

Moral tales of parental living kidney donation: a parenthood moral imperative and its relevance for decision making

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Title: **Moral Tales of Parental Living Kidney Donation: A Parenthood Moral Imperative and Its Relevance for Parental Living Kidney Donors' Decision-Making**

Introduction

The number of living kidney donors has increased in many Western countries during the last 15 years (Cecka 2001, Fehrman-Ekholm 2006). This is due to better medical results in the case of living kidney donation (hereafter referred to as LKD) and to the shortage of deceased donors (Teraski et al 1995). Whereas national guide-lines and laws differ regarding who is to be accepted as a donor, many guide-lines and laws hold free and informed choice to be an ethical basis for LKD.¹

The extent to which choice is present in parental LKD has, however, been questioned. The decision-making process in parental living organ donation has been described as complex. Parents, it has been said, may feel obliged to donate either because of external pressure from other family members or the medical team or because of internal pressure from within themselves (Reding 2005, Forsberg et al 2004). It has been even asked whether it is ethically acceptable to ask parents if they want to donate an organ to their child: may not love severely constrain the potential donor's ability to say no to this donation?² This article presents a narrative analysis of parents' experiences of parental LKD, including their experiences of the decision-making process regarding whether to donate. On the basis of this research, we discuss conditions for decision-making in the context of parental LKD. In this way, the article combines empirical, qualitative and philosophical analysis.

¹ See the German Transplantation law *Gesetz über die Spende, Entnahme und Übertragung von Organen* 1997:para. 8.1, the Swedish Transplantation Act. SFS 1995:831, Council of Europe 1996, Delmonico 2005.

² This is discussed in Crouch and Elliot (1999) and in XXX (self-referencing taken away).

Parents in our study describe saying yes to parental LKD as “natural,” i.e. *as something being done more or less instinctively and without concern for one’s own situation*. This result harmonises with previous research (Franklin and Crombie 2003, Kärrfelt et al 2004, Lennerling et al 2004). However, our research also highlighted that the “naturalness” of this donation needs to be understood as part of a story where parental LKD is designated as a response to the child’s pain *and* as a matter of non-choice. We identified a dominant narrative according to which LKD was something one wanted to do as a parent, should do and did. We also identified two kinds of narratives initiated by parents who were not medically accepted as living kidney donors. These were the narrative of not being allowed to exercise one’s parental responsibility and the narrative of not needing to donate. All three kinds of narratives indicated the presence of a *parenthood moral imperative*: the moral imperative of always putting one’s child’s needs before one’s own.³

This imperative can affect the decision-making process in parental LKD. On the basis of our empirical results and the practice of LKD, we argue for the importance of analysing conditions for decision-making in general and autonomous decision-making. We discuss whether - and if so, in what sense - an internalised parenthood moral imperative can hamper parental decision-making in this area. We also emphasise the need for exploring relational and situational factors in order to understand parental decision-making in the context of parental LKD.

LKD in Sweden

As compared to kidney transplantation from deceased donors, the medical outcome of LKD has shown a better graft and better patient survival (Cecka 2001). Living kidney donors have been shown to have a higher quality of life (Johnson et al 1997, Westlie et al 1993) and to live longer (Fehrman-Ekholm 1997). Studies have also indicated that it can be psychologically rewarding for the donor to perform the act of donation (Simmons and Anderson 1982). However, the better

³ Such a moral imperative has also been found in other narrative studies of parenthood, such as Ribbens

McCarthy et al 2000.

survival rates among donors can be due to the fact that only healthy donors have been accepted for donation (Fehrman-Ekholm 2006). Psychologically, donors may also have a need to interpret the transplantation as a success and report a good quality of life as the expected result (Biller-Andorno 2002).

In order to be accepted as a living kidney donor in Sweden, the donor has to undergo approximately fifty blood and urine tests and ten examination procedures. Donation is only acceptable if it is done voluntarily. The donors receive no incentives apart from the compensation for income loss and other verified costs during hospital stay and sick-leave.

Study Design

Eligible parents for the empirical part of the project were couples where i) one parent had donated a kidney 6-18 months before the interview, ii) the other parent had considered donation and iii) it had not been known from the start that one of the parents was medically unacceptable as a living kidney donor.⁴ Six semi-structured couple-interviews were carried out, each with the mother and the father of the recipient. The interviews followed a narrative form with parents being asked to “tell their stories” of the child’s disease and their experiences of the donation process, including the decision-making process regarding whether to donate and the medical examination period. This approach was chosen in order to give precedence to the ways mothers and fathers themselves constructed and interpreted their experiences. Our aim was not to judge the veracity of the interviewees’ stories. We understand this as a preliminary study with the aim of analysing, in detail, parental experiences of considering parental LKD. For this reason, our small

⁴ An open invitation, with a description of the project, was available at the kidney patient association home-site in Sweden, in the Swedish patient support journal and through the Transplantation Centre at Sahlgrenska University Hospital, Gothenburg, Sweden. If interested in participating in the project, interviewees were asked to contact the project group. The project group did not get access to any medical information about the interviewees.

number of interviewees was appropriate.⁵ All data were transcribed verbatim. The interviewees were also given the transcribed interview for perusal.

The project follows the Swedish research-ethical guidelines (*Forskningsetiska principer inom humanistisk-samhällsvetenskaplig forskning* 2002). Interviewees were guaranteed that the data would be treated in a confidential manner. They were informed that they could interrupt the interview whenever they wanted, without explaining why. Each of them gave their informed consent to the interview and to the audio-taping. All interviews were performed in the interviewees' homes, since this was what they preferred. Three of the recipients were minors (ages 2.5, 6 and 8) and three of them were adults (ages 26, 30 and 32). Four of them live with their parents. Four of the donors were fathers and two were mothers. All names of the interviewees are fictitious.

Narrative Analysis and Empirical Ethics

We understand a narrative as a story of a sequence of events in time which is significant for the person telling it. It has a plot and an internal logic that make sense to the narrator (Langellier and

⁵ We chose couple-interviews with partners in families since this can increase the complexity of interviewees' narratives and encourage more detailed stories than those generated by individual interviewees. This is the case if one interviewee's story-telling encourages the other to tell her or his version of the event or if one person's story-telling jogs the memory of the other and results in further spontaneous reflection. Couples can also corroborate and/or question each other's stories. In these ways, couple-interviews can enable an exploration of the dynamics of, and expose negotiation in, partner relations and decision-making. Of course, a couple-interview may also produce an "official" simplified story and interviewees may feel less free to express their own views. We were interested both in the content of the interview and in the interplay between the parents; for this reason, couple-interviews were suitable. In one case, the interview was carried out with a father and his female partner (i.e. not the recipient's biological mother). Both of these interviewees had considered whether to volunteer as donors.

Peterson 2004). By using the narrative form, the narrator assigns meaning to events, places events within a certain order, invests them with significance and creates and conveys self-images within a particular socio-cultural context. When this is done, the narrator often relates to and uses “master narratives,” i.e. dominant cultural story-lines that serve as a “summaries of socially shared understandings” (Lindemann Nelson 2001:6). Previous studies have explored a variety of motherhood narratives, which draw on a motherhood master narrative according to which motherhood is natural (Romero and Steward 1999; Andrews 2002). Our analysis explored a related parenthood master narrative according to which certain wishes and acts were natural and, also, should be natural to parents. The narrator can also tell “counter-narratives” that question the foundation of the dominant story-lines (Andrews 2002:1). Such counter-narratives need not be in opposition to the master narrative, though they often suggest an alternative way of telling the dominant story. We identified one such counter-narrative. This was the narrative of not needing to donate.

We also explored the narratives’ moral or point.⁶ The narrator point is, following Viveka Adelswärd (1997), closely related to the particular narrator and the particular context of the narrative. This point can be a matter of self-presentation where the narrator presents her- or himself in a particular way. The underlying point highlights implicit value-systems and explains what qualify, for example, as good parenting in encounters with medicine. The underlying point was often made explicit when the narrators evaluated the whole series of events they had told the interviewer.

There is a shift within medical ethics from a purely theoretical focus towards different kinds of empirical ethics (Birnbacher 1997, Musschenga 2005, XXX 2005). Empirical ethics

⁶ Stories with a moral or a point have a long tradition and they are told with a certain purpose; a number of different morals/points can also be identified within a narrative. See Adelswärd 1997 and Polyani 1989.

typically combines empirical research and ethical analysis. In this article, the results deriving from the empirical analysis are used in a critical examination of conditions for decision-making.

The Three Narratives

Narratives of “Natural” and “Successful” Parental Living Kidney Donation

Parents explained that parental LKD was “natural” for them. This naturalness was articulated as a response to the child’s painful experiences of renal dysfunction and previous hospital experiences. Almost all the parents described their child’s pain in detail. They commented upon the experience of watching one’s child suffer as “terrible” and “awful.” In the light of this, volunteering as a living donor was described as “the only thing to do, as a parent” and as a matter of non-choice. There were, parents said, “no alternatives.” Parental LKD was also described in terms of “parental responsibility,” as something one should do “if one had brought a child into this world.” Furthermore, volunteering as a donor was described as important since, interviewees said, it was *not as natural* for other potential donors (i.e. donors who were not parents of the recipient) to volunteer.

In this story-line, the parents were the main actors. They described themselves as needing to act, in a responsible manner, for the sake of their child. Taking on this parental responsibility meant volunteering as a donor. In this sense, our study reflected the “*non-negotiable moral obligation*” of putting one’s child’s needs before one’s own as a parent (Ribben McCarthy et al 2000). A parent may be scared of surgery, she or he may prefer it if the other parent is eventually the donor, but the moral obligation/imperative of putting one’s child’s needs before one’s own and volunteering as a donor was unquestioned in our study.

When a parent had volunteered as a donor, she or he started to undergo the medical tests and the examination procedures. Several of the interviewees explained that they had undergone almost all tests and reached a state when they believed that they would be accepted as donors when “something turned up” which made them medically unacceptable as donors. They

described this as extremely frustrating. The other parent had to start the evaluation procedure, if she or he wanted to do so. Sometimes, this new procedure coincided with the recipient's health status deteriorating. This was what happened to Ann, Eric and their child (the recipient's age: 8).

Eric: It felt unreal, being back at [a previous] stage. It was a horror that one hopes one will never need to experience again.

Ann: It's this, it was so frustrating for us, when he was that damn sick. Eric and I said, 'But hello, there are two kidneys here! Take them out! Take them now and put them in.' The answer we got was that they [the medical professionals] couldn't do it. I couldn't take that. 'No, unfortunately, we cannot do that, because he would not handle transplantation now. That's how ill he is.' He would not handle the surgery.

Interviewer: No.

Ann: No. So what are we waiting for? That was really damn hard to take.

Later on in the narrative, Eric set his own experience in relation to what he had heard about parental LKD from others.

Eric: It is as they say, the problem with transplantation is not that parents don't want to donate, but that they maybe are not allowed to do so. And they [the parents] then say 'It does not matter! Take my kidney! I don't care, it is better that he's living than that I'm living.'

This story-line resulted in a particular self-presentation, i.e. a narrator point, where the medical professionals were described as slow and the parents as more than willing to donate a kidney. Eric also suggested that this was not only his experience; it was something he and Ann shared with other parents.

Interviewees' most commonly stated worry was the worry of not being accepted for donation: of not "being good enough" a parent. This makes it interesting to examine what would count as acceptable reasons for saying no to donation as a parent. Parts of the interviews where

such reasons were discussed often had the character of accounts. Interviewees discussed what could justify or excuse a parental no to donation: they gave “medical reasons” as the only acceptable reasons for saying no to parental donation. An excerpt from the interview with Richard and Jeanette (recipient age: 15) can exemplify this reasoning.

Richard: If you think about saying no to donation, then you must argue for it. The question, then, is what arguments I can come up with, which hold.

Interviewer: For yourself, you mean, or for ...?

Richard: Yes, if one should motivate...

Interviewer: For whom?

Richard: One's own egoism. What could I come up with? Something medical? No. Because if you are accepted from a medical point of view and have undergone the whole [testing procedure], heart, lungs, arteries and I don't know what, there is no hindrance.

Jeanette: We have read about [donation][...]. We have met other parents who have donated. Mostly you're fine [after donation, as a donor.]

Richard described other reasons than medical ones as egoistic. Jeanette added that donors were, most often, healthy after donation. The parental norm, which underpinned many of the interviews, was highlighted: if you get accepted for donation and if you don't want to be egoistic at a time when your child needs a kidney for survival, then there are no good reasons for not donating.

It is noteworthy that “medical reasons” were not medical in a strict sense. If both the mother and the father were described as medically possible donors, interviewees said that doctors preferred female donors since they were “easier” to give anaesthesia to and to operate on. It was

acceptable for men “with potbellies” to say no to donation, since this was a “medical” reason in the interviewees’ stories.⁷

Despite detailed descriptions of frustrating events, this first kind of narrative focused on the successful donation. This was the case even though one of the parents in each interview had not donated. Successful donation was described as a “victory.” As an example, Sara and Johan described how Johan volunteered as a donor. After having undergone the medical evaluation, Johan was told that he was not the most suitable of donors. The doctors asked if there were any other potential donors available. At that time, however, Sara was pregnant, which made her unsuitable as a donor. In the end, Johan was accepted. This is how Sara and Johan commented on the experience of Johan’s first not being accepted and Sara’s not being suitable:

Johan: Even though I could not do anything about it, it was a failure [not to be accepted as a donor at first]. And then, when I could [donate], it was a double victory. I could donate.

Sara: Yes, one wants to do this. It is a failure not to be able to do this for one’s own child. One is, sort of, insufficient as a parent.

Johan: Mm.

Sara: And I think you felt more of this than I did. I haven’t thought much of me not being accepted. I haven’t felt any grief for that. Not even when you weren’t accepted, it was more sort of ‘oh God, how strange that we couldn’t.’ We had decided ... [laughter]

Johan: We had decided that we could [donate]. [laughter]

⁷ Andreas and Emma (recipient age: 26) described this as what settled their discussion of who should donate. Their doctor, they said, had told them that if both of them were equally acceptable as donors, they would prefer Emma. On-going or planned future pregnancies were described as acceptable medical reasons for saying no to donation for parents, if there was another parent who could donate.

Laughter in narratives can indicate embarrassment; it can be a face-saving activity (Adelswärd 1997). Here, Sara and Johan laughed when they described how they thought they could decide that they should be medically acceptable donors. This, they had been acutely aware, was not the case.

When the interviewees evaluated their experiences of the donation process, they emphasised their relief and happiness both at being accepted and undergoing the donation. Many of the interviewees, however, also explained that they had mixed feelings regarding the future. They did not expect the kidney to last the whole of the recipient's life and future donations would probably be necessary.

Narratives of not being allowed to exercise one's parental responsibility

The second kind of narrative started as the first one did. Parents described parental LKD as natural and something one wanted to do and should do as a parent. They gave detailed descriptions of their child's disease and of how they began the medical testing-procedure. However, the focus was on the experience of *not being accepted as a donor*. One father, Andreas, explained that not being accepted as a donor made him "really upset."

Andreas and Emma explained that both of them wanted to donate. Emma underwent the medical tests first. However, the test procedure was not straight-forward and Emma's test results, which were from one hospital, were not sent to the doctors' in charge of the transplantation procedure. The parents described the test procedure as slow and their child's health status as deteriorating. When asked how they experienced this, Emma explained that she experienced their situation as "really hard," both for the child and for them as parents. Andreas commented that despite them calling the professionals to make things go quicker, nothing happened and this "made one angry all the time."

Andreas and Emma's story-line follows, in this regard, the pattern of so-called "atrocious stories," i.e. stories that are characterised by disagreement between parents and health care

professionals *and* that result in establishing the reasonable and moral character of the parents (Baruch 1981). It highlights the experience of being neglected by the medical professionals. It also results in a picture of the parents as responsible parents, who fight – to the extent that it is possible – for their child.⁸

When Emma finally got accepted as a donor she was, she said, “overjoyed.” The parents celebrated the event and started to plan for the transplantation. However, some months later the doctors wanted to re-examine her before continuing with the transplantation plan since they had found a cyst on one of her kidneys. As Emma put it, this was just “terrible.” She described her son as “almost apathetic” and herself as being particularly frustrated since the doctors had known about the cyst for six months without reacting. Emma was not accepted as a donor. At this stage, the doctors turned to Andreas, asking what he thought about donation. Andreas immediately responded that he wanted to donate. He started doing the medical tests, but when the doctors found out that he had rheumatic fever, they said that he couldn’t be accepted.

Andreas: Then I said that I have a right to decide about my own body, haven’t I? Yes.

Interviewer: What did they answer?

Andreas: Well, she [the doctor] responded evasively. [...] I asked ‘Can I force this donation to happen?’ But she said that she did not know if that was possible. Doctors can refuse to perform the transplantation.

⁸ Andreas and Emma’s story can also exemplify the dynamics of couple-interviews. Each of the narrators jogs the memory of the other. When Andreas said that he got angry, Emma responded that she reacted differently. She felt frustrated and this resulted in her “building walls” around herself in order to handle “the many blows” that both of the parents and the recipient received during the test procedure. However, she confirmed Andreas’ statement that “one” got angry. She picked up the narrative thread and explained that this made them call the hospitals involved in order to sort things out.

Andreas said that at this stage, he got angry. He said that if he, later in life, got a kidney disease both of the kidneys would be ruined. Wouldn't it, he asked, be better if one of them had been "saved" and transplanted to his son?

This narrative highlights how parents position themselves as responsible parents who do what they can to help their children. It results in a narrator point of how the parents have *tried* to live up to the moral imperative of putting one's child's needs first. It also results in descriptions of medical professionals who limit parents' possibilities of exercising their parental responsibility. Emma wants to donate, but doctors neglect her test results and prolong the test procedure. Andreas wants to donate but doctors say no. In the end, Emma gets accepted for donation but this is something they comment on more briefly than the lengthy and frustrating procedure prior to it.

The narrative highlights how parents who cannot donate and parents who at least initially get a no from the medical professionals construct a story of good parenthood which questions the authority of the professionals. Have they really the right to say no to parents who want to donate? This questioning also, however, confirms the parenthood moral imperative: parents should, indeed, do all they can to save their children.

A counter-narrative of not "needing" to donate

Counter-narratives are often told when there is a mismatch between our experiences and the dominant cultural story-line. This third narrative is a counter-narrative, which questions the underlying point of the naturalness of the donation act. In this story-line, parents described the experience of not needing to donate as a relief. They also stated that this relief was something they were ashamed of feeling. An excerpt from the interview with Maria and Marcus can exemplify this kind of narrative.

Both of the parents described parental LKD as natural and something they wanted to do. Both of them volunteered as donors and Marcus underwent the medical tests. At this stage,

Maria explained, she was prepared to donate herself, but she said she was relieved that Marcus would – as they thought – do it.

Maria: I felt, to be honest, I was a bit relieved that he would do it. ‘Oh, that’s a relief, I won’t do it.’ I guess it’s human, maybe. That’s how I felt.

Interviewer: Mm

Maria: I was prepared to do it, but I felt nevertheless that it was a big step.

Marcus: Yes.

Maria. They will go in and poke about in one’s body. Things can go wrong and then one didn’t know how it would be for Jimmy [the recipient].

However, the medical tests indicated that Marcus had a “problem” with his own kidneys. He was told that he could not be accepted as a donor, “because one of his kidneys was twice as big as the other.” At first, this frightened him. He said that his feelings were mixed regarding not being accepted as a donor.

Marcus: On the one hand, this feeling of not being good enough. That was a hell of a drawback. And then, at the same time, almost this ‘maybe it’s a relief that I needn’t do it.’

Maria: Mm. And then you feel ashamed for thinking that way.

Marcus: Yes. You vacillate between these two.

Interviewer: You felt ...?

Marcus: Both of these feelings were there.

Eventually, Maria donated. Later on in the interview, Maria and Marcus talked about the experience of not being accepted as a donor again.

Marcus: I was prepared for being [accepted].

Maria: But I think you felt rejected.

Marcus: Yes, I got ...

Maria: [you felt] you weren't good enough. Disappointed.

Marcus: Yes, I guess I wanted to be the hero.

Marcus then said that he was happy that Maria could donate, but he wanted to be “the head of the family” who donated to his child. Not being accepted for donation, he said, was a “real blow to [his] ego.”

On the one hand, this counter-story builds on the “*non-negotiable moral obligation*” (Ribben McCarthy et al 2000). Parents do not question that they should put their child's needs first in the sense of volunteering as donors; the story also builds on the idea that parental LKD is something parents want to do and should do. On the other hand, when narrators admitted that they felt relieved at not having to donate, this resulted in an indirect questioning of the naturalness of the act. The act was not natural in the sense of being done more or less instinctively and without concern for one's own situation. If that was the case, parents would not feel relieved when someone else could be the donor. The narrative also resulted in an emphasis on the parenthood moral obligation, when narrators concluded that the relief that they felt was shameful. It was a relief that parents should not feel.

We can now re-formulate the moral imperative of Jane Ribben McCarthy and colleagues:⁹ parents felt ashamed of their feeling of relief because this feeling contrasted with a moral imperative of gladly doing what one could to improve one's child's health, even if this involved donating a kidney as a living donor. *One should not feel relieved when one must not put the needs of one's child first in this sense.*

⁹ According to their imperative, parents “must take responsibility for the children in their care” and put the child's interests first. Ribben McCarthy et al 2000:789.

The strength of this imperative can be seen in the evaluation part of Maria and Marcus's narrative. Maria returns to how natural it was for both of them to volunteer as donors to their suffering child. She also related this naturalness to her self-image as a responsible human being.

Maria: I wonder, if one hadn't agreed to donate. If we had seen Jimmy get worse and worse [without taking action], then one just couldn't live with oneself.

Interviewer: No.

Maria: One wouldn't have any respect for oneself.

Marcus: No.

Maria: As a human being.

Marcus: No.

In this sense, doing what one can for the improvement of one's child's health and well-being is not only a guide-line. It is an underlying point of the narrative and a recurring moral imperative.

Parental Decision-making in LKD

The Moral Imperative of Parenthood

The parenthood moral imperative recurred throughout the interviews. Not donating, for other than medical reasons, was described as egoistic. No one described themselves as unwilling to donate as a parental living kidney donor.¹⁰ In this sense, our study concurs with previous studies: *inability, not unwillingness*, is described as an acceptable justification for not putting one's child's needs before one's own in a particular regard (Finch and Mason 1993, Ribben McCarthy et al 2000). It is also noteworthy that no one questioned the parenthood moral imperative, i.e. no one questioned that parents should take responsibility for the children in their care and put the child's

¹⁰ Of course, this may be due to our sample of interviewees. Possibly, only interviewees that could present a more or less culturally acceptable story said yes to our project invitation.

interests first. Instead, parents in our study described how natural it was for them to do so in the context of parental LKD. Some of them also articulated the related imperative that one should not feel relieved when one was unacceptable, for medical reasons, as a living kidney donor. We concur with McCarthy and colleagues in holding that the moral imperative of putting one's child's needs first may be one of the few unquestionable moral assumptions in our culture.

The presence of this moral imperative, when applied to the context of parental LKD, is noteworthy from a medico-ethical point of view. If a parent has internalised the view that good parents donate, it can be psychologically difficult for them to say no to donation for other than medical reasons. Now, if a parent has internalised the view that good parents donate as living kidney donors to the extent that she or he is *unable to say no to this donation*, she or he is not in a situation of choice as regards this option. This should be seen as a reason for ethical concern if one accepts the view that living organ donation *should* be a matter of choice. We will take this as a starting-point: LKD can only be ethically justified if this is the result of the donor's choice.¹¹

To what extent, then, can parents say no to donation when their child is acutely ill and needs kidney transplantation? In a thought-provoking article, Robert Crouch and Carl Elliot (1999) suggest that one of the problems with present-day discussions of living organ donation is that we (still) think of human agency in terms of an independence and freedom from the kind of connections that typically bind family members together. For this reason, we see love and emotional bonds as constraints on someone's free choice to donate. It seems as if it is assumed that the "the less moral and emotional motivation a person has for donating an organ, the freer is his or her choice to donate" (Crouch and Elliot 1999:277). This, they comment, is problematic. We agree with them. Decisions made out of love are not *as such* less free than decisions made by "free agents" who have no emotional ties to the recipient of the organ. Nevertheless, love – as well as an internalised parenthood moral imperative – *can* make someone unable to choose. If someone is unable to say no to this kind of donation, she or he is not in a situation of choice, at

¹¹ As seen earlier, this is the approach of a number of laws and policies in this area.

all, in this regard. This should be an ethical concern as long as we want living organ donors to donate by choice.¹²

Empirically speaking, situations where a parent is unable to say no to donation may of course be rare. Such a situation needs to be distinguished from the situation where one option is much more *preferable* than the other: in the latter case, the subject need not be unable to choose differently. The former situations, we suggest, highlight a basic condition for choice. In order to be in a situation of choice, one needs to have certain abilities to come to a decision.

In the following, we will distinguish between the *general concept of choice* and the *subcategory of autonomous choice*. We will argue that this distinction has the theoretical benefit of allowing a more precise discussion of degrees of constraint on conditions of choices. Some constraints hamper choice in general and some hamper only autonomous choice.¹³

Parental Choice

If someone has a choice, she or he needs to be in a situation of choice in which there are at least two alternatives that are perceived as such. This person needs also to have certain abilities and opportunities to come to a decision. The self needs to have abilities for minimal deliberation on alternatives (whether to donate as a living kidney donor or not) and abilities to perform the mental act of deciding which alternative to go for, such as an ability to understand that one is in a situation of choice, an ability to perceive at least two alternatives, an ability to understand basic differences between the alternatives, an ability to intend a certain outcome as well as an ability to decide. The self needs also to have the opportunity to come to a decision. This involves the opportunity for minimal deliberation and the opportunity to decide which alternative to go for.

¹² Note there that even if love and/or an internalised moral imperative motivate my decision, I still have the choice of whether to act in accordance with these motives. Love or an internalised parenthood moral imperative does not dissolve choice or render choice less important.

¹³ We will present conditions for decision-making which one of us has elaborated elsewhere. See XXXX.

We need also to have the opportunity to learn and acquire abilities as well as the opportunity to use them. If any of these abilities or opportunities are lacking, this person is not in a situation of choice at all.

In our research, parents stated that there were no alternatives to parental LKD. They described their situation, when considering whether to donate, as a non-choice situation. A first question to ask is whether parents experienced this as a non-choice situation because they so much wanted to donate that other options were (in comparison) seen as undesirable – or whether the whole situation made them *unable* to say no to donation. We suggest that the most probable interpretation is that parents, because of their strong desire to do whatever was best for the child, considered the other alternatives undesirable. They were not viable alternatives to the parents. This interpretation is justified by parents' repeated emphasis on how much they wanted to donate and how not being accepted as a donor was their worst fear.

This reasoning builds on a distinction between a situation where someone has at least two alternatives and where she or he wants one of them more than others, for various reasons, and a situation where they have become unable to choose in the first place. If the latter had been the case, there would be reason for to be concerned. This, however, seems not to be the case.

The above description of abilities and opportunities to come to a decision can be combined with a positive view of emotions. As noted by others, emotions can play an important role in decision-making. Emotions can enable our processing of complex information (Appelbaum 1998). They are crucial when we try to understand a particular situation *and* our emotional response shows whether we have accurately understood that which we have been told (Nussbaum 1990). A parent that does not react emotionally when told that her or his child is severely ill can be suspected of being in a state of shock. In this way, understanding basic differences between two alternatives – such as the alternatives that the child receives a living kidney transplant or that she or he does not receive such a transplant – involves an emotional response. Of course, emotions also motivate actions.

Descriptions of emotional responses were strongly present in the interviewed parents' stories. They described their despair, frustration and excitement during different stages of the testing and donation procedure. These responses need not be seen as constraints on the parents' ability to come to a decision. Instead, they can be interpreted as highlighting that parents have understood that their child's health is in danger and may deteriorate if nothing is done.

Our empirical results also highlighted the importance of taking into account the interactions between the parents and the child over time in order to understand the decision-making process and the "naturalness" of the donation. It may be years from the first occasion when the child is acutely ill to the actual moment of donation. During this time, parents may have seen their child suffer, without being able to help. They may have cried and laughed together and with the child; all these ups and downs need to be understood in order to understand the fullness of the parental statement that "it is natural." Obviously, a parent who has had years to consider what to do has had more opportunity to come to a thought-through decision than someone who is supposed to make a decision in a rush. This leads us to the discussion of the difference between choice in general and autonomous choice in particular.

Procedural Autonomous Decision-making

A common distinction is the one between formal and procedural accounts of autonomy. In formal accounts, what matters is that we can decide and act. No specific reflection is called for prior to the act and no substantive content of the act needs to be specified. If formal accounts are used, I may come to a decision that others find absurd, irresponsible, rushed-into or harmful to myself, but as long as I am competent to engage in decision-making and not under hampering influences, I am autonomous with regard to my decision. This, we hold, is an inadequate understanding.

If we use a formal account, we cannot distinguish between cases where a parent says yes to donation after really having thought the issue through and cases where, at the first encounter

with the medical professional, a parent impulsively says “of course, I’ll donate.” Formal accounts fail to clarify the difference between decisions made on the basis of instant desires and wants and decisions made after a certain kind of reflection on these desires and wants. This is an unfortunate characteristic since it allows little discussion of different kinds of choices and few nuances between different kinds of constraints on choices. Some constraints may, indeed, hamper autonomous choice but not choice in general.

Parents in our study did not say that they changed their minds after having thought through different alternatives. There is, however, another practice-based reason to prefer an account of autonomous decision-making that helps us to clarify the difference between instant desires and decisions made after a certain kind of reflection. In the case of LKD, a healthy person volunteers to undergo surgery. Though this can be very positive, a healthy person is nevertheless put at surgery-related risk for the sake of another person’s health, by medical professionals. For this reason, it is important that donors have been able to think through their decisions. A procedural account of autonomous decision-making allows us to make this distinction between different kinds of choices. In these accounts, a certain kind of reflection *or* a capacity for a certain kind of reflection is a condition for autonomous choice (Meyers 1989, Dworkin 1996, Frankfurt 1971).

The philosopher Diana T. Meyers’ (1989:627) conception of autonomy is interesting since it tries both to explain possible hampering influences of socialisation on autonomy and why socialisation need not hamper autonomy.¹⁴ In this sense, her conception allows an emphasis on relational dimensions of autonomy; the crucial condition for autonomous choice is not that it is free from others’ (more or less) constraining influences.

¹⁴ This can be the case if someone has been oppressively socialised, Meyers holds, if this person still has developed an ‘autonomy competence’ that involve a number of coordinated skills, such as skills of self-discovery, self-direction and self-definition, *and* exercises this competence. It is only through the exercise of these skills that autonomy is achieved.

What matters, in Meyers' view, if we are to be said to choose autonomously, is that we are able to identify and reflect on what really matters to us with regard to the particular area of choice *and* do so. Though we consider her discussion very helpful, we will use an account of autonomous choice that is different from hers. In line with our previous reasoning regarding conditions for decision-making in general, we suggest that autonomous choice is present only when the conditions for choice in general are met and we *can* perform a particular reflection on what really matters to us with regard to the area, *can* reflect on whether what really matters to us in this area is promoted in an acceptable way by the alternatives present, *can* decide on the basis of that reflection and *can* act on the decision that reflection yielded.¹⁵ One need only be able to and have the opportunity to do these things in order to be in a situation of autonomous choice. This difference from Meyers' account has the benefit of not making autonomous choice so unusual.

Our interviewees stated that what they wanted more than anything else was that their child's health should be better. Their worst fear was not to be accepted as living kidney donors. At first glance, this may lead us to conclude that parents seem to have reflected on in what way alternatives promote, hamper or hide what they really want. No parent described other options than parental LKD as desirable; they emphatically stated that this was what they wanted to do. It

¹⁵ See XXXXX. The person needs to have the ability to identify what values, beliefs and norms she or he holds to be really important with regard to the particular area of choice and the ability to reflect on in what ways particular alternatives promote, hamper or hide these values, beliefs and norms and whether what really matters to her or him, in the particular area, is promoted in an acceptable way by the alternatives present. The person needs also to have the ability to reflect on whether these values etc. are promoted in an acceptable way by the alternatives present. Furthermore, the person needs to have the opportunity to reflect on what is valuable with regard to the particular area of choice, to decide and act, and the opportunity to develop previous abilities. As long as there are no constraints on abilities and opportunities for autonomous choice, I have such a choice.

is important to acknowledge this strong wish of theirs. However, it is *also* important to relate their strong wish to donate to the broader context and to the issue of how the alternatives are presented and interpreted in this context. As shown by others, parental LKD can be described as natural in one context and as implying an inappropriate risk in another context (Crowley-Matoka and Lock 2006). How information is presented and the norms in the broader socio-cultural setting matter for our decision-making. As one more example, the effect of medical professionals' statements on parents decision as to whether to volunteer as a donor becomes evident when one mother explains that she volunteered as a donor since her husband had a potbelly and that he therefore would not be as suitable a donor as she would.

Relational dimensions are present when parents co-construct stories of what qualify as acceptable parental acts in this specific context. Of course, our interviewees are a self-selected group who wanted to talk about their experiences. Other parents, for whom the whole situation resulted in conflict between them, may have told other stories. Yet our data indicates that in these cases of parental decision-making, parents' primary concern is not how they, as individuals, should "fend off unwanted intrusions from others" in order to come to a thought-through decision (Donchin 2006:368). Their decision-making is, typically, enmeshed in relations with others – such as the child, the partner and, also, medical professionals.

Parents' willingness to donate needs to be understood in the light of their relation to their suffering child, to each other, to the norms of parenthood and to what information they are given by medical professionals. Let us now consider situations where parents articulate the parenthood moral imperative. Parents declared that they wanted to do whatever was best for their child. If this meant volunteering as a donor, they stated that they wanted to do so. This need not imply that parents have internalised the parenthood moral imperative to the extent that they are unable to say no to donation. This is crucial: the ethical problem is not that parents articulate or, indeed, internalise the parenthood moral imperative. Difficulties arise, from an ethical point of view, if the imperative makes parents unable to say no to donation and they nevertheless donate.

However, if this moral imperative is strong within our culture (and even if it does not hamper the parents' ability to choose between the two options and come to a decision) it can make it extremely *difficult* for parents to say no to parental LKD.

May an internalised parenthood moral imperative make us able to choose, but unable to choose autonomously? May it hamper our ability to reflect on what we really want, even if it does not hamper our ability to choose in general? This can be the case if someone, because of the internalised imperative, cannot consider what she or he really wants or whether the alternatives present promote or hamper what she or he really wants. If what this person really wants is incompatible with the parenthood moral imperative and if she or he experiences this clash as severely frustrating, she or he may be unable to perform the said reflection. Since less is required for coming to a decision in general, someone may be able to come to a decision – but not to an autonomous one.

The core issue is to what extent this person has internalised the moral imperative and whether she or he has the necessary abilities and opportunities with regard to autonomous decision-making. Still, this does not imply a “rigid focus on cognitive and mental abilities as the sole precondition for being able to donate” (Biller-Andorno et al 2002:367). Our approach allows us to spell out, in some detail, abilities and opportunities to come to an autonomous decision *and* to emphasise the importance of acknowledging relational and emotional dimensions of this decision-making. Our reasoning also allows us to conclude that internalised moral obligations or love need not be seen as ethical problems. As long as parents have the necessary abilities and opportunities with regard to autonomous decision-making, decision to donate as a parental living kidney donor can qualify as autonomous *and* be seen as an expression of love or of the moral imperative.

Conclusions

The narrative analysis of parents' stories of parental LKD in Sweden highlighted the presence of a parenthood moral imperative. As a parent, one should put the needs of one's child first. One should donate. The willingness to donate and the act of donation were described as natural to parents, but this "naturalness" was the result of a longer period of time during which parents had seen the child's suffering, sometimes without being able to do anything to help the child. It highlighted the importance of exploring the interaction between parents and the effect of norms of parenthood on parents' decision-making in this area.

The presence of the parenthood moral imperative is noteworthy from a medico-ethical point of view. If a parent has internalised the view that good parents donate, it can be psychologically difficult for them to say no to donation for other than medical reasons. If a parent has internalised the view that good parents donate as living kidney donors to the extent that she or he is *unable to say no to this donation*, she or he is not in a situation of choice as regards this option. If one believes that parental LKD should be a matter of choice, then these situations should be seen as ethically problematic. However, we also concluded that an internalised moral imperative need not be a constraint on decision-making.

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