitudes of potential donors and others around them complemented each other; disregarding risks enabled potential donors to be strong and positive, while they could rely on others to consider and prepare for possible bad outcomes. In such cases, the attitudes of partners supported each others significance like interlocking pieces of a puzzle.

When the attitudes of family-members toward LRLT and its risk are not mutually attuned and responsive, it is difficult to manoeuvre through the changes that a family is going through, and make sense of them. Elske found less space to negotiate her position in family care. She was placed in a social scheme that was difficult to revise. In this scheme, role divisions were less flexible, making mutual attuning of attitudes toward risk difficult. With five children, one of whom had a life-threatening disease, Elske had great difficulties meeting all the demands of care made on her. In this position she could hardly think about the additional problems posed by living donation and its risks. She found herself alone with concerns that had no salience to her husband and with too heavy a burden of care. Meanwhile, her husband interpreted her attitude toward living donation and its risk as susceptibility to traditional religious arguments, paying less attention to her practical worries nor to her lack of space in which to make up her mind.

Maintenance of relations

The measure of readiness to donate or to accept an offer to donate can potentially be seen as an expression of one's commitments to the recipient or others. Different risk attitudes and reactions to the option of living donation can confirm as well as challenge relations in the family. In Baber's family, Jamal saw living liver donation as an affirmation of the special bond he had with his nephew. Many other family members had made it clear that they would blame Baber's parents for any resulting harm to Jamal if they gave their consent to LRLT. Jamal on the other hand tried to convince his family that donation was his own decision and responsibility, and that any harm to him could not be blamed on Baber's parents. He did, however, reproach Baber's parents for withholding their consent to LRLT and thereby endangering the life of their child. Baber's parents had very little room to articulate their own position. They didn't manage to position themselves with regard to the donor risks. Instead, the risks and the family's opposing understandings of risks positioned them, either as blameworthy or as careless parents.

In contrast to Baber's family, other families often tried to give differences in attitudes toward risk a less challenging place in their relationships. Because living donation can damage these relationships, the attitudes toward living donation and its risk often needed active interpretation in order to reduce pressure and create space for potential donors to determine their own position. These efforts to maintain or rearticulate relations that were challenged by the option of living donation could be more or less successful.

Parents often showed their acceptance of different attitudes toward LRLT and its risk by giving explanations that had no connection to the relation with the child. Different attitudes could for example be ascribed to a different relation with medical practice. About Caspar's father, Caspar's mother explains: *"He is actually not really a hospital person, even the smallest needle horrifies him, so he could not picture this [becoming a donor] for himself, but he said this with tears in his eyes, he found it horrible."* Margaret had been terribly afraid to donate, but her husband indicates that he tried to do justice to their differences in attitude by accepting her limits and respecting them: *'You can never reproach each other, for example, by saying, "You could have donated" if our son were to die – that would be very unfair. Margaret does everything that is in her power and I do what is in my power.'*

Potential conflicts or tension came closer to the surface in Jonathan's family. Jonathan's parents represented their different attitudes toward risk as differences in character. His mother explains that she had been very enthusiastic when she first read about LRLT, while his father had mainly remembered the part about risks. *'We always picked up different things when we read something. I was more impulsive, he was more cautious or deliberate.'* She thought that risks to her were not relevant if she could save her son's life. Jonathan's father, on the other hand, explained that he would donate if necessary, but that for the sake of his wife and children he took a course with the least possible risks to himself: he was screened and kept living donation as a last resort (as proposed by professionals), and would only donate if his son could wait no longer. Jonathan's mother indicated that their differences in attitude held a potential for conflict: *'If the waiting time had lasted much longer, ... this could have become a thorny issue, because we had these different views.'* However, she also pointed out how this potential conflict had so far been avoided: *'But I have always said to myself, "I respect that he wants to donate [under certain conditions], and I have an opinion about it but not a voice in the decision."'*

When parents were unable to become donors and the option of donation was introduced in the wider family circle, the relations between nuclear families became an issue. In John's family, John's uncle had been screened as a liver donor for his nephew. Both John's family and his uncle's lived in the same street and supported each other in many ways. Being so close, it seemed logical for the uncle to see himself as the next candidate after the parents were refused. He and his wife gave a lot of thought to the risk involved. The risks were also a relational issue. The aunt said: *'I thought; what if you become handicapped or even die, can we still look them [John's parents] in the eye, or will it start agonizing, like "was it worth it?"'* But on the other hand, the uncle indicated;

> 'My decision is about two sides, [my family and my brother's family] there is also the other side, ... my decision could also bring it about that John dies. ... Of course my brother said, "If you refuse I will not reproach you." He said that, but of course you can say something like that ten times, but it feels different, as if I decide about John, and that is quite something, in fact, you decide about life and death.'

Both uncle and aunt became more convinced when they saw John in his heartbreaking condition in the hospital. They also felt more positive about living donation after conversations about risks with the surgeon and the internist who did the donor screening.

With their efforts to protect relations from reproaches or tensions that could be raised by different attitudes toward the risks of living donation, family members tried to create space for potential donors and others in the family to negotiate their own position. Respecting differences or interpreting them as part of someone's makeup or personal limits could help to take pressures away in the course of decision making. However, John's uncle and Jonathan's mother indicated that tensions or pressures could arise in spite of these efforts. When the condition of the sick child became more urgent it could become increasingly difficult for family members to nurture their relationships and repress tensions or pressures.

Good Risk Communication

When LRLT is seen as a family matter and risk communication as a collaborative process that gains and gives significance in changing family circumstances, good risk communication must adhere to norms that go beyond those commonly posed by informed consent. The soundness of an informed consent procedure depends on the reliability and intelligibility of the information given, and on the capacity of potential donors to understand the information. In the family contexts that we explored, however, other insights and values attach to risk communication. As the cases of Elske and Baber show, risk-communication here is partly governed by the normative expectations that govern family-relationships. Such normative expectations are often gendered, class bound and formed in specific religious or cultural communities*. We propose that good risk-communication needs to be critical of inherited normative expectations toward parents or other family-members involved. The cases described above about how challenges to relations were addressed can be seen as an example of how family members push back against normative expectations. Good risk-communication in families depends on whether family members, facing changes, manage to push back against the inherited normative expectations, in order to really explore future changes. Here, the capacity to completely understand information about risks seems less important than forming good interpretations about the significance of the donor risks in the family and good responding to the attitudes of others toward these risks. In the stories of our respondents, it is difficult to isolate risk communication from other issues; it is strongly interwoven with other family processes. Good risk communication is dependent on the space that family members manage to create for each other through interpretations of attitudes and their significance for familial relations.

THE ROLES OF PROFESSIONALS IN GOOD RISK-COMMUNICATION

If family processes and risk communication are so closely connected, it is difficult to understand what professionals can do to support good risk-communication. Before we discuss how good professional risk-communication might be understood, we explore what respondents tell about professionals and their communication of risks. In the stories of parents, the roles of professionals in family processes, and the significance of professionals risk communication is diverse.

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* For reasons of anonimity we do not analyse the religious and cultural background in the cases of Elske and Baber.

The transplant team plays a double role in the changes a family is going through. The team helps families interpret and adapt to changes, but it is also a part of the changes: professionals represent the new medical practice in which a family must participate. These roles of guiding changes in family life that result from treating the child's disease and of representing an unfamiliar medical practice can be seen as the two roles in which professional risk communication gains significance for parents or other potential donors in the family. When professionals communicate donor risks, they do not merely sketch possible outcomes and their probabilities; with their style of talking about risk they also show something to potential donors and partners about the kind of medical practice they have entered.

Respondents registered and responded to the attitudes of professionals toward donor risks in different ways. In interviews, respondents remembered very little about the details of the risks that were communicated – the mortality and morbidity statistics or the specific complications that can occur after liver donation. What they remember is the serious tone and emphasis with which risks were communicated and the concerns in the transplant team about these risks. Respondents had collected a general message from this professional communication; in the interviews they speak about small, big, considerable or acceptable risks. As one mother reported: *'They were very clear about the risks, with percentages and so forth, I don't remember exactly, only that there was a big risk.'* As the previously given examples indicate, some respondents felt impelled to give the risks a great deal of thought, whereas others entrusted risk considerations to professionals. When recalling encounters with professionals in which risks were communicated, the two aforementioned roles of professionals alternated. Sometimes respondents took the general message about donor-risk as guidance in their own orientation on questions about living donation, sometimes they took their observations about professionals and professional thoughts and feelings to represent the character of the medical practice they had entered.

Depending on the roles as guides or representatives that professionals receive or manage to play, they have different entrances for supporting risk communication in the family. In a family like Baber's, where stories from different origins circulated about the dangers of living donation, the role of doctors as representative of this unfamiliar medical practice could be an important one. As matters stood, the family (with the exception of Jamal and Baber's parents) had only second- or third-hand stories about living donation and its risk. If Jamal's wife and other opposing family members were invited for a direct conversation, professionals could try to situate the diverse messages and frightening stories about living donors, to try to come to shared understandings about the donor risks and the ways they are handled in this transplant center. When risk information is explicitly communicated as a kind of knowledge that is embedded in a medical subcommunity with certain values, worries, and interests of its own, family members can relate in their own ways to this new and unfamiliar community.

In Elske's family the guiding role of the transplant team, in helping this family handle the changes in family life could maybe be enlarged, to help her make up her mind. The guiding role of professionals in the transplant team (doctors, psychologists or social workers) could be understood in a way similar to that of the "gift-exchange gatekeeper," as Fox and Swazey describe the role played by medical teams in family-processes. They write that since the gift of an organ puts strains on family-relations, gift-exchange gate keeping implies negotiating, mediating and interpreting what happens between family members (Fox & Swazey 1974). In the cases they describe, the involvement of social workers or psychiatrists sometimes brought about significant changes in family-relations, before everyone agreed with the living donor kidney transplantation. It is however the question how far such interference in family-dynamics should go. In Elske's case, the usual conversation that the social worker has with donor-candidates about donation did not help her to make up her mind. As we suggested above, the problem could be that she lacked space and peace of mind to think about living donation and its risk because the whole family was dependent on her, or at least so it was thought. Perhaps good risk-communication in this family would have to be accompanied by an examination and revision of the gendered social schemes. If professionals are hesitant about such far-going interference, the conclusion could also be that the psycho-social conditions in this family are a contra-indication for Elske's donor candidacy.

CONCLUDING REMARKS

The significance of donating or not donating in a family cannot be defined by the potential donor alone; it is carried by different family-members. Attitudes towards donor risks in the time leading up to transplantation account for a great part of the moral meanings. Family attitudes toward the risks to donors and the negotiations and interpretations of risk attitudes in the decision-making process make living donation morally acceptable or unacceptable to family and professionals. At least as important as individual donor considerations are the connections between considerations of risk of the different participants in this practice.

The different attitudes were connected and adjusted in processes of familial care and redefining of familial relations – processes that also interfered with decision-making. Giving attention to risk was often one of the many burdens that were divided in these processes among parents and professionals. With their diverse forms of attention to donor risk, respondents placed themselves, including their fears and concerns, in different positions in the collaborative endeavor of family care and in relations to the patient, donor, or other family members. When different attitudes toward living donation and its risk seemed to challenge family relations, family members often tried to interpret and accept each others' attitudes in more harmless ways, in order to reduce pressures.

In some families, family members took, or allowed each other, less space to negotiate their position in care or in family relations. Respondents did not place themselves; they were placed in a social scheme that was difficult to revise. Respondents' positions in social schemes of family care and family relations could also dispose them to attend to donor risks in certain ways. It seems that a certain fluidity in role divisions and relations enabled families to give donor risks a place in decision making, whereas rigidity of roles or relations could make it very difficult to place the donor risks in the course of decision making.

Although good risk communication depended to a great extent on family processes and relations that are out of the control of professionals in the transplant team, it also depended on the relations between family and team and the roles that the team and its professionals played for a family. In addition to giving intelligible and reliable information, this is something that professionals can take into account as they attempt to practice good risk communication. They can try to get a picture of their own role in family processes, and if necessary adjust the roles they play for a family.

Professionals received different roles in the processes of change a family was going through; they could be seen as guides, or as representatives of an unfamiliar medical practice. In some family's, professionals – as representatives of an unfamiliar practice – can best support risk-communication by expressing the team's concerns about the donor-risks and the ways they are handled. In other families professionals may need to examine how gendered role-divisions have a bearing on the significance of living donation and its risk.

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General conclusions

CHAPTER 7

The introduction of LRLT brought new forms of involvement between the liver transplant team and the family of a patient. The background of moral understandings about parenthood, about what it means to be a good doctor, about good patient-doctor relationships orients the course of decision making about LRLT. The aim of this thesis was threefold: First, I offered a reflective analysis of moral understandings in decision making about LRLT. Reflective analysis involved mapping how participants in the practice of LRLT understood what they were doing. Second, I offered critical reflection on the moral understandings that guide decision making. In critical reflection the authority and adequacy of moral understandings are examined. Most of the reflection offered in this thesis consisted of critical reflection. The third aim was to offer normative reflection on moral understandings about LRLT. Here the question was whether moral understandings about LRLT practice were really good or whether better understandings could be imagined.

In this concluding chapter I will summarize the different forms of analysis and reflection offered in the previous chapters. Furthermore, I will point out how critical reflection offered in the chapters two three and five together can be taken as groundwork for normative reflection on autonomy in decisions about living liver donation. The concluding chapter consists of two parts: first I summarize the reflective and critical analysis of team processes on the one hand and processes of potential donors on the other hand. Second, I offer some normative reflection on moral understandings about decision making and I point out how the critical analysis of these processes may foster further normative reflection.

MORAL UNDERSTANDINGS ABOUT LRLT

Team processes: Changing the moral landscape

The team processes in which responsibilities with regard to living liver donation were negotiated can only be understood in the context of problems of organ shortage and measures that were taken or that failed to be taken to address them. It must be remembered that the liver transplant center in Groningen started offering LRLT as one strategy among several others, all of which formed an important background for the team's views on the moral acceptability of living liver donation. According to the maxim of primum non nocere, the use of healthy persons as liver donors would only be found acceptable when other ways of solving the organ shortage problems had been exhausted. These other ways depended on steps taken in this transplant center, but also on national policies.

In the transplant center, steps included the use of split-liver transplantation; domino transplantation; the use of non-heart-beating donors and loosening the criteria for donors. Another approach to waiting list problems, restricting indications for liver transplantation, was often discussed but never adopted. Not only was it difficult to decide at the team level that some patients would not get a chance of a life-saving treatment, such a restriction in indications for liver transplantation also required a change of policy on a national level if it was to be effective. Finally, it was thought that the donor pool could be expanded if the government changed the current opt-in system into an opt-out system for organ donation. In sum, while the team itself had adopted a set of measures to expand the donor pool, some potential ways of addressing organ shortage problems at the national level were not realized. It was in this context that LRLT was introduced, even though there were still moral reservations in the team about the acceptability of operating on living liver donors.

The process in which team responsibilities with regard to LRLT crystallized can be characterized as a process of careful change. The pressures on professionals and parents to pursue the option of LRLT were carefully managed as far as possible: first the child would be put on the waiting list for postmortem liver transplantation, and only if waiting would lead to an unacceptable deterioration of the child's condition would the team opt for LRLT. In the communication about living liver donation the risks of donation were given particular emphasis. The advantages were discussed more cautiously, with an accent on the time frame: LRLT offered the possibility of choosing a good moment for transplantation. What such a good moment would be was not clear in advance, but would become clear in the course of frequent contacts with the child and family during which the stage of liver disease and condition of the child were assessed.

This cautious approach was a variation on the approach used by many transplant centers and recommended by the Health Council, namely, that a living-donor trajectory should always be paralleled by registration on the waiting list:

> 'These patients should always be put on the waiting list for transplantation with a postmortem donor, also when living donation is chosen. If a postmortem

> donor offer is made during the preparations for living donation, the postmortem offer should be given preference.' (Gezondheidsraad, 2003) (p. 171, translation MK).

As opposed to the more tentative decision making in this center, the Health Council pictured an early choice about the strategy to be followed for a particular child, even though this choice could be overruled by the offer of a deceased donor liver. In its recommendation to start offering LRLT for children the council argued that although no significant difference in survival rates had yet been demonstrated between LRLT and DDLT, it was plausible that pediatric patients had a better chance of survival if they did not have to wait for a postmortem liver donor (Gezondheidsraad, 2003). Choosing and preparing a LRLT trajectory while enrolling the patient on the waiting list for a postmortem donor liver would probably be the best way of optimizing patient health outcomes in a strictly medical sense. However, because of moral reservations and because the transplant team was aware that many parents would not consider living donation as a matter of choice, they structured decision making in another, more tentative way. Also, as will be explained below, the understanding about good outcomes of LRLT was broader than the patient and graft survival.

Starting with their first explanations to parents, pediatricians played an important role as architects of the moral space in which LRLT was considered by different parties. By their cautious tone in discussing advantages, pediatricians tried to avoid two kinds of pressures: those placed on the team by enthusiastic parents urging them to pursue the living donor option, and those placed on parents by a team who presents LRLT as the best option per se. The safety net approach created a sense of time that encouraged parents and professionals to explore their own thoughts and feelings about LRLT in response to changing circumstances of the sick child and family. This approach to LRLT created space for reflection and collaborative decision making in situations in which reflective space was difficult to find.

A disadvantage of the approach to LRLT as a safety net was mentioned before: it was not oriented at obtaining optimal outcomes. This is true from a strictly medical viewpoint confined to transplant recipients: the chances of patient and graft survival, and the recovery of recipients after the transplantation would probably benefit more from LRLT if it were planned in an early stage of the disease. However, good outcomes of LRLT, according to views in the transplant team, encompass more than medical outcomes in a narrow sense. LRLT is a family event that can affect different family members besides donor and recipient, and different psychosocial and economic dimensions of family life. As was explained in chapters four and six, parents and their families go through a turbulent period involving many changes. Practices of parental care have to change when a child needs a liver transplant, and often role divisions and relations between family members also change. Such changes can cause tensions or even conflict if family members do not manage to come to shared understandings of their altered relations and roles. Good outcomes of LRLT therefore encompass more than good medical outcomes n a narrow sense, it also involves a good transition to new practices of family care. The efforts of professionals and parents to explore the significance of LRLT in a family, in spite of pressing medical needs of the child support the transitions that families are going through. Below the reflection on family processes is summarized.

Processes of potential donors and family: Transitional period

To parents, the team's approach to LRLT formed an important part of the moral landscape in which they oriented themselves on questions about living donation. Although the parent-team relationship may look like an obvious one, it is easily forgotten in reflections on whether parents really want to donate. Professionals often discussed the strength of parents' willingness to donate as something that developed independently of the interactions between team and family. If it is recognized that professionals partly define the situation for parents, the will to donate and doubts about donation are put in a different light. This is not to say that parents were completely steered by professionals; they oriented themselves in different ways in this moral landscape. To understand how they oriented themselves, I explored the ways they lived through the time leading up to transplantation.

The time in which parents considered their responsibilities with regard to the option of living donation was a period of transition. The life-threatening disease of their child was often recalled in interviews as a complete disruption of the life they had led before. Parents lived with the knowledge that their child would not be able to live for long with its existing liver but that it would have a good chance of recovery if it managed to survive the waiting time before transplantation. How long the child could wait, and what the chances were of receiving a DDLT in time, was uncertain. The child's condition was constantly viewed as betwixt and between; it could be getting better or it could be getting worse. The option of living donation was often gratefully welcomed, but it also met with mixed feelings. It was a relief to know that their child's life might not be completely dependent on this waiting list with unknown waiting times; however, living donation and its risk brought new uncertainties in the family.

In the interviews parents told about different ways of dealing with this uncertainty and of entrusting to professionals aspects of care for their child and for themselves as potential donors. In chapter three, which was one of the early papers of this research, I suggested that trust should be one of the topics on the ethical agenda of LRLT. However, while trying to understand more about different forms of trust in parents' stories, my attention was drawn to seemingly related but diverse ways of attending to possible future scenarios and all the available information. Parents' understandings about relations with professionals seemed to be part of their specific ways of inviting a future for their child. Instead of zooming in on trust, I tried to set parents' trust in professionals into a larger pattern of their different ways of hoping. In chapter four I described a variety of information-seeking or -avoiding attitudes and diverse roles taken by parents and ascribed to professionals in "economies of hope." The parts that parents took or could take upon themselves to play in care giving and decision making were diverse. Some tried to keep as much control as possible over the steps taken in the transplant trajectory. Others found it more important to be emotionally strong and keep a stable state of mind in the presence of their child and family. These parents preferred to rely more on the imagination and judgments of the team about what should happen next than to confront the disconcerting scenarios involved in exploring their own perspectives and sources of information about their child's disease and transplant options.

Places of donor-risks in family decision making

Professionals considered the quality of their communication about the donor risks to be very important. Surgeons in particular wanted to be sure that donors knew exactly what they were consenting to. The risks of donation were given particular emphasis in conversations between professionals and potential donors. However, professionals had only limited control over risk communication; as argued in chapter six, the risks to the donor were also a topic of intrafamilial concern. Some of the problems with risk communication can only be understood and addressed in these family contexts.

Attitudes toward the risks of living donation positioned donors and partners or other family members differentially in the changing practices of family care. Furthermore, attitudes toward living donation and its risks had the potential of confirming or disrupting family relations. This potential disruption could make it difficult to really think about LRLT and its risks. And so, to create space for each other, family members often gave socially acceptable interpretations of each others' attitudes. In some families however, with more rigidly gendered social and interpretive schemes, there was less space for family members to make up their mind about living donation and its risk. In the normative reflection paragraph I discuss what good risk communication in view of such family processes may be.

NORMATIVE REFLECTION

Economies of Hope

In chapter four, economies of hope were described as the investment and engagement of energy, thought, attention, feeling, and activity made in hoping. Economies of hope can be evaluated as a complement to the informed consent perspective: they connect the dots of what happens in interactions between parents and professionals in other ways. In the informed consent process, potential donors were expected to do specific things; they had to listen to information – especially risk-information – and they were expected to express their wishes. The exploration of different hoping patterns in chapter four gives insight into what other important things parents were doing when they were asked to consider and reflect on information about the risks and benefits of living donation. It was also in these economies of hope that interpretations were formed about the child's condition, the chances of receiving a DDLT in time, the family circumstances, and the need to opt for living donation; in other words, it was within these economies of hope that responsibilities with regard to living donation were negotiated.

When economies of hope are evaluated, questions that go beyond matters of informed consent are asked about the processes of care and decision making. To reflect on the wisdom of specific economies of hope, one can explore whether the exercises of thought, imagination and attention are good investments of energy. One can ask if the hope of a parent elicits a good kind of activity and state of mind, and if it does not lead to neglect of things that deserve attention. Good hope and its "divisions of hoping labor" are also dependent on relations with professionals. Although professionals cannot control the hopes of parents, they can critically examine their own share in these hopes. They can consider whether they can live up to the roles ascribed to them by hoping parents: can they be depended on in the diverse ways parents expect?

Good risk communication

The exploration of significances that living donation and its risks received in family processes invited specific normative questions about risk communication. In this context, a good comprehension of the risks to donors in general, which is considered important in informed consent procedures, is less important than forming good interpretations of living donation and its risks in one's own situation and family. The question here is if risk communication helps the family to make sense of the changes they are going through, and whether the family members involved can find their own position in this process. It is important to pay attention to the social schemes that formed the background for interpretations about living donation and its risk in ones own situation, and to attend as well to whether family members manage to create interpretive space for each other or whether rigid social schemes make it difficult to find this space.

Professionals played different roles in these family processes. Sometimes they were seen as guides in the turbulent time of disease and treatment, sometimes they were seen instead as representatives of an unfamiliar medical practice. Depending on the roles they played for a family, professionals had different opportunities to support risk communication in families. As guides they could support families in handling the changes they were going through. In some cases this could involve questioning the gendered social schemes in a family and exploring possible changes. Where such schemes make risk communication in a family difficult, good risk communication may require a "gift-exchange gatekeeper," a role that was described by Fox and Swazey. As gift-exchange gatekeepers, transplant teams negotiate, mediate, and interpret what happens among family members considering living donation. (Fox et al. 1974)

In Baber's family some family members would not accept professional guidance in their thoughts about living donation and its risk. Part of this family felt that that living liver donation was a strange and dangerous medical practice. Professional support of good risk-communication in this family would require a different approach because professionals had no authority as guides. Here they could take on the role of representatives of the medical practice under discussion, to help family members understand the medical practice in which they were participating, with its values and concerns. If family members would feel more familiar with this practice, it could also become easier to interpret the risks of living donation and their significance for the family.

Good risk communication from the side of professionals can thus require different approaches. Good risk communication requires sensitivity to the social significance of living donation and its risk in a family. Furthermore to support good risk communication between family members, professionals have to explore the roles they can play for a specific family.

Autonomy in decision making about living liver donation

The explorations of team and family processes in which responsibilities crystallize shed a new light on autonomy in decisions about parental liver donation, decisions that often involve a lot of pressure. The teams approach to LRLT was guided by specific understandings about the pressure to donate and conditions for autonomous decision making. Earlier I indicated that the approach to LRLT as a safety net was not directed at obtaining optimal medical results for the patient. This may be a reason to consider offering LRLT in a different way, as a choice that can be recommended from a medical point of view. However if the team would consider such changes it is important to take the understandings about donor autonomy that guide the safety-net approach, into account as well.

The value of the team's manner of creating conditions for autonomous decision making has to be considered in connection with understandings of parents about living donation. Parents frequently said that liver donation is not a matter of choice. As explained in chapter five this experience should be understood in the context of family commitments in which the option of living donation is considered. I will argue that in this context, autonomous decision making calls for specific conditions in which potential donors and family members can explore the significance that LRLT may have for them.

Seeing no choice should not be understood as expressing something essential about parental donors, as was suggested by Forsberg et al., nor does it point to coercion (Forsberg et al. 2004). Instead I propose that the phrase should be understood as indicating that previous choices or pre-existing commitments to the child are seen as more decisive than any of the choices that are made in the course of the transplant trajectory. The phrase sometimes also seemed to be a reaction to the common practice of framing a medical decision as an unfettered choice.

If choice is not an adequate characterisation of autonomous decision making about living parental liver donation, transplant teams need an alternative understanding of the potential donor's autonomy. Annemarie Mol argues that the alternative to choice does not have to be coercion; interactions can be ordered in other ways. (Mol 1997) In the context of family relations and commitments, living donation can come to be seen as something that may become a necessity, depending on changes in the child's condition, the waiting list, and the interpretations that parents develop together with doctors of these circumstances. Decision making about liver donation should not be seen as a matter of choosing, but of interpreting and responding to circumstances in the light of ones ongoing commitments. In itself, this understanding about donor decision making does not have to raise suspicion about the autonomy of a potential donor. The expression "having no choice" indicates that decisions cannot be aptly characterized by choice, even if it involves choices in different moments. Overall, decision making is patterned in other ways by the interpretive space created in interactions with professionals.

Within this picture of decision making as interpretive processes, autonomy is not at issue in a single act of voluntary and informed choice, it is rather something that concerns the transitional period that potential donors and their families go through. One of the challenges of this transitional period that were described in chapter four, becoming accustomed to an unfamiliar medical practice, also has implications for notions of autonomy. The notion of 'conscientious autonomy' put forward by Rebecca Kukla can be useful in this context (Kukla 2005). Kukla describes conscientious action as 'responsible commitment to the norms that govern it' (p38). In this view actions are not autonomous because they were self chosen, actions are autonomous when they are in keeping with someone's commitments. Kukla further argues that conscientiousness or responsible commitment to certain norms or practices require that one is capable of stepping backward and questioning commitments. To become autonomous in this sense, after "tumbling" into an unfamiliar medical practice with its own particular norms and habits, parents have to reorient themselves. They have to learn how to interpret their child's condition, the opportunities and limits of waiting for a post-mortem donor liver, and the risks and benefits of living donation.

Professional concerns about the autonomy of potential donors are therefore best addressed by creating conditions for this process of reorienting, interpreting and responding, not by offering living donation as a matter of choice. The moral landscape formed by the team in Groningen, with its specific ways of discussing risks and advantages of LRLT and creating time and space, offers one example of how such conditions can be created. The cautious approach had impact on the decision making patterns and dynamics. In Chicago, donors have reported that agreeing to donate was an automatic response or a spontaneous, split-second decision.(Crowly-Matoka et al. 2004) In this study in Groningen some parents also reported that they instantly resolved to donate when they first heard about this option. However, as explained in chapter three, this first spontaneous resolve was not yet seen in this center as a decision made by parents; it was merely a first step in the donor trajectory, in which living donation could be considered from moment to moment. In this process, potential donors could explore what living donation and its risks would mean to them and their family.

The analysis and reflection on moral understandings about LRLT generated a broad perspective on good decision making about LRLT: Good outcomes of LRLT involve more than strictly medical outcomes. It also involves good transitions in a family and its care practices. Good donor decision making involves more than autonomy and informed consent, it also involves good hope. Good risk communication involves more than comprehensible and truthful explanations about donor risks, it also involves sensitivity to the family processes in which donor risks gain significance. And finally, a valid informed consent is not a sufficient condition for a potential donor's autonomy, autonomy is also conditioned by time and space for moral reflection in the practice of LRLT.

The insights about good decision making were developed in a study of a LRLT practice in which there was time for mutual fine tuning, reflection, and downplaying pressures. But this very fact also gives a limitation to this study. The results of this research might not be applied to situations in which decisions have to be made under time pressure. Here I have underscored the value of the outlined approach to LRLT. However, one would need to know more about other forms of decision making about LRLT, in order to judge if this is really the best approach to LRLT, and to recognize situations in which quick decisions may be appropriate. Further research is needed to investigate the moral understandings in these kind of situations. It is important though, that these investigations must start with a reflective and critical analysis of that very concrete practice before any normative results can be given.

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SUMMARY

Since 2004 children waiting for a liver transplant can also receive a partial liver graft from a living donor, usually a parent. The introduction of parent to child LRLT changed the character of the involvement between the transplant team and the family of a patient. When this option of living liver donation was introduced, professionals and relatives around a patient faced new responsibilities. Parents of young patients or other relatives had to consider whether to donate or wait for a deceased donor liver graft, whether their family could cope with an extra patient, and if they were willing to accept the risk. Professionals also had to reconsider their responsibilities. Under which circumstances could they account for the involvement in risking the life and health of a healthy donor? How should they handle different views of colleagues on the subject? How could they inform and talk with parents or other relatives about the option of living donation without pressuring them? In the views that parents and professionals developed on such questions, understandings about professional and family relations formed an important background. This background of moral understandings about parenthood, about what it means to be a good doctor, about good patient-doctor relationships surround the course of decision about LRLT.

The aim of this thesis is threefold. 1. To undertake a reflective analysis of moral understandings in decision making about LRLT. Reflective analysis involves mapping how participants in the practice of LRLT understand what they are doing. 2. To offer a critical reflection on the moral understandings that guide decision making. In critical reflection the authority and adequacy of moral understandings are examined. 3. To offer a normative reflection on questions about good moral understandings. Are the moral understandings good or better than others that might be imagined? These different forms of analysis and reflection are intertwined, and they are based on qualitative ethical research.

Chapter two explores how processes of considering living parental liver donation were structured by the Groningen liver transplant team in the first years of its LRLT program. LRLT was introduced in this center in spite of moral reservations about this procedure that still existed in the team. Team members held different views on the acceptability on donor-risks and on the political context in which LRLT was introduced. In interactions with parents, pediatricians pro-

pose specific understandings about LRLT as a safety-net. With this understanding about LRLT they created room for synchronization and collaborative decision making in spite of different views.

Chapter three offers a discussion of the complex roles of the family of a patient. The family of a child in need of a transplant has a double role. It has a role of patient on the one hand, receiving professional care, and of caregiver on the other hand, sharing responsibility with the medical caregivers. In order to reflect on the complex intertwining of responsibilities connected to this double-role, chapter three proposes a change of the agenda of moral questions about living parental organ donation. The moral discussions about living donation usually focus on informed consent, risk-benefit ratio and voluntary choice. Although these issues are important, this chapter shifts the attention to three other, related moral concerns: process, trust, and emotions. These issues were derived from a qualitative study consisting of observations in a liver transplantation team and semi-structured interviews with parents who donated or considered liver-donation to their child.

Chapter four explains the significance of hope in decision making processes. In which ways can the future that parents of liver transplant patient's hope for be present in hoping? And how are professionals involved in the hopes of parents? In this empirical-ethical study about liver transplantation of children and living parental liver donation, the various answers to these questions were mutually related: Ways of attending to the future were geared to the way parents entered relations with professional caregivers and vice versa; relations were geared to specific patterns of hope and inviting a future.

In interviews with parents about the liver transplantation of their child, the time leading up to transplantation is depicted as a period of transition. The illness of their child and the uncertain prospects of transplantation had abruptly interrupted their lives. In this period they had to learn how to live with the child' disease and threats to its future and they had to find their way in a complex medical practice that was new to them. Parents testified to different ways of carving a route through this period of transition. In this process, hope seems to be a central quality.

A focus on the futurity and social character of hoping in this study sheds light on some interesting variations in 'economies of hope'; the investments of thought, attention, imagination and feeling, and in divisions of 'hoping labor' between patients, parents, professionals, or other caregivers. Respondents had different ways of involving others in their hopes. Recognition of these variations in economies of hope is important if we want to estimate the value and vulnerabilities of specific hoping patterns.

Chapter five examines experiences of parents with decision making about living liver donation that raise questions about voluntariness. Parents' perception of having no choice and strong emotions like fear about the prospect of living liver donation can lead professionals to question the voluntariness of their decision. This chapter offers a discussion of the relation of these experiences (no choice and emotions), as they are communicated by parents in our study, to the requirement of voluntariness. The perceived lack of choice, and emotions are two themes that were found in the interviews conducted within the "Living Related Donation; a Qualitative-Ethical Study" research program. As a framework for the interpretation of these themes views of moral agency are discussed. We adopt a view in which relations are seen as constitutive of moral agency. Judging from this view, the perceived lack of choice can best be understood as a sign of commitment. This chapter argues that neither seeing no choice, nor emotions in themselves should be seen as compromises of a voluntary consent. However both experiences draw attention to aspects that are important to come to an evaluation of consent to donation. The story of one mother is discussed as an exemplary case to show how both themes can intertwine.

Chapter six is about good risk communication. In the process of decision making about LRLT, the donor-risks are regarded differently by different participants; family members and professionals. This paper explores communication about the donor-risks in family-processes. Risk-communication is commonly framed as an informed consent issue; however, some of the problems or qualities of risk-communication in families are difficult to grasp in the terms of informed consent. Risk-communication plays an important role in the transitions a family is going through, and in giving significance to changes. We propose that besides adhering to informed consent norms, good donor-risk communication should also be supportive of the changes that a family is going through when LRLT is considered.

Chapter seven offers a summary of the different levels of analysis and reflection in the previous chapters. The concluding chapter consists of two parts: first a summary is offered of the reflective and critical analysis of team processes on the one hand and processes of potential donors on the other hand. Second, it offers normative reflection on good outcomes of LRLT, good hope, good risk communication and potential donor's autonomy. Finally, some questions for future research on the moral practice of LRLT are formulated.

SAMENVATTING

Sinds 2004 kunnen in Nederland patiënten met een indicatie voor levertransplantatie ook in aanmerking komen voor transplantatie met een deel-lever van een levende donor uit de familie (LRLT). Vanaf dat moment biedt het transplantatieteam in Groningen de mogelijkheid van een ouder-kind levende donor levertransplantatie. Wanneer een kind op de wachtlijst wordt geplaatst voor een levertransplantatie, worden ouders ook geïnformeerd over de mogelijkheid van levende leverdonatie. De introductie van de mogelijkheid van levende leverdonatie is niet zonder gevolgen. De omgang tussen het transplantatieteam en de families van patiëntjes verandert, en ook de samenwerking tussen individuele professionals en familieleden onderling verandert. Professionals en ouders van levertransplantatie patiëntjes zien zich gesteld voor nieuwe verantwoordelijkheden en vragen. Ouders vragen zich af of ze zelf donor willen worden of dat ze beter kunnen wachten op een postmortale donorlever. Kan het gezin wel een extra patiënt aan en zijn de risico's van levende donatie acceptabel? Professionals zien zich voor de vraag gesteld onder welke omstandigheden zij het toelaatbaar achten schade toe te brengen aan een gezonde leverdonor. Daarbij moeten ze zien om te gaan met verschillende visies en perspectieven binnen het team op levende leverdonatie.

In de oriëntatie op deze vragen over levende lever donatie spelen morele vooronderstellingen en opvattingen over goed ouderschap, goede medische zorg, arts patiënt relaties en familierelaties een belangrijke rol. De Amerikaans filosofe Margaret Urban Walker vat deze opvattingen samen met de term 'moral understandings'. Deze 'moral understanings' kunnen op drie niveaus geanalyseerd worden. Op het eerste niveau van reflectieve analyse wordt in kaart gebracht hoe mensen hun eigen handelen in een specifieke praktijk begrijpen. Op het tweede niveau van kritische reflectie wordt onderzocht in hoeverre bepaalde 'moral understandings' gedeeld worden, waar ze hun autoriteit vandaan halen, en of ze een goed begrip van interacties in een praktijk ondersteunen. Een derde niveau van reflectie is normatieve reflectie. Hierbij is de vraag of 'moral understandings' in een praktijk goede 'moral understandings' zijn, of dat er betere denkbaar zijn. In dit proefschrift worden deze 'moral understandings' over LRLT onderzocht.

De doelstelling van dit proefschrift is daarom drieledig 1) Een reflectieve analyse bieden van 'moral understandings' die besluitvorming over LRLT omgeven. 2) Kritische reflectie bieden op 'moral understandings' die de besluitvorming over LRLT omgeven. 3) Normatieve reflectie bieden op 'moral understandings' die de besluitvorming over LRLT omgeven. Voor deze verschillende niveaus van analyse en reflectie is gebruikt gemaakt van de resultaten van kwalitatief empirisch onderzoek. De hoofdstukken zijn opgebouwd rond thema's die in het kwalitatieve onderzoek naar voren komen, daarbij wisselen verschillende vormen van analyse en reflectie elkaar af.

In hoofdstuk twee wordt ingegaan op de wijze waarop het transplantatieteam in Groningen is omgegaan met de mogelijkheid van levende donor levertransplantatie. Binnen het team vond men het gebruik van levende leverdonoren pas dan gerechtvaardigd als eerst alles geprobeerd was om de problemen ten gevolge van de schaarste van donorlevers op andere wijze op te lossen. Toen het LRLT-programma in 2004 van start ging bestonden binnen het team nog verschillende visies op de vraag of dit aanbod gerechtvaardigd was. Vandaar dat er voor een voorzichtige aanpak van LRLT werd gekozen. De optie van levende donatie wordt in gesprekken met ouders als vangnet voorgesteld: als wachten een probleem wordt, kunnen ze eventueel overgaan op levende donatie. De voorzichtige benadering van LRLT als een vangnet vormt een antwoord op de onderling verschillende morele overwegingen over LRLT binnen het team. Het opvatten van LRLT als vangnet stelt de betrokkenen in staat om deze optie in de loop van de tijd te verkennen. Met deze benadering creëeren ze ruimte voor reflectie en afstemming. Deze tijd en ruimte kan echter begrensd worden door de voortschrijdende ziekte van de patient. Soms komt het voor dat de beslising over LRLT alsnog snel genomen moet worden. Dat laatste is het geval wanneer de patiënt ernstig achteruit gaat en er dus een urgente situatie ontstaat.

In hoofdstuk drie wordt stilgestaan bij de complexe rollen die de ouders van levertransplantatiepatiëntjes vervullen gedurende het traject. Ouders hebben vaak een dubbelrol. Enerzijds ontvangen ze net als hun kind professionele zorg, in die zin zijn ze zelf ook patiënt. Anderzijds geven ouders ook zorg aan hun kind en zijn zij daarmee ook zorggever net als professionals. Er is sprake van een complexe praktijk van gedeelde verantwoordelijkheden die soms kunnen botsen. In dit hoofdstuk wordt ingegaan op het proces van afstemming van verantwoordelijkheid. Om tot goede beluitvorming te komen is het van belang aandacht te hebben voor dit proces en de betekenis van emoties en vertrouwen daarin.

In hoofdstuk vier gaat het over verschillende “patronen van hoop” die naar voren komen in de verhalen van ouders over de transplantatie van hun kind. In interviews met ouders wordt de periode voorafgaand aan de transplantatie van hun kind afgeschilderd als een overgangsperiode. Het leven dat ze tot dan toe leefden lijkt ineens stil te staan. Ouders leven plotseling in de wetenschap dat hun kind met haar of zijn oude lever nog maar een beperkte tijd te leven heeft. Het wachten en hopen is op een nieuwe lever die op tijd komt. Ouders gaan uiteenlopende routes: zij doorleven als het ware verschillende patronen van hoop. Die vormen van hoop vragen hun eigen betrokkenheid en zorg. In dit hoofdstuk worden verschillende noties van hoop verkend. Daarbij worden interviews gebruikt om vragen over goede hoop te verkennen.

In hoofdstuk vijf gaat het over het vrijwillige karakter van de besluitvorming over levende leverdonatie. Veel ouders zien LRLT voor hun kind niet als een kwestie van kiezen. Deze ervaring, en de soms heftige emoties bij het vooruitzicht van donorschap, kan bij professionals in het transplantatieteam vragen oproepen over de vrijwilligheid van besluiten over donatie. Daar komt bij dat het binnen de kaders van informed consent, die vooral zijn toegesneden op individuele toestemming, lastig is om de nauwe betrokkenheid van familieleden te beoordelen. Door de neiging in het hedendaagse westerse denken om vrijheid en onafhankelijkheid als synoniemen te beschouwen, worden onderlinge verplichtingen en afhankelijkheden in de besluitvorming vaak gezien als teken van dwang. In dit hoofdstuk wordt betoogd dat de ervaring geen keuze te hebben en angst voor donorschap, op zichzelf genomen niet als teken van dwang of onvrijwilligheid gezien moeten worden. Nadere interpretatie van “geen keuze” en van emoties, kan wel helpen om de betekenis die donatie heeft voor een donorkandidaat te verhelderen.

In hoofdstuk zes staat de communicatie over donor risico’s centraal. Risicocommunicatie wordt gewoonlijk gezien en geëvalueerd als onderdeel van een informed consent procedure. Bij LRLT vindt echter een deel van de risicocommunicatie plaats in familieverband, buiten de controle van professionals om. Sommige problemen met risicocommunicatie, die samenhangen met onevenwichtige rolverdelingen of relaties in een gezin, vragen daarom om een aanpak die meer inhoudt dan het volgen van de voorgeschreven informed consent procedures. LRLT is een familieaangelegenheid waarbij niet alleen de potentiële donor maar ook anderen betrokken zijn. In de periode van ziekte en lever transplantatie van een kind verandert er veel in een gezin. In dit hoofdstuk wordt daarom betoogd dat goede risicocommunicatie het omgaan met die veranderingen in het gezin ondersteunt. Professionals moeten zich niet alleen richten op het begrijpelijk overbrengen van de risico's, maar ook op de betekenis die die risico's hebben voor familiale verhoudingen.

In hoofdstuk zeven, de conclusies, worden de verschillende lijnen uit de voorgaande hoofdstukken samengenomen. De conclusies zijn opgebouwd uit twee delen. Het eerste deel biedt een samenvatting van de reflectieve en kritische analyse van processen van besluitvorming in het transplantatie team en in familieverband. Het tweede deel biedt normatieve reflectie op goede hoop, goede risicocommunicatie en op de voorwaarden voor autonomie van potentiële donoren. Ten slotte worden op basis van dit proefschrift vragen voor toekomstig ethisch onderzoek naar LRLT geformuleerd.

DANKWOORD

Toen ik na mijn afstuderen plannen aan het maken was voor een verblijf van enkele maanden op een biologische kaasboerderij in Zuid-Frankrijk, hoorde ik van Marian Verkerk over het LRLT programma dat in Groningen van start zou gaan. Vanuit het Expertise centrum Ethiek in de Zorg (EEZ), maakten Marian Verkerk en Els Maeckelberghe, in samenwerking met de chirurg Maarten Slooff, plannen voor een onderzoek naar de ethische aspecten van LRLT. Tussen de koeien in Frankrijk las ik af en toe bericht over de vordering van deze plannen en probeerde ik me een voorstelling te maken van het onderzoek. Na een studie waarin vooral veel nadruk lag op theorievorming zag ik dit praktijk-gebonden onderzoek als een mooie nieuwe uitdaging. Die uitdaging bleek groter te zijn dan ik me van te voren had voorgesteld. De overgang van godsdienstwetenschap naar de medische context was lastig, maar daardoor ook spannend en interessant. Met toenemend plezier heb ik dit onderzoek uitgevoerd. Ik wil hier graag de mensen bedanken die me daarbij geholpen hebben.

Allereerst wil ik mijn promotor Marian Verkerk bedanken voor de inspirerende begeleiding. In onze gesprekken hielp je me om van alle ideeën over het lopende onderzoek de beste uit te kiezen en te ontwikkelen. Daarnaast ondersteunde je me bij veel andere grote en kleine vragen die ik over mijn rol als onderzoeker en ethica had. Maarten Slooff, mijn tweede promotor, wil ik bedanken voor de enthousiaste begeleiding op beslissende momenten in het onderzoek. Ik heb veel gehad aan de gesprekken met jou en aan jouw uitgebreide commentaar op concept-teksten. Els Maeckelberghe, mijn co-promotor: bedankt voor de begeleiding in het onderzoek, je deur stond altijd voor me open. Tevens wil ik je bedanken voor jouw betrokkenheid bij ethische discussies in het lever transplantatie team. Wanneer er ethische vragen speelden die verheldering nodig hadden, gaf je leiding aan de gesprekken hierover. Hierdoor onstond er een goede samenwerking tussen het EEZ en het transplantatie team, een samenwerking waar ik veel baat bij heb gehad.

Ik dank het college van zorgverzekeringen (CVZ) voor de financiering van dit onderzoek.

Ik ben in mijn onderzoek geholpen door veel mensen die als professional of donor(kandidaat) persoonlijke ervaringen hebben met levende donor lever transplantatie. Mijn respondenten, de ouders, en enkele ooms en tantes van lever transplantatie patiëntjes, wil ik bedanken voor de openhartige interviews. Anneke de Bruin en Greetje Sekema wil ik bedanken voor het leggen van contact met respondenten. Het transplantatie team wil ik bedanken voor de gelegenheid die ik kreeg om aanwezig te zijn bij de wekelijkse besprekingen en de refereeravonden. Ook de artsen en leverconsulenten van de kinderpoli waar ik mocht observeren wil ik bedanken. Daniëlle Nijkamp, transplantatie coördinator, bedankt voor je hulp bij het opstellen van de verklarende woordenlijst.

Hilde Lindemann, zal ik je in het Nederlands bedanken, or should I thank you in English? I am sure you would understand both. Thank you very much for the great help with articulating my thoughts in proper English. It was always a pleasure to read the smooth alternatives you proposed to some of my stumbling formulations. Apart from the linguistic support I also enjoyed the times we met in Groningen or Rijeka, and it is an honour to be a member of "the gang".

Voor het plezier in en om het onderzoek ben ik veel dank verschuldigd aan collega's en ex-collega's: Menno de Bree, Annemieke Brouwers, Sara Epenhuysen, Enne Feenstra, Pier Jaarsma, Amelia Kloppenburg, Esther Koning, José Pennings (in herinnering), Catarina Rodrigues, Tjeerd Tijmstra, Donald van Tol en Wenda van Veen. Het is leuk om deel uit te maken van zo'n kleine maar wel veelzijdige groep waar voor vele onderwerpen een goede gesprekspartner te vinden is. Annemieke, dank voor alle praktische hulp: vanaf het begin van mijn werk bij het EEZ was je een onmisbare vraagbaak, en in de afrondingsfase van mijn proefschrift dacht je met me mee over organisatie en planning.

Graag wil ik ook de leden van de leescommissie bedanken voor het lezen en beoordelen van dit proefschrift: Inez de Beaufort, Margaret Walker en Dick Willems. I want to give special thanks to Margaret Walker. Your work has given me guidance in this research, and your questions about my work have been very helpful.

Voordat het manuscript naar de drukker ging kreeg ik hulp van Marie-José Coenen die de omslag van dit proefschrift heeft ontworpen en haar collega Hannie Pijnappels die het binnenwerk ontwierp. Bedankt voor het meedenken en de mooie ontwerpen!

Bij mijn ouders en zussen kon ik altijd terecht. Mijn ouders, Ronald en Annemie wonen aan de andere kant van dit land, en mijn zussen, Kim, Robin en Bonne wonen in drie verschillende steden, maar samen vormen ze nog steeds een dierbare thuisbasis.

Arjen, Jantsje, Bouke, Jelske en Trynke, het is een feest om zo'n schoonfamilie te krijgen. Bedankt voor de warme ontvangst in jullie familie en ook voor alle steun die Emke en ik kregen bij grote en kleine gebeurtenissen de afgelopen jaren. Emke, mijn man, ik weet niet goed welke dank ik voor jou op papier moet zetten. Je hebt me op vele manieren gesteund tijdens het onderzoek, als enthousiaste luisteraar en als collega promovendus. Het was leuk om zo samen op te lopen met twee verschillende onderzoeken. Maar ik ben vooral dankbaar voor alles wat ik met je kan delen buiten ons onderzoek: muziek, bergen, rotsen, boeken, detectives, lekker eten, en vrienden.

CURRICULUM VITAE

Mare Knibbe, geboren 1978, groeide op in Borgharen (Limburg) aan de Maas. Na het afronden van de Vrije School in Maastricht haalde ze haar VWO eind-examen in Amsterdam. In 1997 verhuisde ze naar Groningen om de studie Godsdienstwetenschap te volgen. In de doctoraalfase koos ze als hoofdvak ethiek en als bijvakken Godsdienstpsychologie, Vraagstukken geestelijke verzorging, en Oude Testament. Ze studeerde af met een scriptie over ethiek in de psychiatrie. Voor deze scriptie ontving ze de Hubbelingprijs, een prijs die eens in de drie jaar wordt uitgereikt voor de beste scriptie aan de Faculteit Godgeleerdheid en Godsdienstwetenschap. In 2004 begon ze bij het Expertisecentrum Ethiek in de Zorg (EEZ) aan het promotie-onderzoek dat uitmondde in dit proefschrift. Ze is momenteel werkzaam als onderzoeker en docent ethiek bij het EEZ. Haar nieuwe onderzoek dat ze samen met Marian Verkerk schreef voor het ZonMW-programma ‘ethiek en gezondheid’ gaat over goed patiëntschap.

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Ontwerp omslag Marie-José Coenen
Ontwerp binnenwerk Hannie Pijnappels
Drukwerk Facilitair bedrijf / Grafimedia, Groningen

ISBN 978 90 77113 882

Dit onderzoek werd gefinancierd door het college van zorgverzekeringen (CVZ). De druk van dit proefschift werd financieel gesteund door graduateschool Share en de Graduate school Guide.

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