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Just love in live organ donation [1]

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Abstract

Emotionally-related live organ donation is different from almost all other medical treatments in

that a family member or, in some countries, a friend contributes with an organ or parts of an

organ to the recipient. Furthermore, there is a long-acknowledged but not well-understood

gender-imbalance in emotionally-related live kidney donation.

This article argues for the benefit of the concept of just love as an analytic tool in the

analysis of emotionally-related live organ donation where the potential donor(s) and the recipient

are engaged in a love relation. The concept of just love is helpful in the analysis of these live

organ donations even if no statistical gender-imbalance prevails. It is particularly helpful,

however, in the analysis of the gender-imbalance in live kidney donations if these donations are

seen as a specific kind of care-work, if care-work is experienced as a labour one should perform

out of love and if women still experience stronger pressures to engage in care-work than do men.

The aim of the article is to present arguments for the need of just love as an analytic tool in

the analysis of emotionally-related live organ donation where the potential donor(s) and the

recipient are engaged in a love relation. The aim is also to elaborate two criteria that need to be

met in order for love to qualify as just and to highlight certain clinical implications.

**Keywords**: Live organ donation, ethics, love, the just, choice, gender

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#### **INTRODUCTION**

Emotionally-related live organ donation (hereafter referred to as LD) is different from almost all other medical treatments in that a family member or, in for example Sweden, a friend contributes with an organ or parts of an organ to the recipient. Furthermore, in emotionally-related live *kidney* donation (hereafter referred to as LKD) there is a long-acknowledged but not well-understood gender-imbalance. In cases of LKD, previous studies have shown that female partners donate significantly more often than male partners. Mothers also donate significantly more often than fathers (Schicktanz et al 2006, Thiel et al 2005, Bloembergen et al 1996).

This article argues for the benefit of the concept of *just love* as an analytic tool in the analysis of emotionally-related LD where the potential donor(s) and the recipient are engaged in a love relation (hereafter referred to as loving LD). The concept of just love is helpful in the analysis of loving LD even if no gender-imbalance prevails. It is *particularly* helpful, however, in the analysis of the gender-imbalance in LKD if live donation can be seen as a specific kind of care-work, if care-work is experienced as a labour one should perform out of love, if women still experience stronger pressures to engage in care-work then do men and if the gender-imbalance cannot be fully explained by medical reasons.

The aim of the article is i) to present arguments for the benefit of just love as an analytic tool in loving LD, ii) to elaborate two criteria that need to be met in order for love to qualify as just and iii) to highlight certain clinical implications. The article is divided into four parts. First, I present statistics regarding the gender-imbalance in LKD and arguments as to why this imbalance should be of ethical concern. I also discuss live liver donation. Second, I argue that the analysis of loving LD needs to acknowledge the specific features of such donation (such as the fact that it is an act within a love relation) and that it is unsatisfactory to focus only on love in analysing that which can take place in such relations. Third, I discuss the concept of just love. I concur with scholars who emphasise the importance of combining that which is just with love or care in the analysis of intimate relations (Moller Okin 1989, Baier 1995, Friedman 1995). However, while many have called for such a combination, little has been said about how these perspectives can be combined. The recent work of the theologian Margaret A. Farley (2006) is an exception to this tendency. While I take hers to be a promising conception of just love, I also suggest some modifications of it. Love is just, I suggest, when it takes into account and affirms the concrete reality of the lover and the loved-one and when it implies not the exploitation of the lover, nor the domination of the beloved. Fourth, I apply this conception of just love to a story of loving LD and outline some of its clinical implications.

#### LIVE KIDNEY AND LIVER DONATION

# LD and gender aspects

There is a prevailing gender-imbalance among live kidney donors in many countries. In Germany, it has been shown that among emotionally related donors, mothers donated most frequently (27% of the donors in this group were mothers who donated to their children), followed by wives who donated to their husbands (19%). Fathers donated less than half as much as did mothers (13%), husbands donated, again, less than wives (11%) (Eurotransplant 1999). The

difference remained, by and large, in 2004 (Eurotransplant 2004). In Switzerland, during the period 1993-2003, with regard to 653 registered live kidney donors, 65% of the donors were women and 64% of the recipients were men. Again, more women (84%) donated to their partners than did men to their partners (24%) (Thiel et al 2005). These are just two examples.[2]

There are probably both medical and socio-cultural reasons why women and men, as groups, engage in LKD to different extents and in different senses. In cases where the gender-imbalance can only partly be explained by medical reasons, it has been suggested that it could also partly be explained by traditional male-female roles, where women feel obliged to care for the sick family members (Thiel et al 2005). In line with this reasoning, care-work has been described as a labour of love, which women still experience a stronger pressure to engage in than do men (Lewis and Giullardi 2005). It has also been suggested that more women, as a group, see moral dilemmas not in terms of rights or justice, but in terms of responsibility for relations over time and, again, of care-giving (Gilligan 1982)[3] and that this may matter to their behaviour in LD. It has been suggested that women may be more sensitive to family pressure to donate and less able to resist such pressure and that this may make them more inclined towards LKD than men, as a group (Zimmerman et al 2000).

Empirical research has, however, questioned some of these suggestions. A Canadian study designed to test whether female donors were more likely to be subtly influenced by family pressure to donate and to display gender-typed nurturing behaviours than male donors did not support these hypotheses. Instead, it did show that men took longer to make the decision to donate and that more men than women expected "negative repercussions" if they changed their mind once they had offered to donate (Achille et al 2007). If women are faster in their decision-making and faster in volunteering as donors than men, is it then the case that women get accepted as donors while men are still engaged in the decision-making process?

Now, LD can qualify as a kind of care-work in cases where the act of donation is (fully or partly) motivated by love and concern for the recipient, if the procedure of going through the medical tests, the donation and the recovery after donation is seen as kind of labour (where a healthy person offers to undergo surgery for the sake of someone else). If the donor not only donates, but also stays at home and cares for the recipient after the donation, this is of course also care-work. If this reasoning is accepted, LD can be compared with other kinds of care-work, such as care of elderly parents, care of children, care of sick relatives. In all these areas, gender-imbalances still prevail (see Jecker 2002).

There is, however, no similar gender-imbalance in live liver donations. Instead, more men donate than women.[4] This reversed gender-imbalance needs to be further explored. So far, focus has been on medical reasons for this gender-imbalance: there is an increased risk of graft failure in male recipients of female livers (Rustgi et al 2002, Choukèr et al 2004).

There are major differences between LKD and live liver donation. The risks involved in live liver donation are higher, for the donor. There are also similarities. Both kinds of LD imply anaesthesia- and surgery-related risks for the donor and the recipient. Both kinds of LD can also result in vulnerability of the donor. As long as this vulnerability is self-afflicted and the result of a voluntary act by an autonomous person, some may claim, it should not be a matter of ethical

concern. In the case of loving LD, I will argue, this view builds on too simplistic an understanding of decision-making in intimate love relations. I will also argue that if the gendered distribution of vulnerabilities among live kidney donors prevails because of gender-roles (and not, for example, for medical reasons), and these gender-roles make women assume that they should volunteer as live donors because of their being women, then the said gender-roles should be an ethical concern.

# Vulnerability, Choice and Love

The term vulnerability is derived from the latin *vulnero* and *bilis*. To be vulnerable is, basically, to be capable of being wounded or harmed. While there are diverse definitions of vulnerability, many of them combine the elements of risk faced by the agent and her or his conditions for handling such risks (Guimaraes 2007).[5]

In a broad sense, vulnerability can be seen as a universal human life-condition. The human being is vulnerable to bad treatment by others or, one might say, there is a basic vulnerability involved in many human-to-human interactions (I may be duped by others, I may trust them but they may let me down etc.). Such a broad usage has also been questioned. If too much is implied in vulnerability, the concept loses its analytic strength (Levine et al 2004). However, being "persistently vulnerable in ways typical of the whole species," as Onora O'Neill (1996:192) puts it, is different from being "variably and selectively vulnerable" in specific circumstances.

Live organ or tissue donors are selectively vulnerable. They are so to the extent that LD implies *risk of physical harm* to the donor because of the donation. Furthermore, depending on the national live donation economic compensation system, donors may be at *risk of financial harm*. This is the case if donors, after donation, cannot return to paid work because of donation-related illness and are not fully compensated for this loss of income. This is also the case if donors stay at home and care for recipients and are not fully compensated for this loss of paid work.

In the case of LD, it is often claimed that donors donate voluntarily and that they are, in most cases, autonomous persons. Some may hold that, for these reasons, donation-related risk of harm to the donor should not be an ethical concern. Consider now three scenarios that indicate why this view is problematic.

Consider first a case of parental LKD in which the father, for some reason, does not want to donate. The mother donates partly out of love for the recipient, partly out of love for her partner, i.e. the father, and partly because she feels that "she was not allowed to say no," as has been reported in some empirical research (Kärrfelt et al 2000). Now, if the mother has internalised the view that mothers should volunteer as live donors because of their being mothers, to the extent that this makes her *unable* to say no to donation, she cannot be said to be in a situation of choice in this particular regard (compare Zeiler 2005:176-207). She may be able to choose between *post mortem* kidney donation and LKD but not between LKD and not LKD. For this reason, in scenarios such as this it is not reasonable to conclude that donors donate by choice and that risk of harm should not therefore be an ethical concern.

Consider also a scenario in which no one, initially, volunteers as a live kidney donor. After some discussion, the diseased person's brother says that that if no one else volunteers as a donor

then he will do so. The brother explains that though *post mortem* kidney transplantation and dialysis are medically possible alternatives, he knows that LKD is better for his sister from a medical point of view. This, he explains, settles it. He can't see his sister suffer this much without doing something. Since he loves her and wants what is medically best for her, he feels that there is no other viable alternative, for him, than to donate as a live kidney donor.

Now, the brother's feeling that there is but one viable alternative implies not that there is, as such, only one alternative nor that there is an ethical issue at stake. Yet it is important to consider his feelings. If he feels that there is but one viable alternative, i.e. to donate, and if this feeling is so strong that he becomes unable to choose not to donate, then he is not in a situation of choice as regards whether to become a live donor. Again, in scenarios such as this it is not reasonable to conclude that donors donate by choice and that risk of harm should not therefore be an ethical concern.

Consider also another case of loving LD. Love typically makes us concerned about the good of the loved-one. We care about those we love in a different way than we care about just anyone and we voluntarily make sacrifices for those we love. The loved-one can also take advantage of this love. We can imagine women who return from work and then do the majority of the house-work and the care-work for the children out of love. If their partners are inattentive they may let them make these sacrifices without even seeing their acts as sacrifices. Furthermore, and as noted by others (for example Radzik 2005), such partners may not believe that they are doing something wrong even if they let their spouses sacrifice their well-being. After all, the spouses act out of love. Of course, the partner who makes sacrifices (or the inattentive partner) may be a man or a woman.

It is important to note that I do *not* mean that love need to be a constraint on someone's free choice (a view that will be discussed below), nor that the making of sacrifices out of love should as such be an ethical concern. Certainly, a loving act of sacrifice for others can be, and indeed often is, utterly positive. Nevertheless, some loved-ones may take advantage of the lovers who make sacrifices, time after time, to the detriment of the lover's health and well-being. Such behaviour on the part of loved-ones can be ethically questionable. If live donors donate out of love, if they time after time make sacrifices for the sake of the loved-one to the detriment of their own health and well-being, and if loved-ones take advantage of this to the extent that lovers are exploited, then this should be an ethical concern (and this view will soon be further discussed).

Finally, consider also the gender-imbalance in LKD. Whereas this gender-imbalance can partly be explained by hypertension and kidney disease leading to renal insufficiencies being more common among males than females (Hallan et al 2006), it is also argued that medical reasons cannot fully explain the gender-imbalance (Zimmerman et al 2000, Thiel et al 2005). If the resulting gender-imbalance is partly due to gender-roles which make women assume that they should take on this kind of care-work and if such gender-roles constrain women's (and men's) choice in this particular regard, then these gender-roles should be an ethical concern. Such would be the case if women or men, because of their gender-roles, believed that they should donate as live organ donors and this constrained their ability to choose whether to donate or not.

#### WHAT ETHICS IS NEEDED IN LOVE RELATIONS?

The decision-making process in parental loving LD has been described as particularly 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). 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 exercise free and autonomous choice? It may not be easy to say no to donation within a love relation.

In a thought-provoking article, Robert Crouch and Carl Elliot (1999) suggest that one of the problems with present-day discussions of emotionally-related LD 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, they say, we see love as a constraint 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 view, they comment, is problematic. I agree with them. Whereas internalised pressure to donate can result in constraints on someone's capability and/or possibility of coming to a decision not to donate, 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, (and this is important) love can make someone unable to choose. This should be an ethical concern as long as we want live organ donors to donate by choice.

It is problematic to focus *only* on love in discussions of loving family relations and the ethics of these relations, since lovers may be exploited by loved-ones. Such scenarios should be of ethical concern. In these cases, the perspective of love needs to be combined with that which is just. I will now discuss some examples where family-members' relations are talked about in terms of love only.

#### Love and the family

According to Michael Sandel (1982:31), the family is an intimate group, held together by love and by "more or less clearly-defined common identities and shared purposes." In his discussion of the family, the focus is on affection and generosity between family members. It is assumed that family members share important parts of their being with each other and that the good of each family member matters to the others, as individuals and as parts of the family. Others have followed this route: as family members, we "share our selves" and we "share significances" with each other in a deeper way than we do with non-family-members (Shoeman 1980, Crouch and Elliot 1999:284). Whereas this is unproblematic (provided, of course, that we acknowledge that this sharing does not always take place), Sandel's discussion gets more questionable when he contrasts love with justice.

In his view, family members should be guided by "nobler virtues" than justice. Love is such a noble virtue. Indeed, Sandel (1984:172) says, to his family members he owes "more than justice requires and even permits, not by reason of agreements I have made but instead in virtue of those more or less enduring attachments and commitments which taken together partly define

me as the person I am." Sandel (1984:172) does not tell us what the exact content of these commitments is, nor when they begin, but his point is that allegiances such as those between family-members consist of more than values and goals that anyone may have at "any given time." Because of these relations, we will owe – to some – more than justice requires and, in his view, if justice is to enter the picture it shall so as a "remedial virtue" when things have gone astray (Sandel 1982:32).

The ethics of this family conception can be framed in different ways. It may be said that family ethics should be guided by love as opposed to the "cold" logic of justice or it may be said that family ethics is "beyond" justice. An alternative route could be to omit the perspective of justice in discussions of family ethics.

Interestingly, the last approach is exemplified in Crouch and Elliot's discussion of LKD between family-members: they address the issue of love and omit the issue of justice. They emphasise that family members cherish each other for each other's sake and that the family is a source of value and meaning: to be a family member is to "recognize the importance of strongly 'shared significances'" (Crouch and Elliot 1999:283, 277) They focus on love and on the interconnectedness of family members. The interests of family members are often intertwined, they explain, and this needs to be recognised also in discussions of LD.

According to Crouch and Elliot, family members are motivated to engage in LD because of who they are. They are loving family members for whom sharing is important. It is important, they also hold, *not* to see love as a constraint on family members' ability to make decisions in the context of LD. In the case of a mother who donates to her child, love can instead "give voice to her autonomy and say something about the kind of agent she is" (Crouch and Elliot 1999:285).

In order to elaborate an ethics of intimate love relations, we need to acknowledge the emotional character of these relations. This is a major benefit with Crouch and Elliot's view. They highlight how misleading it is to contrast, in an easy way, freedom and love if we want to understand what takes place in intimate love relations. Emotional bonds should not be understood as a problem, but as a prerequisite for moral selves *qua* family members. Furthermore, Crouch and Elliot's position allows us to understand the self as relational. Family members contribute to the shaping of each other. This is important.

However, in order to understand the relation between choice and love we need to make a distinction between on the one hand scenarios in which emotional bonds such as love make us want to choose one alternative instead of another, and on the other hand scenarios in which love make us unable to choose, at all, in a particular regard (and/or scenarios in which a mixture of love, experienced pressures and obligations makes us as potential donors, unable to say no to live donation). Whereas love can give voice to our autonomy in the first case, it cannot in the latter cases.

Furthermore, I am not convinced of the reasonableness of leaving the discussion of that which is just out of the discussion of emotionally-related LKD. Ideally, family members are loving. In reality, however, family-members are not *always* acting out of love for the other members. A family-member who always puts the others' needs before her or his own needs, out of love for the others, may be exploited by these others. For this reason, though we need to

acknowledge the importance of love in the elaboration of an ethics of intimate love relations, it is not sufficient to do so. The more promising understanding of the ethics of the family, in my view, acknowledges i) that family members should strive to be guided by love and ii) that no family operates always in this way. For this reason, an ethics of intimate love relations benefits from combining the perspective of love with that which is just. Loving and just families, I suggest, are better prepared to handle the moral complexities in life than merely loving families, as long as these families live in societies with systematic gender inequalities.[6]

Just love is needed in intimate love relations and this for three reasons. First, though no love is entirely without value, there are better and lesser loves and the lesser loves can occasion both jealousy and egoism. This, in turn, can be devastating for those in the love relation. In order to critically analyse love relations that become devastating to those involved in them, we need a conception of just love. Second, and as already said, loving families live in societies with systematic gender inequalities. These inequalities and norms may also shape loving family members' interaction with each other, even if these interactions do not qualify as devastating (but, for example, as detrimental) to some of those involved in them. Such inequalities between family members need also to be analysed and, I believe, the concept of just love can enable such an analysis. Third, and as noted by others, love may at times put conflicting demands on us and the goods of the loved ones that we cherish may be in opposition (Rawls 2005:476, Ricoeur 1995:329). In such cases, the just is needed in order to guide love.

#### **JUST LOVE**

In the following, I will discuss Margaret Farley's (2006) conception of just love. I will discuss two of Farley's criteria of just love in some detail, I will present some alternative criteria and I will end by discussing Farley's last criterion. Love is just, I will argue, (i) when it takes into account and affirms the concrete reality of the lover and the loved-one and (ii) when it does not lead to the exploitation of the lover nor to the domination of the loved-one. I take it to be uncontroversial that we, when loving, greet the loved-one not only with the statement "you are," but also with the more emphatic "I want you to be, and to be firm and full in being" (Farley 2006:170). Lovers who want each other to be, firmly and fully, are concerned about the good of each other.

# Criteria of just love

Farley describes love as an "affective response to, union with, and affirmation of an object." Just love is a qualified love. Just love, in Farley's view (2006:200), (i) aims to affirm "truthfully" the loved-one's concrete reality, (ii) is "true" to the lover and (iii) is "true" to the "nature of the relationship between lover and loved." The reasoning builds on the view that not all love is just love. I take this to be accurate since love can occasion possessive violence and it can lead to the domination of the other. Such love should not qualify as just. Indeed, the benefit of the concept of just love, as an analytic tool, is that enables a discussion of nuances in love.

Consider now Farley's first criterion. Just love, in her view, aims to affirm "truthfully" the loved-one's concrete reality. While the meaning of Farley's term truthfully (or true, in her second criterion) is not altogether clear and while her formulations evoke questions of who defines truth

and by which criteria truth is defined, some of her examples are informative. Love is not just, she explains, if it affirms only parts of the loved-one, if it affirms only parts of her or his concrete reality or if it affirms the loved-one's reality in such a way that it unintentionally distorts or misses important parts of it. She offers two examples. A parent who affirms her or his child without attending to the fact that this child is a child and not another (though small) adult, fails to affirm the child's concrete reality. A similar failure takes place, Farley holds, if a lover affirms only what the loved one does for the lover.

I take this to be important. Love risks being misguided if it does not take into account the beloved's concrete realities. If it is misguided to the point of not seeing the beloved's concrete life situation, dreams and plans, it may easily fail to affirm the beloved. Such love may only or primarily reflect the lover's own dreams, plans or ideal pictures of how the loved-one should be. It may be detrimental to the loved-one or, at least, be experienced as unfair and frustrating to her or him. Such will be the case if the loved-one believes that she or he ought to become the idealised person in order to be loved and if she or he really wants to be loved yet does not want to change into an idealised version of her- or himself. It would be helpful to have a concept that can help us to see the nuances between i) love that does affirm the loved-ones concrete reality and ii) love that for different reasons fails to do so.

Yet there is something troubling about this first criterion of Farley's. Her focus is on intention. Love is just, she says, when it *aims* to affirm the loved one's concrete reality. As a criterion of just love, this is too broad. When we engage in love relations, when we are concerned about the good of the other and when we want the loved-one to be, fully and firmly, we (often) do intend to affirm the loved-one as a concrete human being. The "problem" is that we sometimes fail to affirm this person.

In order to make her point, Farley (2006:200) asks us to consider the cases of "mistaken love" and "lying' love." The first of these loves, she suggests, implies that we affirm some aspect of the loved-one's reality, but we do this in a way that unintentionally misses important parts of it. The latter love implies that we intentionally ignore or distort aspects of the reality of the loved-one. Though these are examples of love, Farley says, such love is not just love. However, it should be noted that Farley's mistaken love could indeed qualify as just love if we use her criteria (even though she uses this as an example of a love that qualifies not as just love). Though the lover who loves with this love unintentionally misses parts of the loved-one's concrete reality, her or his aim could still be to affirm this realty.

Her second criterion of just love is troubling for similar reasons. Just love, she says, is "true" to the lover. This means that love is not just if it allows the lover to let herself or himself be destroyed as a person because of the way in which she or he loves. However, it is after all not very difficult to imagine scenarios in which a lover explicitly acknowledges that the loved-one deceives her or him from time to time and that the relationship is at times destructive to the lover. Still, as long as the lover is not destroyed as a person because of love and provided that the other criteria are met this love qualifies as just. Again, as an analytic tool, the concept of just love is too blunt. Too much gets included.

We need a concept that allows us to distinguish between scenarios where lovers' health and well-being are destroyed (even if they are not yet destroyed as persons) because of love and scenarios where this doesn't take place. We need a concept that allows us to make distinctions between, for example, scenarios in which lovers are exploited by loved-ones and scenarios in which lovers make sacrifices for others without being exploited. If there is little difference between love and just love, the concept of just love will not be of much analytic help. For this reason, I suggest a modification of Farley's criteria: love is just i) when it takes into account and affirms the concrete reality of the loved-one and the lover and ii) when it does not lead to the exploitation of the lover nor to the domination of the loved-one.

In its Marxist context, the concept of exploitation is used to highlight the process through which the results of the work of one social group are transferred to the benefit of another social group. When feminists apply the concept of exploitation to intimate relations, focus is not only on the transfer of the results of women's work to men, but also on the transfer of energies and/or power to the benefit of men, such as is the case when women work full-time and, when they return home, also take care of most of the house-work and care-work (Young 1990:50-51). This is also how I will use the concept. Exploitation of persons in intimate love relations takes place when one partner takes advantage of the other's love, time after time, even if she or he does so subconsciously, and when this results in the lover's well-being, health or person being sacrificed for the sake of the other through a process of transfer or energies and/or power. Exploitation can take place before it has led to the destruction of the person because of the way she or he loves. This person may be a woman or a man. Furthermore, just love should not lead to the domination of loved-ones, i.e. it should not lead to the imposition of the views of the lover on the loved-one. As an example, a sister dominates her brother if she constrains him from participating in determining his own acts or the conditions of his acts. If she by so doing manages to convince him that he should volunteer as a live donor, and if she explains that she does this out of love, then this does not qualify as an act of just love.

Farley (2006:201) suggests that love, finally, is just when it is (ii) "true" to "the nature" of the relation between lovers. Again, this is important. A relation between two more or less equals is different from the relation between a parent and a small child (see for example Koehn 1998). The parent-small child relation, the parent-teenager relation and the partner-partner relation differ from each other in terms of (among other things) the asymmetry in the relation and the degree of vulnerability. The parent-small child relation is more asymmetrical than the partner-partner relation and, though present to a great extent, the asymmetry in the parent-teenager relation manifests itself differently in this relation than in the parent-small child relation. The difference between different kinds of love relations needs to be acknowledged. However, there is no call for another criterion, since it can be seen as a second-order endorsement of the first-order attitude of taking into account the concrete reality of the lover and of the loved-one. The love relation is part of the concrete reality of lover and loved-one. Taking into account these realities already implies that we take into account the nature of the love relation.

# JUST AND LOVING LD

Consider now the story of Ann, Josef and Sarah. Ann and Josef love their two young children. Ann is the one who does the lion's share of the care-work for them. She delights in the closeness to the children. This does not, however, imply that things are easy. It is hard work to take the children to and from the day-care centre almost every day, and to care for them when they are ill. Josef travels quite a lot in his work, but Ann tells herself that "that's fine; he needs his freedom." She realises that this sounds stereotyped, but she consoles herself by thinking that this is what Josef himself says. In her dark, but honest periods, she admits to herself that she would also love to travel as part of her work. Nevertheless, she certainly loves Josef. She is willing to make sacrifices for him.[7]

During the last year, however, their daughter Sarah has been severely sick. Ann and Josef have been told that Sarah has a rare kidney disease called focal segmental glomerulosclerosis. Sarah has been given dialysis. Her parents have also been told that Sarah may need a live kidney transplant in the close future. When they were told this, both of them declared that they could volunteer as donors.

Now, the last year has been turmoil. Ann and Josef have been filled with frustration and worry. Nevertheless, when the doctors again inform Ann and Josef that their daughter needs a kidney, preferably from a live donor, Josef hesitates about volunteering. Hospitals fill him with angst. When they discuss the situation, what donation would imply for donor and recipient, Josef looks at Ann and asks: "You're not so afraid to donate, are you?"

Now, some may claim that Ann can simply say "No, I'm not, but I think you should be the donor," if this is what she really thinks. In theory, this may seem straightforward. In practice, however, there may be many reasons why Ann may not want to say this. Lovers are emotionally engaged with each other. They are, typically, emotionally interdependent. Ann may volunteer as a donor, partly because she wants to protect Josef. He may, consciously or subconsciously, take advantage of her love, and this may result in the sacrifice of her health or well-being because of love. If this happens time after time and if it results in Ann's health and well-being being sacrificed for his sake through a process of transfer of energies (such as if she engages herself as a care-worker in the sense of becoming a live donor on top of her everyday care-work so that he need not do so), their love does not qualify as just love.

My point here is *not* that fathers don't donate as live kidney donors to the same extent as mothers. Instead, my point is to highlight how the decision-making process of both women and men, who are potential donors, can be enabled. This is needed since the decision-making in the context of loving LD is complex. It is important that potential donors get the opportunity to reflect thoroughly on whether to donate.

# **Clinical Implications**

In an ideal situation, Nikola Biller-Andorno and Henning Schauenburg (2001) have suggested, live donors contact transplantation units without having been asked to do so by health-care professionals. Since some people may not be aware of this possibility, however, live donors may need to be contacted by transplantation personnel. When this is the case, Biller-Andorno and

Schauenburg continue, professionals should inform patients' relatives and friends of this alternative in a non-directive manner. In the next step, *pace* Biller-Andorno and Schauenburg, potential donors should discuss LD with an independent expert. It is most important, I add, that this person is not a part of the transplantation unit. She or he should not be an expert on transplantation as such, but on how to enable potential donors' thorough reflection on whether to donate – at a time when they and the recipient may be in crisis. This person could be a psychologist.

The aim of this encounter is to enable a thorough reflection on whether to donate; possible topics for the encounter would be the motivation of the donor, the history of the donor's offer to donate, the "psychosocial stability" of the donor and the donor's awareness of the fact that the medical outcome may be worse than expected (compare Biller-Andorno and Schauenburg 2001). Whereas such a questioning of the relationship between donors and recipients, of donors' motives etc. would be most intrusive in many other areas, the special features of LD call for it. LD implies that a healthy person is put at risk for the sake of another person's health, by medical professionals. It is important that the decision to accept a donor is made in a responsible and adequate manner *and* that the potential donor has thought through her or his decision.

Now, the concept of just love and the two criteria of just love are beneficial if they function as tools that enable these reflections. This is possible if the psychologist is sensitive to the presence of phenomena of exploitation or domination in the potential donor-recipient relation and in the relation between potential donors and the extended family and if she or he can enable the potential donor's reflection on whether she really wants to donate, by questioning these phenomena in a nuanced and careful manner. If the potential donor is a woman who lives in a socio-cultural context with strong gender-roles according to which she should donate, the psychologist may need to help her question these gender-roles. This does *not* imply that the expert should talk her into not donating. The very point is that if gender-roles hamper women's or men's ability to choose whether to donate or not, the psychologist needs to be trained to question these gender-roles for the sake of enabling a thorough decision-making process on the part of potential donors.

The psychologist needs also to be sensitive to the donor's and the recipient's awareness of the concrete reality of the other. Are both of them, for example, aware of what live donation can mean to the other person's concrete reality? Finally, the psychologist needs to be highly aware of the possible tension between love and choice. She or he needs to be sensitive to the fact that love can give voice to our autonomy but can also make us unable to say no to live donation. This being the case, the donor is not in a situation of choice. This should be an ethical concern.

# **Endnotes**

- 1. I borrow the "Just Love" part of the title from M.A. Farley's (2006) Just Love.
- 2. For data on Norway, see Oien et al (2005). For data on the USA, see Bloemenburg et al (1996).
- 3. Reasoning based on Gilligan's research has been critiqued for encouraging stereotyped thinking. It is one thing to say that at that time, in that context, more women reasoned in a certain manner than did men.

- From this, it need not follow that a similar difference prevails today, in other countries. Furthermore, Gilligan's research tells us nothing about the *reasons* for the difference in ethical reasoning.
- 4. In a U.S. study on long-term survival after live liver donation, more men than women donate. Of all donors (n=764), 42.5% were female. Similar data is available in a Taiwan study, on all liver donors at Chang Gung Memorial Hospital, during the period 1996-2005. Of all donors (n=204), 40% were female (Thuluvath and Yoo 2004, Ibrahim et al 2006).
- 5. For discussions of vulnerability in intimate relations, see Moller Okin 1989, O'Neill, 1996, Kottow 2003, Levine et al 2004, Goodin 1985.
- 6. However, I consider it equally problematic to focus only or primarily on justice, as is sometimes done when scholars apply the social contract model to the family, in order to enable a moral evaluation of intimate relationships. I concur with those who claim that this model, in this context, fails to do justice to "the emotional density" of at least many of the bonds involved. Though one may claim that certain rights and duties/obligations follow from the kind of vows that partners have exchanged or from the fact that parents have begotten the children and that they should therefore care for the other partner/the children, the language of duties and rights between family members fails to do justice to the complex moral interplay within family relation with clear asymmetries. Whereas contracts enable us to make explicit what we expect of ourselves and of others within the contract and whereas contracts can enable us to make explicit what will happen if the contract is breached, family members may not make explicit their expectations, *precisely* because they are engaged with each other in close relationships.
- 7. For examples of live kidney donors' donation stories, see the home-site of Swedish kidney donors. Available at <<u>http://www.nrj.se</u>>. Accessed 2008-01-15.

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