

Self-determination in Living Organ Donation: an Empirically Informed Contribution to Ethical Issues in Decision Making

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Autodeterminación en la donación de vivo: una contribución empíricamente informada a las cuestiones éticas de la toma de decisiones

ABSTRACT: Living organ donation has become a routinized procedure in transplantation medicine in Germany. Despite the existence of a normative-legal framework ethical questions concerning self-determined decisions remain unanswered. This article, based on a qualitative socio-empirical study, addresses how family decisions are made concerning living organ donation and to which extent internal and external constraints affecting the voluntary nature of this decision are found among the interviewed people. The analysis revealed that the central decision for living organ donation was made in the context of the family. The decision was thereby decisively encouraged by the donors, the recipients, on the other hand, were rather passive in the decision-making process. Especially among the organ recipients no purely autonomous decision took place. The empirical results, which will be presented in a first step, provide the framework for the medical ethical recommendations regarding living organ donation in Germany developed in a second step.

RESUMEN: La donación de órganos de vivo se ha convertido en un procedimiento rutinario de la medicina de trasplantes en Alemania. A pesar de la existencia de un marco normativo-legal, algunas preguntas éticas relacionadas con la auto-determinación de las decisiones siguen sin contestar. Este artículo, que se basa en un estudio socio-empírico cualitativo, se centra en cómo las decisiones familiares son tomadas en relación con la donación de órganos de vivo y hasta qué punto las personas entrevistadas son sometidas a presiones internas y externas que afectan al carácter voluntario de esta decisión. El análisis muestra que la decisión central para la donación de órganos de vivo se toma en el contexto familiar. La decisión es promovida principalmente por el donante, mientras que el receptor permanece relativamente pasivo en el proceso de toma de decisión. Entre los receptores de órganos, la decisión no es totalmente autónoma. Los resultados empíricos presentados en la primera parte sirven como marco para las recomendaciones éticas acerca de la donación de vivo en Alemania que serán desarrolladas en la segunda parte.

KEYWORDS: living organ donation, self-determination, decision making, qualitative empirical study

PALABRAS CLAVE: donación de órganos de vivo, auto-determinación, toma de decisiones, estudio empírico cualitativo

1. Introduction

The media increasingly reports about living organ donation – and these reports are predominantly euphoric in terms of successful lifesaving. However, the very significant, ethically relevant questions remain unaffected regarding how these decisions actually are an expression of a voluntary choice in the respective families. Furthermore, it remains unclear which ethically relevant conflicts may arise beyond the physician-patient relationship, i.e. between the donor-recipient pairs due to social and emotional dynamics of gratitude and feelings of guilt; these issues, to date, find insufficient attention in the field of medical ethics.

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2. Background

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In Germany, according to the German Transplant Act¹, only first or second degree relatives as well as friends can be considered living organ donors. Organ removal is legitimized by verification of self-determination and voluntariness of both the donor and the recipient, which should serve the best interest of the recipient. Voluntariness and self-determination thus do not only build the legal but also the ethical framework for living donation. Therefore, voluntariness is a trait that belongs to the action itself (Beauchamp & Childress, 2001; Spital, 2001). Autonomous and voluntary action, first and foremost, entails not making decisions under coercion or being subjected to manipulation, thus precisely not being determined by others (Feinberg, 1989).² Voluntariness and autonomy relate to each other in the form of determination. Despite the multi-faceted interpretations "autonomy" has undergone in the past years in philosophical ethics, it can be assumed, as a form of fundamental consensus, that autonomy entails the ability of human beings to consider themselves free beings and to act out of this freedom (ibid.). In the context of severe acute or chronic illness these notions, however, rarely comply with reality. A weakened person, whether acutely or chronically ill, is dependent on the support and care of his or her environment. Thus it is necessary to examine to which extent voluntariness and autonomy are present; this issue also highlights the intensive engagement with autonomy and voluntariness in the field of medical ethics. Under the changing conditions of a severe illness, in which those affected are dependent on third parties and social support, it can be assumed that individuality is a fragile acquisition (Tietjens Meyers, 2005, 154).

The priority of voluntariness, for example, in the context of perceived obligation to donate due to alleged duty to provide care or due to economic reasons is flanked by the normative premise of inflicting no harm. In the German Transplant Act a detailed medical and psychosomatic evaluation of donors and recipients is required to prevent an involuntary decision, as could occur, e.g., by means of social pressure exerted by the family. The research results are incorporated into independent decisions of a living donor commission, which is responsible for verifying the voluntary nature of the decision and the exclusion of organ trafficking (Wagner & Fateh-Moghadam, 2005). Biller-Andorno, Agich, Doepkens, & Schauenburg (2001) with their psychosomatic and medical ethical evaluation refer to the intricacy of psychological verification of voluntary decisions on the part of the medical and psychological disciplines

and argue for further development of psychosomatic consultations supporting the decision-making process³ in living organ donation. The aspect of voluntariness in the decision-making process, to date, has not been empirically analyzed from the perspective of the affected⁴.

In addition to the situation of chronic illness, family dynamics such as material and emotional dependencies or gratitude play a role in living donation. In families, decisions are mostly made in emotionally highly charged and socially close relationships whose members dispose of reciprocity relations in a differing manner and intensity. The question thus arises to which extent voluntariness even is possible in families with a chronically ill family member? Laws often rather resort to an individual-ethical concept of autonomy which assumes patients to be autonomously acting individuals. The patient or the potential donor individually should be able to make voluntary and informed decisions and, with conscious consent, should also be able to bear the consequences of a therapeutic measure which is described as informed consent (Appelbaum, Lidz & Meisel, 1987).

The following set of questions was pursued by means of socio-empirical analysis: How is a family decision made for living donation and to which extent do internal and external constraints concerning the voluntariness of this decision become apparent? Which implications arise for the discussion about autonomy and voluntariness in medical practice?

3. Methodology

For elucidating the decision-making process for living donation, a qualitative-empirical approach with open questions was chosen. The focus was on donors and recipients who opted for living kidney transplantation. In addition, potential donors and recipients were interviewed for whom living organ transplantation was not an option. Data was collected from 2007 to 2009⁵, this considerably large sample for a socio-empirical study in total included 46 participants.⁶ Six focus group discussions were conducted with these participants and, in addition, structured interviews were conducted with 31 of those affected (Kelly, 2010).⁷ In addition, semi-structured interviews were conducted. The interview guideline was identical for all participants and included six themes: disease biography, decision-making, relationship of the donor-recipient pair,

body conceptions, laypersons in the context of biomedical knowledge and giving and receiving. The interviews lasted between 30 and 120 minutes; donors and recipients were interviewed separately. In the individual interviews, the research interest's emphasis was on the detection of biographical and narrative information, while the group discussions rather focused on a reconstruction of attitudes and opinions as they are represented in the context of homogeneous groups.

Due to the unusually large size of the data sample, which was created with a balance in terms of socio-demographic factors, generalizing interpretations could be made in the analysis. The approach of my focus groups is based on the fact that the affected who have become experts play an important role due to their experience in the entire organ transplantation discourse. The discussion topics of the focus groups were commercialization, the role of gift giving and the question of body concepts. Each focus group was moderated by two researchers. The moderators therefore took up the position of "supportive leadership" by maintaining a low profile but at the same time making sure that all participants could finish speaking or had a chance to speak (Krueger, Casey 2000). The analysis of the data was carried out according to rules of qualitative content analysis (Mayring, 2000).

3. Empirical results

The analysis of the data shows that those affected are mainly guided by two motives in the decision for living organ donation: An improvement of quality of life and safeguarding survival of a family member (life extension).

For the majority of the respondents, self-determination was considered an important criterion, which was often justified on the basis of the valid German Transplant Act. By contrast, the exertion and negotiation of autonomy within the family was considered to be somewhat difficult to describe and was experienced as well as internalized as part of their individual socialization. The statements illustrated that autonomy within the family was not clearly perceived in daily behavior. Accordingly, it was difficult to classify, in some cases, whether a decision was good or bad, or in other cases was simply not thought through in a differentiated manner. Thus, it was difficult for those affected to classify and evaluate the differently shaped (or molded) autonomy within the family concerning which concrete social conditions

are considered critical presuppositions in the respective family. Therefore, many resorted to general statements about autonomy.

In the following, criteria which require and influence a family-dependent autonomous decision are listed separately according to the donor and recipient perspective. The division seems useful because relationship structures within families as well as the manner in which families deal with chronic illness can lead to an exclusion of some family members regarding the decision on living donation. Further, criteria may possibly not be met which allow for a voluntary decision, for example, undermining social pressure.

3.1. Self-determination from the donor perspective

The initiative of offering living donation mostly came from the donors. Strikingly many recipients described their donor's offer as being spontaneous, this, however, did not mean that the decision was not made voluntarily. Some donors introduced the offer in the presence of a third person and made use of a joint visit to the doctor's office making the offer in the presence of the treating physician. For some recipients, the offer of living donation was made on their birthday. Here, dynamics in the relationship become visible that indicate the presence of control and power relations within the relationship on the side of the donor.

Time also played an essential role. A group of donors considered themselves to be in a dramatic situation during the decision-making process; the diseased relative's health was already in such bad condition that no temporal space for reflection seemed to exist:

Ms. Hartmann⁸: "I think you have to be in the situation, you have to be so desperate that you say no other way is possible, a piece has to come from somewhere now. Otherwise one can no longer exist." P11 FG S4.08 (donated a kidney to her daughter)

Aspects such as own risk assessment were here moved to the background. However, this situation did not challenge the voluntariness of the decision; free choice of the decision was at most lacking in these examples. Those affected, however, approved when faced with the situation. In contrast to these dramatic examples, the vast majority of donors had sufficient time to examine their own motivation for or against donation.

Donors (but also recipients) stressed that the voluntary decision for living donation can only occur in families which have an intact reciprocity relation, thus, dispose of a balanced relation of *mutuality*. Decisions therefore should be free of intra-familial, emotional pressure. They emphasized that such serious decisions such as living donation should be borne by all family members as tensions and conflicts could otherwise arise in retrospect.

Conflictual intra-familial dynamics can occur in the decision-making process for living donation and can intensify already existing conflicts among family members, especially if a family member considers himself or herself restricted in his or her autonomy:

Ms. Hartmann: "And then my mother came with us. She then stood in front of the bed next to Vanessa and said quite devotedly: 'Oh, child, don't worry, you have an identical twin sister, nothing can happen to you.' And this identical twin sister then stood there and said 'mhm' Well, and then the whole thing took its course." P29 SW01 (donated a kidney to her daughter)

Lacking communication among family members, as in the case of the Hartmann family, could lead to the suppression of individual family members' self-determination by first nominating the twin sister as the best donation option. The twin sister for months was not able to defend her own needs against this family decision. This example was not an isolated case: In some families living donation was expected by siblings as a kind of "service to the family."

These intra-familial conflicts not only challenged self-determined voluntary decisions of potential donors but also challenged their acceptance of the family which, in some cases, led to new conflicts.

Independent of role expectations, donors emphasized that a fundamental element of the voluntary choice within the family must also be respecting a decision rejecting donation:

Mr. Petersen: "I also think that a decision based on fear can also be rejected, fear concerning one's own survival has to be respected, also within the family." P13 FG_S06.09 (donated a kidney to his significant other)

This statement also illustrates that families did consider motives of decisions arguing against the decision of living donation. For donors, the fear of surgery was not

relevant as the acceptance of one's own health risks would ensure the survival of a closely related person. Thus, in the discussion about voluntary decisions in the context of living donation it was remarkable that the aspect of necessary physical harm to help the diseased family member was tabooed by the donors. This could be a reason why donors seldom discussed their decision with the family in advance.

A married couple's intense engagement with the possibility of living donation, especially concerning self-determination within their relationship, for her, resulted in the rejection of living donation:

Mr. Rohrbach: "I have to say that is something that triggers a guilty conscience within me. I have also not spoken about it very much. I did ask every once and then but did not insist for the purpose of clearing her inhibitions. Because I, of course, somewhere also am relieved, well, she did not insist." P27 SM02 (together with his wife decided against living donation)

Only few donors were able to describe such ambiguity, on the one hand, being happy about one's physical integrity but, on the other hand, feeling responsibility and an obligation which arose from the emotional connection. This ambiguity could also cause partners to feel guilty because they decided against living donation.

3.2. Self-determination from the recipient perspective

The recipients acted rather passively or reactively in the decision-making process. It was the donors who approached the recipients with the offer. There were only few statements about the extent to which recipients made their decision voluntarily in this process. For the recipients, balancing the nature and scope of the decision regarding living donation had priority as negative consequences, especially regarding the health risks of the donor of their choice, concerned the entire family.

Children had less concerns regarding the acceptance of a parent's organ if they were a minor at the time of transplantation, which corresponds to a normal relationship between parents and children. By contrast, this attitude changed when parents wanted to donate an organ to their adult child. Before accepting the offer of donation, children and parents sought to clarify their relationship. At this time, the affected adult children who received the offer challenged the voluntary nature of their parents' offer by questioning suspected motives. In fact, some of the adult

children in the interviews admitted that they could never accept a parent's organ due to their conflict-ridden relationship.

The recipients' statements showed that certain strategies were used to guarantee voluntary acceptance of the organ. Only few recipients specifically addressed tensions and conflicts in donor-recipient pairs. Thus, a young recipient discussed the concept of voluntariness in order to understand her mother's actions. The recipient emphasized which conditions would have to be met for her to accept the organ. Accordingly, the donation must be voluntary and may not be regarded as a form of compensation. The difficulty of a voluntary decision, on the part of potential recipients, consisted of classifying the decision for living donation as an action element in a reciprocal relationship. It is necessary to consider their choices as well as motives driven by emotions such as unfulfillable gratitude or guilt that came to mind as future prospects. In symmetrical relationships, recipients weighed the decision in the context of their relationship with their partners. Contrary to asymmetric relationships, recipients in symmetric relationships oriented their decision towards their donors' expectations. Some recipients, however, described that they felt pressured by spouses and physicians to accept an organ:

Ms. Probst: "My doctor, Dr. C. always said: 'Woman, just say yes. See, your husband wants to give you a kidney, just take it now.' He actually spoke with both of us, separately with my husband, separately with me. And my husband and the doctor, actually were the ones who got this going." P51 EW04 (received a kidney from her husband)

Ms. Probst's relationship became imbalanced after the donation because the healthy partner could no longer cope with the unfamiliar situation of a much more active partner, so that the couple eventually separated. The number of couples in this study sample which had conflicts due to living donation demonstrates that, for those affected by living donation, bodily medical intervention is only interpreted as something secondary. To a greater degree, relationship motives stand in the foreground which, in these cases, are to be fixed by means of living donation.

In other cases, self-determination stood in conflict with other family criteria causing disruptions in the decision-making process. This can be illustrated with the example of a father-in-law who could not tolerate that the patient (his son-in-law) rejected

his kidney. The donor assessed recipient's rejection as irresponsibility towards his family. In this case, living organ donation was perceived as a paternalistic order:

Mr. Eisner: "But he was so confused. I told him, you can't do this to me! It was all for nothing, everything I did to help you, and then you say: no, I don't want this. He cried like a little child until I called the doctor. Then they gave him a sedative shot, and then he slept and that was good." P28 SM09 (donated a kidney to his son-in-law)

Mr. Eisner stressed the importance of his voluntary willingness to donate, which he rated higher than his son-in-law's autonomous decision. The overarching goal was the preservation of his daughter's family. The impression was created that the son-in-law's health only served as a means to an end. Here, the family barely gave the recipient an opportunity to make an individual and voluntary decision. In this in-law family, decisions were made by the "head of the family" in a paternalistic fashion.

Lack of communication in the decision-making process could produce latent pressure in diseased children; especially if parents had previously decided without the child's presence that a parent would donate a kidney. In another example, the father's living donation to his daughter was formulated as the last wish of the dying mother:

Ms. Gröbe: "The decision was made by my father, not me, I did not want it, we argued for half a year. I really did not want it because my mother had died a year and a half ago. But the two of them had already discussed it. And my father put pressure on me, I really didn't want it." P10 FG E2 09 (received a kidney from the father)

The decision was thus influenced by familial stabilization mechanisms. The mother was concerned about the welfare of her daughter, however, reciprocity was to be passed on to her child through her husband's living donation which she could not afford herself due to health reasons. The daughter, in turn, was able to care for her grandmother as a result of the organ transplantation.

3.3. Self-determination in the context of medicine and the legal system

During the interviews, voluntariness in the decision-making process for or against living donation was initially considered on a more general level. A voluntary decision was justified with respect to the state or society by, for example, referring to the German Transplant Act, rather than to the respective family. Missing agency appeared

as something unrealistic which the affected only suspected in the context of criminal acts, such as in organ trafficking. It was frequently mentioned in this context that state responsibilities and regulations existed for the examination of voluntariness (with reference to the German Transplant Act). Thus, the donors initially expressed a high degree of trust in the constitutional state. However, while donors underlined the envisaged inspection process legitimized by the German Transplant Act, they also added that voluntary decisions in families were difficult to verify. The inspection process by the living donor commissions thus was regarded as critical.

Voluntariness is defined in the German Transplant Act and is verified by various authorities prior to transplantation. Potential donors were often not until the initial physician-patient consultation confronted with the term. A number of donors reported that they had emphasized the necessity of voluntariness to their treating physicians. The voluntary decision for living donation during the entire decision-making process and up until the surgery date comprised the option of revoking the decision. Ms. Hartmann reported that the declaration of revocation, which was given to her by her physician, had helped her to strengthen her decision:

Ms. Hartmann: "Dr. Klemenz said something wonderful. 'If you decide this now, then you, so to speak, are standing on the platform. And you'll see the entire process like a train ride.' I remembered this very well. Until shortly before, he said, there are people who have gone through the entire process, and then stand here in their hospital gown and say, 'I can't do it.' Well, this is a long journey and on this journey you always have the possibility to say stop, I can't do this anymore." P29 SW01 (donated a kidney to her daughter)

The possibility of withdrawal, however, was only mentioned by this donor. The other interviewees were concerned that the decision made in the decision-making process should no longer be called into question. They regarded the possibility of revocation as a form of weakness which might even have a negative effect on them during their preparatory process for living donation. The majority of donors in this context explained that they had already made their own decision before sharing it with the family. Accordingly, it seems that donors had not further dealt with the nature and scope of a voluntary decision within the family. Instead, the concept of revocation seemed disconcerting to them considering the social interaction within their own family.

The interviewees perceived the appointment with the psychologist not only as an "examination" but also as a means of protection allowing for clarification concerning the extent to which the entire family was able to cope with this procedure. The vast majority of respondents, on the other hand, perceived the hearing with the living donor commission to ensure voluntariness as unsettling. The idea that payments could take place within a family (as otherwise common as a form of support service within families) in the context of a living donation seemed very strange to respondents and corresponded neither to their reality of life nor to their reality of values. For many donors, the appointment with the living donor commission was unpleasant. The meaning of this institution, also in retrospect, remained unclear to them. The vast majority of respondents thus also described it as an "ethics committee", a "medical association" or a "parity medical commission." Some donors criticized the approach of the living donor commission:

Mr. Timme: "So, I see this very critically, this ethics committee, completely went against the grain, because we were only allowed to go in separately, the other one had to sit outside (...). There were three, a psychologist, a lawyer, and a doctor. They asked us questions, and I found it, so I found it simply absurd." P13 FG_S06.09 (donated a kidney to his brother)

Those affected did not recognize the benefit of this institution and criticized that it was a mandatory event on the part of the transplantation system to ensure compliance with legal requirements. Interviewees had no verification of the actual use of the living donation commission. In addition, they were certain that with the practiced process of the commission, financial payments between both of the affected would not have been discovered.

4. Ethical reflection of the empirical results

Not least because of the claim in the German Transplant Act, a high priority is attributed to voluntary action in the context of decisions for living organ donation. This study can be regarded as the first systematic qualitative empirical research focusing on ethical aspects in Germany. Furthermore, this empirical study can be regarded as the first German study that interviewed donors and recipients of living kidney transplantations as well as their relatives regarding their decision-making

process. This is a qualitative empirical-ethical study which means that the results cannot be transferred to the entire group of those affected by living organ donation. However, this explorative analysis considers the complex relations of the decision-making process and provides the opportunity to incorporate the perspective of those affected into the current discussion with regard to self-determined decisions within the family for living donation (Mackenzie, 2015).

Those affected accordingly frame voluntariness in the context of living donation, primarily, as a legal parameter. However, within their decision, they also made recourse to a relational autonomy concept. This concept also included a reference to the respective roles within the family structure according to which decisions were made in the context of the family. It became apparent that the self-determined decision for living donation was heavily influenced by other family members. The present analysis refers to the explosive nature of the decision dynamics found within families. It appears that the decision has a predominantly collective character, the decision-making process in the family, however, was initiated and dominated by the donor.

The reconstructed intra-familial dynamics in living donation showed that potential recipients often were neglected in this process. Recipients had insufficiently questioned the voluntary nature of their own decision, leading to some feeling excluded from the decision-making process. This differentiation of the donor and recipient perspective illustrates that self-determination in the decision-making context may be at risk or, especially for the recipient, may only be given under certain conditions. However, those affected actually are critical of supporting the reflection of the (im)possible self-determined decision-making process in the context of the living donor commission. Therefore, the question remains how adequate support can actually be carried out successfully.

The discussion of significant aspects of personal autonomy shows that an autonomous person often makes decisions in the context of his/her perceived obligations towards a group. The inclusion of these social constraints in the concept of autonomy is referred to as relational autonomy (Mackenzie & Stoljar, 2000). Annette C. Baier, for example, asserts that traditional ethical theories of self-determination and personal autonomy are not wrong or obsolete; however, they only cover a part of a larger moral world. The results refer to family obligations that arise out of love and, in turn, are negotiated in differently developed reciprocal relationships. These dynamics are difficult to integrate into a rational-cognitive autonomy concept which, for example,

focuses on the single individual. The statements of those affected illustrate that highly different emotional bonds exist within families between parents, spouses, or siblings which, on the one hand, are mutually dependent and, on the other hand, can limit the autonomy of an individual within the family. It would therefore be advisable to extend existing concepts to, for example, an ethics of trust (Baier, 1995). This orientation is particularly relevant for moral relationships in which people interact with each other directly, as is the case with a family decision for living donation. An obligation driven by love can lead to "taking care of someone" or "concerning oneself with someone" – this is triggered by individual loyalty to another person or group (Oshana, 1998). The empirical findings show that this loyalty is partly assumed as an expected norm linked to the interaction within the family without public or institutional constraints. This norm can also be regarded as a moral burden in decisions. Social pressure is not only quoted as a recurring term for potential donors but also for recipients. It is primarily used as a convincing argument against living donation. The concept of social pressure includes the weight of the expectation that is placed on the other as well as implicit or explicit threats of social exclusion from the group (Wilkinson, 2011).

Involving the perspective of donors and recipients makes it possible to understand the influence of behavioral patterns through dependencies and subtle forms of exercised power in social relations in the context of patient autonomy. A number of statements of those affected refer to hierarchies within families by means of representative decisions for the donor. Here, forms of relational autonomy and its limits become evident. At the same time, the empirical findings reveal the existence of burdened relationships prior to donation in which, among others, an obligation existed. This questions which meaning autonomy must be given in this context if the relationship was imbalanced concerning reciprocal conditions prior to donation. The overt or covert influences of potential coercion mechanisms that are caused by emotional ties are difficult to describe to outsiders or difficult to distinguish from reciprocity (Veatch & Ross, 2015).

The empirical results also point to the continuation of a traditional understanding of roles in donor-recipient relationships (also between siblings and friends). In contrast to parent-child donations, caring for the donor, in donations among adult siblings, was interpreted as restricting self-determination concerning one's own body. This shows that coercion within the family can play a significant role in the decision for

living donation. For some family members, it seems almost impossible to reject organ donation (Zeiler, 2008). This, however, does not mean that people principally donate out of coercion in relationships. After all, the existence of coercion within the family does not mean that family members automatically conform to it (Donchin, 2001; Zeiler, Guntram, & Lennerling, 2010).

The analysis shows that those affected make a decision concerning living donation under socially and discursively predetermined conditions which overly neglect the relationship aspect of donor-recipient pairs. The framework conditions for voluntary decisions are negotiated in the different relationship constellations. These conditions were based on different interpretations of self-determination which, thus far, have not yet been theoretically integrated. Empirical findings thus not only have the potential to highlight this issue but also can differentiate it.

5. Future directions

Self-determination does not become obsolete in a relational autonomy concept in the context of complex medical decisions. However, it must be conceived in a different manner than it has been in the past moving beyond purely individualistic approaches. A form of joint *common sense morality* is used for weighing decisions within families which, in turn, presupposes a consensus concerning living donation and assumes that the family perceives itself as a decision-making group.

The medical decision for or against living donation is based on normative value orientations which, on the one hand, have individual value preferences but, on the other hand, include legally anchored, general values as manifested in the German Transplant Act. From an ethically descriptive perspective, 'morality' can be understood as a regulation of action which serves as a guiding principle for those affected.

In order to support patients and their relatives, medical practice should look for solutions for developing an appropriate procedure in the future which does justice to a family decision. Alternatives to the classical "informed consent" should be developed. One possible solution would be to organize the decision-making process in a more transparent manner, especially for the recipient, by more strongly focusing on the different forms of motivation for donation. The experts involved in the

transplantation system (physicians, transplant coordinators, psychologists) should contribute more strongly to the decision-making process as consultants, thereby strengthening and supporting the active decision-making process of the recipients. The empirical findings showed that some recipients felt pressured by their spouses and by their treating physicians to accept an organ. This can be counteracted by means of a critical-open discussion at the onset of chronic disease by stimulating the decision for or against the exchange of body parts as early as possible for patients and their relatives, rather than having this discussion in the advanced stage of chronic disease.

In concrete terms, this means that the concept of *shared decision-making* (Charles, Gafni, & Whelan, 1997) must, on the one hand, be critically examined and, on the other hand, should be expanded by the aspect of family decisions. Shared decision-making encourages a holistic view of the patient. Acknowledging that the individual patient might have preferences, values, and experiences etc. that are at odds with a biomedical view of what is in the patient's best interest should imply that the patient is invited to participate in the decision about care (Sandman, Munthe 2010). Examples from other medical fields, such as oncology, highlight the strengths of this approach. However, empirical studies from this field point to considerable differences between the patients' preferences, on the one hand, and the medical assessment, on the other (Perry, Wöhlke, Heßling & Schicktanz, 2016). While these different notions are associated with the prognosis of advanced cancer in oncological treatment, the improvement of quality of life, which affects the family directly, is the focus in living donation. The decision-making process, which takes place in families, should therefore be more strongly addressed as an integral part of the physician-patient consultations in transplantation centers and professionals should also be trained concerning such consultation sessions.

The results illustrate that decisions on living donation ultimately are dominated by care-driven arguments on the side of the donor. On the other hand, the aspect of inflicting no harm and the associated unpredictable physical and psychological risks are also neglected on the side of the recipients and are pushed to the background. However, these issues often become culpable entanglements in families after living donation.

The requirements formulated in this context necessitate additional qualified specialists such as family therapists apart from physicians and psychologists. These

specialists could provide insight into the “black box” of families and their inside perspectives which, thus far, have received insufficient attention in the context of medical decisions and autonomy concepts. For those affected, living donation not only is considered a medical process but also involves a highly complex decision-making process. This process requires an interdisciplinary team of experts which could enable the still very theoretical concept of *shared decision-making* in the practice of living donation.

References

- Appelbaum, P.S., Lidz, C.W., & Meisel, A. (1987): *Informed Consent: Legal theory and clinical practice*, Oxford University Press, New York.
- Baier A.C. (1995): The Need for More than Justice In: *Moral Prejudices Essays on Ethics*. Edited by Baier A.C. Cambridge: Harvard Univ. Press; pp. 47-58.
- Beauchamp T.L., & Childress J.F. (2001): *Principles of Biomedical Ethics*, vol. 5. New York: Oxford University Press.
- Biller-Andorno, N., Agich, G.J., Doepkens, K., & Schauenburg, H. (2001): Who shall be Allowed to Give? Living Organ Donors and the Concept of Autonomy, *Theoretical Medicine and Bioethics*, 22, 4, pp. 351-368, <http://link.springer.com/article/10.1023/A:1011842211016>
- Charles, C., Gafni, A., & Whelan, T. (1997): Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Social Science & Medicine*, 44(5). pp. 681-692, <http://www.sciencedirect.com/science/article/pii/S0277953696002213>
- Donchin, A. (2001): Understanding Autonomy Relationally: Toward a Reconfiguration of Bioethical Principles. *Journal of Medicine and Philosophy*, 26(4), pp. 365-386, <http://www.tandfonline.com/doi/abs/10.1076/jmep.26.4.365.3012>
- Feinberg, J. (1989): Autonomy. In: *The Inner Citadel Essays on Individual Autonomy*. Edited by Christman J. New York, Oxford: Oxford University Press, pp. 27-53.
- Gesetz über die Spende, Entnahme und Übertragung von Organen und Geweben (Transplantationsgesetz - TPG), <https://www.gesetze-im-internet.de/bundesrecht/tpg/gesamt.pdf>
- Kelly, S.E. (2010): Qualitative Interviewing Techniques and Styles. In: *Qualitative Methods in Health Research*. Edited by Bourgeault I, Dingwall R, De Vries R. Los Angeles, pp. 307-326.
- Krueger, R.A., Casey, M.A. (2000): Focus Groups. A practical Guide for applied research, 3rd Ed., Thousand Oaks.
- Mackenzie, C. (2015): Autonomy. In: Arras, J.D.; Fenton, E.; Kukla, R.: *The Routledge Companion to Bioethics*, New York, pp. 277-290.
- Mackenzie, C., & Stoljar, N. (2000): *Relational Autonomy. Feminist Perspectives on Autonomy, Agency and the Social Self*. Oxford: Oxford University Press.
- Mayring, P. (2000): Qualitative Content Analysis, *Forum qualitative social research*, 1(2), Art. 20. URL: <http://www.qualitative-research.net/index.php/fqs/article/view/1089/2385>

- Oshana, M.A. (1998): Personal Autonomy and Society. *Journal of Social Philosophy*, 29(1), pp. 81-102, <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-9833.1998.tb00098.x/full>
- Perry, J.; Wöhlke, S.; Heßling, A.C.; & Schicktanz, S. (2016): Why take part in personalised cancer research? Patients' genetic misconception, genetic responsibility and incomprehension of stratification—an empirical-ethical examination, *European Journal of Cancer Care*, DOI: 10.1111/ecc.12563
- Sandman, L., Munthe, C. (2010): Shared Decision Making, Paternalism and Patient Choice, *Health Care Analysis*, 18 (1), pp 60-84.
- Schicktanz, S., Schweda, M., Wöhlke, S. (2010): Gender issues in living organ donation: medical, social and ethical aspects. In: Klinge, I.; Wiesemann, C. (eds.): *Sex and Gender in Biomedicine – Theories, Methodologies, Results*. Göttingen, Universitätsverlag Göttingen, pp. 33-55.
- Schweda, M., Wöhlke, S. (2013): Lasting Bonds and New Connections: Public Views on the Donor-Recipient-Relation and their Implications for the Ethics of Organ Transplantation. In: Camilleri-Zahra, A.L., Mary A. (eds.): *Organ Donation and Transplantation: An Interdisciplinary Approach*. New York, Nova, pp. 170-188.
- Spital, A. (2001): Ethical issues in living organ donation: Donor autonomy and beyond, *AJKD*, 38(1), pp. 189-195, <http://www.sciencedirect.com/science/article/pii/S0272638601647280>
- Tietjens Meyers, D. (2005): Decentralizing Autonomy. Five Faces of Selfhood. In: Christman, J., Anderson, J. (Eds.) *Autonomy and the Challenges to Liberalism*. New York, pp. 27-55.
- Veatch, R., Ross, L. (2015): *Transplantation Ethics* (2nd edition), Washington DC: Georgetown University Press.
- Wagner E., Fateh-Moghadam B. (2005): Freiwilligkeit als Verfahren. Zum Verhältnis von Lebendorganspende, medizinischer Praxis und Recht. *Soziale Welt*, 56(1), pp. 73-99, http://www.jstor.org/stable/40878484?seq=1#page_scan_tab_contents
- Wilkinson, T.M. (2011): *Ethics and the Acquisition of Organs*. Oxford: University Press.
- Wöhlke, S. (2013): The morality of giving and receiving living kidneys: Empirical findings on opinions of affected patients. In: Randhawa, Gurch; Schicktanz, Silke (eds.): *Public Engagement in Organ Donation and Transplantation (from the ELPAT Public Issues Working Group)*. Lengerich, Pabst Science Publishers, pp. 144-152.
- Wöhlke, S. (2015): Geschenkte Organe? Ethische und kulturelle Herausforderungen bei der familiären Lebendniere spende, Campus.
- Zeiler, K. (2008): Just love in live organ donation. *Med Health Care Phil*, 12(3), pp. 323-331, <http://link.springer.com/article/10.1007/s11019-008-9151-1>
- Zeiler, K., Guntram, L., Lennerling, A. (2010): Moral tales of parental living kidney donation: a parenthood moral imperative and its relevance for decision making. *Medicine, Health Care and Philosophy*, 13, pp. 225-236, <http://link.springer.com/article/10.1007/s11019-010-9238-3>

Notes

1. <https://www.gesetze-im-internet.de/bundesrecht/tpg/gesamt.pdf>.
2. In organ donation this would entail all forms of organ trafficking.

3. The term *decision-making process* was explicitly used here opposed to deliberation as I am mainly concerned with the decision-making process of those affected and their families. Deliberative approaches are often used in the Netherlands, for example, and have only received minor attention in the field of transplantation medicine in Germany.
4. The term *affected* in this article includes donors, recipients of living donation and where applicable their relatives.
5. Spouses, partners, parents, children, siblings, cousins, nieces, nephews, friends, and in-laws were interviewed for this study. Donors, recipients and relatives who rejected living organ transplantation or who were not able to donate were also included in this study.
6. The empirical results presented here are part of my PhD project titled: Medical anthropological and ethical perspectives towards decisions and motivations of living kidney donations with a special focus on gender differences (translated title; original in German). The results were published in 2015 in the monography: "Geschenkte Organe? Ethische und kulturelle Herausforderungen bei der familiären Lebendniere spende", pp. 202-241. Some of my empirical findings were also published: Schweda, Schicktanz, Wöhlke, 2010; Schweda, Wöhlke, 2013.
7. Approval was given for this study by the Göttingen ethical review committee, Ak 11/11/07.
8. The names of the interviewees as well as all names and places that were mentioned in the interviews were anonymized.