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## WHO SHALL BE ALLOWED TO GIVE? LIVING ORGAN DONORS AND THE CONCEPT OF AUTONOMY

**ABSTRACT.** Free and informed consent is generally acknowledged as the legal and ethical basis for living organ donation, but assessments of living donors are not always an easy matter. Sometimes it is necessary to involve psychosomatics or ethics consultation to evaluate a prospective donor to make certain that the requirements for a voluntary and autonomous decision are met. The paper focuses on the conceptual questions underlying this evaluation process. In order to illustrate how different views of autonomy influence the decision if a donor's offer is ethically acceptable, three cases are presented – from Germany, the United States, and India. Each case features a person with questionable decision-making capacity who offered to donate a kidney for a sibling with severe renal insufficiency. Although the normative framework is similar in the three countries, different or sometimes even contrary arguments for and against accepting the offer were brought forward. The subsequent analysis offers two explanations for the differences in argumentation and outcome in spite of the shared reference to autonomy as the guiding principle: (1) Decisions on the acceptability of a living donor cannot simply be deduced from the principle of autonomy but need to integrate contextual information; (2) understandings of the way autonomy should be contextualized have an important influence on the evaluation of individual cases. Conclusion: Analyzing the conceptual assumptions about autonomy and its relationship to contextual factors can help in working towards more transparent and better justified decisions in the assessment of living organ donors.

**KEY WORDS:** autonomy, clinical ethics, decision-making capacity, informed consent, living organ donation, vulnerable donors

### INTRODUCTION

Living organ donation has developed as an important alternative to cadaveric organ procurement [1, 2]. In the United States, kidneys from living donors constituted 34 percent of all kidney transplants in 1998;<sup>1</sup> in Germany the percentage was 16 percent in 1998, having risen steadily from just 4 percent five years earlier.<sup>2</sup> Other programs, like partial liver or lung donations, are being explored and established [3]. These efforts are stimulated by the fact that cadaveric organs cannot meet the demand, particularly in countries whose legislation does not use the 'presumed consent' or 'opting out' model.<sup>3</sup> Indifference, doubts about the brain death



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concept, religious reservations about post mortem organ donation, and fear of possible abuses by irresponsible physicians are likely further factors contributing to the shortage of organs.<sup>4</sup>

National laws and guidelines provide specific frameworks for living organ donation. We shall briefly review the legal regulations that apply to the cases presented in the next section. The *German Transplantation Law* (1997),<sup>5</sup> requires (among others) that a donor be an adult, competent to give informed consent, medically suited, and at no increased risk for organ explantation. The recipient has to be a relative or a person who stands in an obviously close relationship to the prospective donor. The explantation, which has to be performed by a physician, is permissible only for therapeutic uses when there is no suitable cadaver organ available (§8.1). Anonymous donations are not allowed.

In the *U.S.*, the law provides less certain guidance. There is no Federal legislation regarding living donation and State transplant laws do not address the question. It is illegal to sell organs and informed consent is required for the surgical procedure associated with donation. Beyond these conditions, the law provides little direction. A few cases involving living donation by an incompetent individual have been brought for adjudication. In one widely-cited case, *Strunk v. Strunk*, a State of Kentucky Court of Appeals affirmed a trial court's decision to allow a kidney donation from an incompetent 27-year-old man, because the incompetent's well-being would be jeopardized more by the loss of his brother than by the donation of his kidney.<sup>6</sup> In the absence of a previous legal determination of incompetence, assessment of the prospective donor's capacity to consent would generally be left to the medical profession. Nearly 90 percent of kidney programs using living donors are reported to support the use of spouses and 63 percent favor the use of friends; only 50 percent had ever used such an 'emotionally-related' donor [4].

In its *Transplantation of Human Organs Act of 1994*,<sup>7</sup> *India* requires that living donors have to be related to recipients – exceptions have to be authorized by a special committee at the level of the states. The living donor has to be an adult who voluntarily authorizes the donation in the form of a written consent (Art. 2). Both donor and recipient have to be informed of the risks and side effects by a medical practitioner. Commercial dealing in human organs is prohibited.<sup>8</sup>

Only the federal laws of Germany and India require a particular relationship between donor and recipient and the legal majority of the living donor. In the *U.S.*, anonymous donation is possible, and the use of children as living organ donors has been debated in a series of legal cases [5]. The three legislations concur, however, on the prohibition of organ trading,

therefore rejecting financial incentives as a motivation for donation. They also concur on the legal requirement of informed consent for organ removal from a living donor. Not only medical law, but medical ethics as well generally considers free and informed consent – and therefore a donor's autonomous and voluntary decision – a necessary prerequisite for allowing a physician to hurt one person in order to help another.<sup>9</sup> At the same time it is beyond doubt that the concept of informed consent is an ideal that is rarely if ever reached in practice.

Regardless of the guidance afforded by law and ethics, it is sometimes difficult to assure that a potential donor meets the required criteria. Determining what is an ethically acceptable level of decisional capacity for organ donation is far more complex than it would first appear. Questions that naturally arise in the assessment of a living organ donor's competence to consent include not only operational or methodological aspects, like the minimal mental faculties a living organ donor must possess and how can they be identified clinically. They contain a whole array of other considerations, e.g. Can an autonomous decision include familial or emotional influence? Can a detached external observer adequately appreciate the emotional structure and dynamics of a particular family? Does the presence of expected material advantages or other 'secondary gains'<sup>10</sup> mean that a prospective donor should be ruled out? Can acceptability of the motivation for donation be judged independent of the particulars of the donor's situation? In light of the preference in the law and clinical practice for an emotional or familial attachment, is an anonymous nondirected donation ethically problematic? Contrariwise, does the principle of respect for autonomy require acceptance of anonymous nondirected acts of donation?

While consent for donation is a universally accepted necessity given the invasive nature of organ removal and the more than negligible risk, just how the capacity to consent should be assessed is too often put aside as a purely empirical or technical matter. The following cases are drawn from three different cultural, legal, and social situations to illustrate the breadth of the concrete practical issues associated with assessing the acceptability of a prospective donor for living kidney donation. In discussing these cases, we focus on the various ways that different interpretations of the meaning of autonomy are involved and the relation of these considerations to other background commitments and concerns. We aim neither at a comparative study of cross-cultural differences nor at a critical discussion of these cases. Instead, our goal is to highlight the ways that autonomy operates in the context of living donation.

CASE PRESENTATIONS<sup>11</sup>*Case 1 (Germany)*<sup>12</sup>

Mrs. Netter was diagnosed with renal failure due to glomerulonephritis after the birth of her first child two years ago. Since that time, the now 30-year-old patient has been on dialysis three times a week. She describes this necessary intervention as tolerable, although it “wipes her out for the rest of the day”, leaving her with fatigue, nausea, and headaches. Her husband, however, seems to be severely affected by her health troubles. He has lost his job and developed a significant alcohol problem.

Talking to other patients during dialysis Mrs. Netter learned early about the possibility of a kidney donation from a living donor. Her physician had informed her that she would probably have to wait at least about three years for a cadaveric organ. So she and her husband started thinking about possible living donors in her family. Mr Netter himself had a different blood group than his wife, which precluded him from donation. Mrs. Netter has three siblings, two of whom are not in good health, suffering from cardiovascular problems. Her father, from whom she is somewhat estranged, is fighting sequelae of severe chronic alcohol abuse. Her mother, with whom she entertains a good relationship, has kidney troubles herself after repeated bouts of pyelonephritis.

This left her youngest brother Simon, who had just turned 18. He is moderately mentally retarded and has attended a special school from second grade on. He lives at home, but is not under guardianship. Currently, he is in a training program as a carpenter. Mrs. Netter’s husband addressed the issue at a family gathering after an aunt’s death, when they “were sitting together all night and could not sleep anyway”. In that situation, Simon agreed to donate a kidney for his sister.

When Mrs. Netter informed her physician that she had found a related living donor, a psychosomatic consult was called in to evaluate the donor’s capacity for free and informed consent. During the first interview, Mrs. Netter and her brother were present together. Simon, who seemed rather inhibited, did not talk much, and replied to questions only with incomplete phrases. He could not reproduce any risks of the operation for himself. His sister tended to answer for him when not prevented. When asked how she would react in case of his refusal, she replied, “Well, I would be disappointed, but I’d have to accept it”. Their parents, she said, had supported and lauded Simon’s willingness to donate. None of them, she assured, had ever tried to pressure him into donating.

This interview was summarized by the psychosomatic consult service to the effect that Simon, although not obviously coerced, did not appear

able to grasp more complex consequences of his offer. The team therefore decided to draw on additional resources, like the family physician, experiences of colleagues in the field, and legal advice, before making a final decision. Simon's offer was eventually declined after he had expressed doubts about his wish to donate during a meeting with the family physician.

*Case 2 (USA)*

The 51-year-old sister of a kidney dialysis patient offered to donate a kidney for her brother. She is mentally retarded, lives at home, and has had no outside employment and very little outside activities. In the recent past, she has had only episodic involvement in a day care program. She has intact and loving parents, and has been utterly dependent upon them for her entire life. It is not clear whether she has the capacity to function independently. The brother offered his sister as a donor, but the renal team declined to assess her for two reasons: first, the sister was mentally retarded (which they assumed meant that she was unable to give an informed consent) and, second, the brother had only recently been listed for transplant, had a good chance for cadaveric donation, and was tolerating dialysis with no complications.

The ethics committee advised that disqualifying individuals for donation based on their membership in a class, which was not a medically contraindicated class such as suffering from congestive heart failure, would be ethically objectionable. It would be appropriate to disqualify a prospective donor who was retarded if the retardation were severe enough to make valid consent impossible. Inability to consent is an ethically defensible basis for exclusion, not membership in a class of the mentally disabled. Autonomy would require that a prospective donor be rejected not because the individual is retarded, but because the individual lacked the ability to consent. Surrogate consent from the parents might be problematic in this case, and would also need careful scrutiny. The medical team agreed to an assessment of the patient beginning with an evaluation of the potential donor's decisional capacity.

The woman was first seen by the Transplant Coordinators who provided information about living kidney explantation. She was then assessed by the Ethics Consultation Service, which found that the woman was able to communicate at a normal level. However, her understanding of donation was quite superficial. She was assessed alone and with her parents present. The woman's stated reasons for donation were remarkably identical in language and phrasing with those of the parents. Nonetheless, the ethics consultant did not judge that the patient was unduly pressed to donate by

the family, because the individual spoke of her affection for her brother and his commitment to her. She was able to talk about their daily interactions and her belief that benefiting her brother was important for her own future.

Social Work characterized the family as intact and functional, a working class family with close emotional and social ties. The social work assessment did raise questions about whether the donation was truly voluntary, because the woman could not separate her personal reasons for wanting to donate from the family's interest in organ donation. A family physician had provided a letter that strongly supported the sister's willingness to donate. In it, the physician indicated his conviction that the sister understood the risks associated with donation and is motivated by a deep emotional attachment to her brother. Psychiatry also assessed the potential donor and agreed that she had an adequate ability to understand information, but expressed reservations about her actual understanding of the process of transplantation and risks of donation. She had a gynecological surgery 10 years previously and claimed that she knew about the pain associated with surgery based on that experience. She could not remember anything specific about the procedures involved in removing her kidney or of the risks. All three assessments weighed in on the side of supporting her candidacy with the proviso that the marginal quality of consent needed to be reviewed by the Selection Committee in light of the risks to the donor kidney for the particular patient in question. The ethics assessment, in particular, stressed that the decision to accept this woman as a donor should involve a judgment that weighed a less-than-ideal consent against the risks to the donor and benefits for the patient. On this basis, the Transplant Service undertook a medical assessment of the sister.

Acceptance of this individual as a potential donor thus turned away from consent toward a risk benefit assessment that included her ability to consent, and the degree and kind of influence on her decision, her medical condition, and the benefits to be gained for the patient in light of his present therapeutic alternatives, including dialysis and possible cadaveric transplantation.

Medical assessment for kidney transplantation uncovered several findings that created doubt, most important of which were hypertension and pulmonary insufficiency that would have to be resolved before she would be accepted. All of these facts were reviewed by the Selection Committee and the decision was made that because the patient was not urgently in need of transplantation, it would be unethical to expose this particularly vulnerable donor to the risks and burdens of organ donation at this time. Were the situation different, namely, were the patient experiencing significant difficulty on dialysis or the questions raised about the sister's health

resolved positively, the decision might have been otherwise. It was agreed that her medical problems might not completely bar her from donation, but that further work up would be required. However, given that a decision had to be made in the context of the patient's having no problems with dialysis, she was rejected.

*Case 3 (India)*<sup>13</sup>

In this case, a 40-year-old patient with end stage kidney failure had received a kidney from his 36-year-old brother, who is deaf and mute since birth.<sup>14</sup> Being from a very poor family, he had never received any special education, and "was thus incapable of communication" [6]. According to the transplantation surgeon "there was no way we could make him comprehend what he was asked for" [6].

The transplantation was performed after the physicians had sought ethical and medicolegal advice and after a several weeklong evaluation of the brothers' relationship. Having found that a "genuine affection exists between them," as an involved nephrologist put it [6], and in light of the fact that there was a perfect tissue match,<sup>15</sup> they went ahead with the operation. Other factors that influenced the decision to remove the kidney included the handicapped brother's absolute psychological and material dependence on the patient, who had no access to dialysis due to financial constraints.

The physicians took the perspective that with a relatively low-risk surgical procedure they could save the lives of the two brothers, the patient needing a transplant and the donor who was utterly dependent on the patient. Due to the perfect matching no costly immunosuppressant medications would be required after the transplantation. They pointed to the fact that India has only a small number of dialysis units and that cadaveric donations are difficult due to logistic problems including an inadequate transportation system for organs, a lack of intensive care units to sustain cadavers before explantation, and an insufficient number of surgeons trained for that purpose. Furthermore, there is no adequate national database for matching organ and recipient.

#### SYNOPSIS OF ARGUMENTS AND OUTCOMES IN THE THREE CASES

The three cases differ in some important respects: Only in Case 3 (India) does the donor's well being or even continued existence depend on the recipient's survival. Donor and patient are thus linked in a very particular

way. For the patients in Case 1 (Germany) and 2 (USA) continued dialysis or cadaveric organ transplant is a real therapeutic alternative. In Case 2 (USA), an additional complication is the suboptimal medical condition of the donor, which would not, however, categorically preclude a donation.<sup>16</sup> In spite of these differences, the basic constellation is the same in all three cases: The potential donors are not evidently in possession of a full decision-making capacity. At the same time, the normative framework in all three countries requires informed consent as a precondition for the donation. It is therefore interesting to note that different, sometimes even contrary arguments and background considerations were reflected in the discussion and outcome of the cases.

### *Protection or Benefit?*

It has been argued that procedures involving incompetent persons can be justifiable only if they involve minimal risk, regardless of any potential secondary gain. This is the consensus developed for non-therapeutic research with human subjects not capable of autonomous decisions.<sup>17</sup> Just what constitutes minimal risk, of course, is open to question. But even if nephrectomy is considered a routine procedure in many centers, the removal of a kidney does not fit the conditions of minimal risk. The dangers associated with the operation itself or the long-term effects of kidney removal are not sufficiently understood to establish the risks as minimal [1]. Considering the seriousness of the act of donating an organ, surrogate decision-making usually is not seen as a viable option either [7]. In Germany, some voices call for an even more complete protection of incompetent persons, declining categorically their participation in non-therapeutic research, no matter how minimal the risk involved. This dissent was one of the reasons why Germany so far has not signed the European Convention on Human Rights and Biomedicine. Similarly, children under 18 years of age cannot be accepted as living organ donors in Germany. These circumstances provide an important background for the argumentation and outcome in the German case.

In the United States, on the other hand, where statutory law does not address the question, cases have come before the Courts and have allowed removal of an organ from an incompetent.<sup>18</sup> The argumentation has usually referred to the benefit for the – albeit incompetent – donor [5]. There may indeed be gains that were not primarily intended, but follow from donating an organ. For example, studies show an increased quality of life after a living organ donation for the donor [8–10]. Such benefits have also been reported for adolescent kidney donors [11]. This may be due, for example, to a heightened self-esteem or to an improved status in the

family. Although the relationship of cause and effect of these psychosocial benefits is still poorly understood, their presence has been empirically demonstrated. The existence of a benefit for the donor could tip the risk benefit calculation in favor of donation. A much more dramatic benefit for the donor, indeed his own long-term survival, was the major consideration forming the living organ donation in Case 3 (India).

*Abuse of Handicapped Persons or Discrimination?*

The argument that persons without full decision-making capacity should not be used as living organ donors due to their vulnerability to exploitation is of special importance for Case 1 (Germany), where the abuse of handicapped people and other groups during the Third Reich is a constant background social and ethical consideration. There is a strong concern that a person who is unable to consent to the risks of donation could be used as a means to benefit another in an immoral way. Fear of exploitation thus creates a social bias against involving a member of a vulnerable group even when the capacity to consent is present. In Case 2 (USA), however, the fact that the prospective donor belonged to a class of persons regarded as vulnerable was a reason *not* to exclude her from donation just because of her membership to that class but to carefully evaluate her individual ability and motivations.

It could even be argued, as it happened indeed in Case 2 (USA), that the refusal of donor because of a mental handicap amounts to discrimination. Such an argument might appear strange in cultural or social settings that do not focus on rights to such an extent, but it does emphasize the obligation to treat members of minorities or vulnerable populations fairly. The injunction to protect vulnerable groups can lead to paternalistic action toward them. In Case 2 (USA) this concern did not directly decide the case, but it did carry sufficient weight to afford the prospective donor a formal assessment for donation rather than being excluded simply on the basis of her status as handicapped.

*Relationship or Individual Choice?*

Another argument against using persons without full decision-making capacity as living organ donors is that donation of an organ can be ethically justified only if the donor is rationally motivated to donate without being influenced by emotional or other attachments to the prospective recipient. The decision is regarded as autonomous if made by an individual in isolation from others. Despite the prevalence of such an individualistic view in bioethics, transplantation programs have been reluctant to accept anonymous donations from living donors preferring, instead, that there be

an emotional or familial relationship between the donor and recipient. A non-relational view of autonomy is suspicious of such connections, because they contaminate what should be a rational and free choice. A relational view accepts emotional or other influences as essential elements of autonomous choice [12, 13], but has to confront the question whether the emotional connections with the recipient can compensate for compromised intellectual or judgmental abilities.

To some degree, a relational view of autonomy functioned in all three cases, probably least in the German and most in the Indian one. In each case, an assessment of the emotional attachment of the donor to the recipient was carried out and played a role in the consequent considerations. In Case 3 (India), even though one could insist that the nature of the relationship was inadequately evaluated, at least as far as one can tell from the case report, the donor was seen to be inextricably linked with his brother who needed a transplant. The existence of a relationship of affection between the two brothers was thus a major point in the defense of the transplantation.

What were the practical consequences of the specific argumentative patterns and the concrete circumstances in the cases presented? In Case 1 (Germany) the potential donor had withdrawn his offer after being given opportunities in different settings to express his doubts. However, even had the donor not been reluctant, acceptance was highly unlikely because of the protective attitude concerning vulnerable groups.<sup>19</sup> In Case 2 (USA), the offer to donate was declined on medical grounds, but the decision might have been reconsidered had the transplantation been more urgent. Although the transplant team appreciated the emotional attachment between donor and recipient, it was initially reluctant to accept a retarded individual as a donor. However, there was no strong objection on the grounds of the mental handicap comparable to the first case. In Case 3 (India) the donor was accepted without offering any evidence of consent, at least not according to the available description of the case. Given the deaf-and-mute man's affection for his older brother and his reported complete dependence on him, the transplantation was carried out without further evidence of the donor's decision-making capacity. Here respect for autonomy, if it operated at all, can only be understood relationally.<sup>20</sup>

This synopsis of three cases in different cultural, legal, and social settings illustrates some of the complexities associated with living donation as well as the degree to which context can shape the way that individual cases of living organ donation are approached. Remarkably, considerations of autonomy were explicitly or implicitly invoked on the pro- as well as on the contra-side in these cases: When a potential donor's

capacity for autonomous decision-making is in doubt, should the risk-benefit ratio play a role or should such an offer be rejected in any case, given that it involves more than minimal risks ('Protection or benefit')? Should someone with a decision-making capacity that appears compromised by a mental handicap rather be rejected from the outset in order to prevent exploitation of the vulnerable or does such a case on the contrary require particularly scrutiny ('Abuse or discrimination')? And finally, what role do relationships and emotional attachments play – are they to be considered obstacles to a genuine individual rational choice or do they constitute morally relevant factors in almost every decision ('Relationship or individual choice')? As the synopsis of pro and contra arguments illustrates, different understandings of autonomy and its relationship to other morally relevant factors crucially influence the handling of borderline cases in living organ donation.

#### AUTONOMY – FROM GENERAL PRINCIPLE TO THE PARTICULAR CASE

Autonomy provides the theoretical basis for both a free and informed consent and is usually considered the prerequisite for the ethical acceptability of living organ donation. Determining an individual's decision-making capacity is thus a central, but insufficiently discussed task in the assessment of living organ donors. This task is particularly challenging for two reasons: First, it requires the transfer from the level of a general principle to the individual case. The difficulty of the operationalization of such a theoretical concept is reflected by the vast literature that characterizes the assessment of decisional capacity as complex and controversial. 'Understanding relevant information', 'appreciating the current situation', 'manipulating information rationally', and 'communicating a choice' have been identified as central elements in the informed consent process [14]. Similar criteria have been identified as characteristic of a legally valid decision [15]. But still, the application of different standards yields a confusing array of results concerning a patient's decision-making capacity [16]. There does not seem to be an easy, straightforward solution to the problem. Rather, the long and extensive discussion of methodological issues associated with assessment of decisional capacity in medicine [17–21] warns against accepting any simplistic approach.

The second reason for the difficulties encountered in determining who fulfills the ethico-legal requirements for living organ donation goes beyond the technical level of evaluating an individual's rational decision-making capacity. Some authors regard current assessment procedures as concep-

tually inadequate or deficient [22, 23, pp. 56–59]. They argue that strictly positivist approaches with their exclusive focus on “a patient’s ability to make independent, rational choices to consent” [24, p. 1313] can produce dichotomies of competent vs. incompetent persons that overlook gradations. But borderline cases like the ones discussed above demonstrate that other factors enter in the judgment if someone is regarded as ‘autonomous enough’ to be a living organ donor.

### *The Situational Context*

The situational context provides the characteristics of a particular case: What are the medical risks, what benefits can be expected for the donor? What other therapeutic options are available to the recipient? These individual features are complemented by the larger frame of the respective cultural or national context, for example the social role of family ties in India or the tendency to exclude handicapped people from nontherapeutic research or organ donation in the German society in the light of past abuses.

There are different views as to what degree situational factors enter into the concept of autonomy or modify its relevance in ethical decision-making. For some autonomy trumps other considerations, no matter what the circumstances are.<sup>21</sup> Others presume that depending on the situational context, the ethical relevance of a person’s autonomy can vary. They argue that the assessment of decisional capacity should be contextually determined according to the medical circumstances and the risk and benefit of the procedures involved [25, 26]. Medical practice has traditionally accepted such a model relying on different operational standards of informed consent for different situations [25, p. 463]. Guided by a commitment to patient welfare, expected risks and benefits as well as the availability of alternatives traditionally shaped the situational context of medical decision making. For living organ donation that would mean that autonomous choice would be given greater weight in the case of a high risk donation coupled with small expected benefits for the donor, a purely altruistic motivation [27, p. 166],<sup>22</sup> and the availability of therapeutic alternatives for the recipient, like continued dialysis or cadaveric organ transplantation. Autonomy would receive less attention if the risk was low, there was an important benefit for the donor,<sup>23</sup> and there were no alternative therapeutic options.

*The Emotional and Relational Context*

Whereas it is commonly agreed that coercion invalidates autonomous choice, the influence and effect of emotion and relationships on the capacity for autonomous choice is controversial. However, there have been many voices calling for the consideration not only of the cognitive, but also the affective dimension for a more complete understanding of autonomous decision-making. Feminist thinkers, in particular, have insisted that relationship and emotional cues, not just deliberative rationality, play an important part in moral judgments [12, 13, 28]. In particular, it has been argued that emotions are not factors that disturb autonomous choice as much as they are commonly regarded [29]. Instead, the constructive role of emotions for decisional competence has been described on at least four levels:

- emotion aids in processing information [30, p. 377]
- it is necessary for appreciating a current situation and possible options [29]
- it plays an important part in determining a person's goals [31] and,
- it is a source of motivation for action [31].

An ethically adequate consent for living organ donation would thus require not only a rational estimation of risk and benefit, but an affective estimation based on the awareness of the need for transplantation. In the context of living kidney donation from a cognitively compromised person, it might be argued that an adequate emotional grasp of the recipient's situation can compensate for intellectual deficits. This is, however, one of the points where controversy arises, as this argument can be considered a dangerous erosion of standards set up for the protection of vulnerable persons.

Another contextual factor consists in the web of relationships a potential donor is embedded in. It is a common practice to extend decisional authority to surrogates who are empowered to make medical decisions for another person based on their knowledge of the person's values and beliefs or what is in the person's best interest. This practice, however, is not commonly considered acceptable for a living kidney donation [5, p. 45]. A relational concept of autonomy that sees humans as interconnected beings rather than as isolated individuals may be more prone to accept a donor who manifests such connectedness even if they lack high cognitive capacities. For individuals who care about one another, benefit for the recipient will also be a benefit for the donor. Such a view might have the effect of reducing the classic conflict between paternalistic protection vs. respect of choice [32, pp. 320–321]. Within the family setting, this

may lead to the conclusion that “the joint welfare of the family members may outweigh a deontological regard for their rights as separate persons” [33, p. 253]. With regard to living donation, the relational model might even “permit bodily invasions of an incompetent” [33, p. 241] if an intense relationship of high quality exists between donor and recipient. As in the case of emotional attachment as a compensation for cognitive capacities, such a move raises concerns about the danger of abuse, given the difficulty to determine which kinds of relationships and influence are to be valued and which are ethically problematic.

Situational, emotional and relational factors do matter in the actual assessment of borderline cases. As the case presentation and the synopsis of arguments demonstrated, decisions on the acceptability of a living donor cannot simply be deduced from the principle of autonomy. The varying contexts provide one explanation for the striking discrepancy between the shared reference to autonomy as the guiding principle and the differences in argumentation and outcome in each case. A second explanation might be provided by different ideas about how these contextual factors should weigh into moral considerations and judgment. This uncertainty on how to contextualize autonomy applies not only to practical decision-making in individual cases, but to ethical theory as well. Although autonomy is given center-stage in bioethical analysis and has been a central theme from the beginning of the bioethics movement, there is no consensus about its relationship to psychosocial and situational factors.

The aim of this paper was not to provide a solution as to how to integrate contextual information into moral reasoning. Neither did we try to set up general rules on how to deal with handicapped organ donors. Our intention was to point to the fact that the principle of autonomy needs to be contextualized when applied to concrete cases. Autonomy is more than rational decision-making capacity that can be determined regardless of the particulars of a concrete situation. How these particular circumstances relate to the concept of autonomy is subject to discussion. They can either be considered external factors or part of the concept itself [34]. But no matter what model is adopted: The application of the principle of autonomy to individual cases – as required for the decision if a person is capable of giving informed consent to living donation – cannot be treated as a purely technical question. Each assessment presents a complex ethical question that hinges on the underlying understanding of autonomy and its relationship to contextual factors.

Compared to a rigid focus on cognitive or mental abilities as the sole precondition for being able to donate, emotional, relational or situational factors greatly enrich the ethical analysis of living organ donation. Atten-

tion to these factors allows for a higher degree of differentiation and provides a more adequate framework for the discussion of individual cases. How to weigh and balance these components requires considerable patience, diligence, and the advice of different professional perspectives.

## CONCLUSION

In this paper, we have focused on the ways that different understandings of autonomy and its relationship to contextual factors operate in the ethical assessment of living organ donors with questionable decision-making capacity. Judging a potential donor's suitability in a concrete clinical context is frequently more difficult than would appear when viewed either from the perspective of the law or ethical theory. Decisions in borderline cases in fact depend on how contextual information is integrated into considerations related to autonomy. Analyzing the conceptual assumptions about autonomy and its relationship to the situational, emotional and relational context can help in working towards more transparent and better justified decisions. Such an approach provides a more comprehensive framework for the discussion of controversial or counterintuitive situations like the case of a living organ donation without full informed consent than an exclusive focus on the donor's rational decision-making capacity. Pressing a larger collection of difficult cases that includes the arguments, outcomes, clinical conditions, and sociocultural contexts would prove invaluable for the development of an ethically sound theory about who should be allowed to give.

## NOTES

<sup>1</sup> Cf. United Network for Organ Sharing (UNOS). *Transplant Patient Data Source*. <http://www.unos.org>, 1999.

<sup>2</sup> Cf. Smit H. Sasse R. Molzahn M. Schulin B. *Organspende und Transplantation in Deutschland 1998*. 4. Bericht der Deutschen Stiftung Organtransplantation. Neu-Isenburg: Deutsche Stiftung Organtransplantation, 1999.

<sup>3</sup> Like Germany or the Netherlands.

<sup>4</sup> Anthropological studies have tried to elucidate the cultural or national contexts that shape these reasons; for Germany see e.g. Hogle L. *Recovering the Nation's Body. Cultural Memory, Medicine, and the Politics of Redemption*. New Brunswick, NJ: Rutgers, 1999.

<sup>5</sup> Bundesministerium für Gesundheit. *Gesetz über die Spende, Entnahme und Übertragung von Organen (Transplantationsgesetz)*. Bonn: Bundesministerium für Gesundheit, 1997.

<sup>6</sup> Kentucky Strunk v. Strunk (1969, Ky) 445 S. W. 2d 145; 1969 Ky. Lexis 151; 35 A. L. R. 3d 683.

- <sup>7</sup> Act NO. 42 of 1994 (Republic of India).
- <sup>8</sup> This law, however, has not been ratified and implemented by all Indian states.
- <sup>9</sup> Cf. for example the Nuremberg Code or Declaration of Helsinki of the World Medical Association.
- <sup>10</sup> I.e. any kind of emotional or relational reward resulting from the donation.
- <sup>11</sup> Positions presented in the cases refer to the respective transplant team's considerations and do not necessarily reflect the opinion of the authors of this paper.
- <sup>12</sup> Names and personal data have been changed to protect the privacy of those involved.
- <sup>13</sup> This case was reported in the British Medical Journal of March 20, 1999 [5] and has caused controversial reactions from the readership, documented by a number of letters to the editor that were published in the Journal's website.
- <sup>14</sup> Of course this does not necessarily mean that he was mentally handicapped. However, it can be assumed that his decision-making capacity was compromised.
- <sup>15</sup> Testing had apparently also been performed without the donor's consent.
- <sup>16</sup> It has to be stressed that these differences and particularly the lack of more detailed information on the Indian case do not allow for a comparison or any causal attribution to cross-cultural differences.
- <sup>17</sup> Cf. e.g. Council of Europe: Convention on Human Rights and Biomedicine. Oviedo, 1997.
- <sup>18</sup> Strunk v. Strunk (1969, Ky) 445 S. W. 2d 145; 1969 Ky. Lexis 151; 35 A. L. R. 3d 683; cf. also Bonner v. Moran: US Court of Appeals, DC, F. 2d 126:121, 1941 and Hart v. Brown: Superior Court of Connecticut A. 2d 29:386, 1972.
- <sup>19</sup> The widespread negative attitude towards topics like euthanasia or research on minors and the restrictive German law for the Protection of the Human Embryo (Embryonenschutzgesetz) could be interpreted as further indicators of such a commitment to protect vulnerable groups.
- <sup>20</sup> Beyond autonomy, the donation and transplantation were thought justified, because two lives were saved that would otherwise have been lost. Consequentialist not deontological considerations appeared to operate, but the case could also have been based on relational considerations as well.
- <sup>21</sup> Cf. e.g. [7], p. 41.
- <sup>22</sup> There are different viewpoints in the literature as to whether altruistic motivation is a necessary and whether it is an acceptable precondition for living organ donation [35–37].
- <sup>23</sup> There may be 'negative' benefits like the absence of discrimination and 'positive' benefits, like increased self-respect.

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