bioethics

Bioethics ISSN 0269-9702 (print); 1467-8519 (online) doi:10.1111/j.1467-8519.2012.01982.x

LIVING ORGAN PROCUREMENT FROM THE MENTALLY INCOMPETENT: THE NEED FOR MORE APPROPRIATE GUIDELINES

KRISTOF VAN ASSCHE, GILLES GENICOT AND SIGRID STERCKX

Keywords
organ transplantation, living donation, mentally incompetents, ethical criteria

ABSTRACT
With the case of Belgium as a negative example, this paper will evaluate the legitimacy of using mentally incompetents as organ sources. The first section examines the underlying moral dilemma that results from the necessity of balancing the principle of respect for persons with the obligation to help people in desperate need. We argue for the rejection of a radical utilitarian approach but also question the appropriateness of a categorical prohibition. Section two aims to strike a fair balance between the competing interests at stake and to define the conditions under which organ harvest from mentally incompetents might be morally acceptable. To this end, we morally assess the main requirements that have been put forward to allow organ removal from incompetent donors. We conclude that the current Belgian legislation is far too permissive and that national regulations that do not permit the harvest of non-regenerable organs from mentally incompetents in exceptional circumstances are too restrictive. On the basis of this discussion, we propose a number of guiding principles for decision-making in this area.

INTRODUCTION

Confronted with a growing demand for organ transplants and an inadequate supply of cadaveric organs, transplant centres and desperate patients have increasingly looked to living donors.[1] In a further effort to address organ scarcity, various strategies to enlarge the pool of living donors are being examined. For instance, some commentators argue that in order to attract more donors the principle of non-commercialization should be relaxed in favour of a system of financial incentives.[2] Additionally, transplantation teams have been adopting new allocation models that allow willing but incompatible donors to donate to their intended recipient indirectly through an exchange program.[3] Furthermore, criteria for acceptance of organs have been extended to include donors that were previously deemed to be unsuitable.[4] Continuing liberalization of living donor criteria may even result in the mentally incompetent being considered as an additional and easy source of organs. However, since the mentally incompetent are incapable of giving free and informed

[1] As a result, in some countries the quantity of living donor organs even exceeds the number of deceased donor organs. See L.D. Horvat, S.Z. Shariff & A.X. Garg. Global Trends in the Rates of Living Kidney Donation. *Kidney Int* 2009; 75: 1088–1098.

[2] C.A. Erin & J. Harris. An Ethical Market in Human Organs. *J Med Ethics* 2003; 29: 137–138; J. Radcliffe-Richards et al. The Case for Allowing Kidney Sales. *Lancet* 1998; 351: 1950–1952; S. Satel, ed. 2008. *When Altruism Isn't Enough: The Case for Compensating Kidney Donors*. Washington, DC: AEI Press; J.S. Taylor. 2005. *Stakes And Kidneys: Why Markets In Human Body Parts Are Morally Imperative*. Aldershot: Ashgate.

[3] F.L. Delmonico et al. Donor Kidney Exchanges. *Am J Transplant* 2004; 4: 1628–1634; J.I. Roodnat et al. Successful Expansion of the Living Donor Pool by Alternative Living Donation Programs. *Am J Transplant* 2009; 9: 2150–2156.

[4] A. Kumar et al. Expanding the Living Related Donor Pool in Renal Transplantation: Use of Marginal Donors. *J Urol* 2000; 163: 33–36; A. López-Navidad & F. Caballero. Extended Criteria for Organ Acceptance: Strategies for Achieving Organ Safety and for Increasing Organ Pool. *Clin Transplant* 2003; 17: 308–324; A.J. Matas. Transplantation Using Marginal Living Donors. *Am J Kidney Dis* 2006; 47: 353–355.

Address for correspondence: Dr Kristof Van Assche, Vrije Universiteit Brussel – Faculty of Law and Criminology, Pleinlaan 2 Brussels 1050, Belgium. T: 0032476637846. Email: kristof.van.assche@vub.ac.be
Conflict of interest statement: No conflicts declared

consent, their use as living donors[5] is bound to raise serious ethical issues.

This problem may be especially pressing in countries whose transplantation regulations are very lenient with regard to the use of mentally incompetents as organ donors. In this respect, Belgian legislation is clearly extremely permissive when compared to other Western countries. Since the amendment of the organ transplantation law on 25 February 2007,[6] organ removal from mentally incompetents is explicitly allowed, even for organs that cannot regenerate. Moreover, the conditions that have to be met are disconcertingly lax and leave the door wide open for exploitation. Indeed, organ procurement from mentally incompetents is permitted if the recipient's life is in imminent danger, if the transplantation of organs from a deceased person would not produce an equally satisfactory result, and if the legal or personally appointed representative has given consent.

On 12 February 2010 Laurette Onkelinx, Federal Minister for Social Affairs and Public Health, decided to consult the Belgian Advisory Committee on Bioethics regarding, *inter alia*, the 2007 amendments to the organ transplantation law pertaining to organ procurement from mentally incompetents. The Minister wondered whether those amendments did not violate the dignity of the persons concerned.[7] This was the first time the Committee was asked to issue an opinion on an existing (rather than a draft) legislation. On 9 May 2011 the Committee issued its Opinion,[8] which expressed a unanimous agreement that the provisions on organ procurement from mentally incompetents in the current Belgian law are ethically unacceptable.[9] The Committee made recommendations for revision.[10]

With the case of Belgium as a negative example, this paper will evaluate the legitimacy of using mentally incompetents as organ sources. The first section examines the underlying moral dilemma that results from the necessity of balancing the principle of respect for persons with the obligation to help people in desperate need. We argue for the rejection of a radical utilitarian approach but also question the appropriateness of a categorical prohibition. Section two aims to strike a fair balance between the competing interests at stake and to define the conditions under which organ harvest from mentally incompetents may be morally acceptable. To this end, we morally assess the main requirements that have been put forward to allow organ removal from incompetent donors. We conclude that the current Belgian legislation is far too permissive and that national regulations that do not permit the harvest of non-regenerable organs from mentally incompetents in exceptional circumstances are too restrictive. On the basis of this discussion, we propose a number of guiding principles for decision-making in this area.

SHOULD ORGAN HARVEST FROM MENTALLY INCOMPETENTS EVER BE ALLOWED?

Why organ harvest from the mentally incompetent is morally problematic

The practice of living organ donation by competent adults is based on a very delicate balance between the principle of respect for persons and the obligation to help people in desperate need. Organ retrieval invariably risks significant harm to the donor. However, allowing it may be very beneficial to the intended recipients, because it could greatly alleviate their medical condition or even be life-saving. Moreover, by decreasing health care costs and shortening organ transfer waiting lists, living organ donation may also be commendable from the standpoint of justice. In view of these conflicting pressures, the decisive factor in determining whether donation should be permitted is the potential donor's autonomous decision. In short, organ procurement is only warranted if the prospective donor voluntarily decides that the risks are acceptable. The autonomy of the donor is only limited by the constraints of reasonable medical practice. Living donation will not be allowed if the transplant team is of the opinion that the benefits to the recipient do not outweigh the risks to the donor or if it considers the absolute level of risk to the donor to be too high.

Where the prospective donor is mentally incompetent, this balance is severely affected. Clearly, an enormous benefit to the recipient would still be the fundamental reason why organ retrieval is being considered. However, the potential harm of surgical intervention cannot be justified on the basis of an autonomous decision by the person who will be subjected to it, as individuals suffering from severe mental impairment are incapable of giving

[5] Because a mentally incompetent person cannot give proper consent, she is not to be considered as an organ *donor* in the strict sense of the term, but rather as an organ *source*.

[6] Wet betreffende het wegnemen en transplanteren van organen/Loi sur le prélèvement et la transplantation d'organes. Available at http://www.ejustice.just.fgov.be/cgi_loi/change_lg.pl?language=nl&la=N&cn=1986061337&table_name=wet (Dutch) and http://www.ejustice.just.fgov.be/cgi_loi/change_lg.pl?language=fr&la=F&cn=1986061337&table_name=loi (French) [Accessed 19 Feb 2012].

[7] Letter from the Minister to the Committee, 22 March 2010.

[8] Belgian Advisory Committee on Bioethics, Opinion No. 50, 9 May 2011. Available at: http://www.health.belgium.be/eportal/Healthcare/Consultativebodies/Commitees/Bioethics/Opinions/index.htm (in Dutch and French) [Accessed 19 Feb 2012].

[9] See p. 109 of the Opinion (Dutch version) or p. 104 (French version).

[10] The Belgian government is currently preparing a bill to bring the organ transplantation law in line with EU Directive 2010/45/EU. This opportunity may be taken to modify the provisions regarding organ procurement from mentally incompetents.

free and informed consent. Consequently, all medical decisions have to be taken by a legal guardian, who must ensure that the personal interests of her ward are respected. In view of this constraint, it is hard to see how organ retrieval from a mentally incompetent person could ever be appropriate, given the lack of any therapeutic benefit for the organ source herself. Indeed, concerns for the personal integrity and dignity of mentally incompetents strongly militate against allowing an intrusive medical procedure when the person benefiting from it is someone else.

Bearing these considerations in mind, it has been rightfully stressed that a radical utilitarian justification of organ retrieval from mentally incompetents would invite unchecked abuse.[11] For one, mentally incompetents would be burdened with a so-called 'duty to donate' that is not imposed upon the rest of society.[12] Although unequal treatment may be allowed if it is justified by objective criteria and a legitimate aim, the vulnerable position of mentally incompetents should demand increased rather than decreased protection. More importantly, if a radical utilitarian approach were to be adopted, mentally incompetents risk being sacrificed on the altar of morally problematic cost-benefit calculations. Balanced against the health care profit for society and the medical benefit for the competent recipient, compelled organ 'donation' by mentally incompetents may all too often appear the right thing to do. Using maximization of societal prosperity as the yardstick, the mentally incompetent potential donor will very often draw the shortest straw when pitted against a competent recipient or a competent alternative donor.

Why a total ban may nevertheless also be problematic

Recognizing that organ retrieval from mentally incompetents poses severe moral problems, some commentators have advocated a total ban on such organ harvests.[13] Although it would clearly prevent abuse of mentally incompetents, a categorical prohibition could also be morally problematic. A duty to fully protect vulnerable people may conflict with a duty to help people in need.[14] When the foreseeable risks to a donor are comparatively low and the potential benefits to the recipient are huge, transplantation may be morally desirable. However, as will be argued below, in such (presumably very rare) cases, several threshold requirements would have to be satisfied, in order to compensate for the reduced autonomy on the part of the donor. Furthermore, a total ban on organ harvests from mentally incompetents might be contrary to their own interests since it may be the case, in very specific circumstances, that the benefits they would receive from providing an organ could reasonably be expected to significantly outweigh the risks, exceptionally even if it concerns a kidney. We will come back to this in the following section. Finally, it could be objected that a total refusal to involve mentally incompetents might not be congruent with the obligation to treat vulnerable individuals fairly. In the event of moderate mental disability or only diminished autonomy, uniformly disregarding a genuine willingness to donate, thus condemning mentally incompetents to being in a uniquely receiving posture, might be morally problematic as well, just as is the case when they are considered to be the preferred organ donors.

AN ETHICAL EVALUATION OF EXISTING CRITERIA

Looking at examples of regulations allowing organ procurement from mentally incompetents, one notices that various substantive and procedural conditions may apply.[15] As to substantive requirements, we can distinguish between five categories.

The medical condition of the recipient

The first of these focuses on the *medical condition of the recipient*, stipulating that organ removal from a mentally incompetent individual is only allowed for the direct

[11] B.A. Schenberg. Harvesting Organs from Minors and Incompetent Adults to Supply the Nation's Organ Drought. *Ind Health L Rev* 2007; 3: 319–359: 347.

[12] It is an established principle that a competent adult has every right to decline organ donation, even if she is the only person who can save the intended recipient. This fundamental principle has been forcefully articulated in the infamous *McFall v. Shimp* case of 1978. Petitioned by a terminally ill man to require a potential life-saving bone marrow donation by his first cousin, the Pennsylvania District Court ruled that, although it found the refusal of the defendant to be morally indefensible, a competent adult is under no legal obligation to submit to an intrusion of his body for the benefit of a third party. In rejecting the motion of the plaintiff, the court emphasized that for a society founded upon respect for the individual and an absolute right to bodily security, ordering forcible extraction of living body tissue for the sake of someone else would be revolting. See *McFall v. Shimp* (1978) 10 Pa. D. & C. 3d 90.

[13] See, for instance, C. Cheyette. Organ Harvests from the Legally Incompetent: An Argument against Compelled Altruism. *Boston Coll Law Rev* 2000; 41: 465–515.

[14] This dilemma has been eloquently formulated in a dissenting opinion by Justice Steinfeld in *Strunk v. Strunk*: 'My sympathies and emotions are torn between compassion to aid an ailing young man and a duty to fully protect unfortunate members of society.' See *Strunk v. Strunk* (1969) 445 S.W. 2d 145 (Ky Ct of App) at 149.

[15] We focus on Belgium, Ireland, Sweden, the United Kingdom and the United States, where procurement of a non-regenerable organ from mentally incompetents is (or can be) allowed in certain cases.

therapeutic benefit of the recipient. Usually, it is explicitly mentioned that the intended recipient's life has to be in imminent danger. From a moral point of view, it can be rightfully argued that only an enormous benefit for the intended recipient could justify intruding upon the physical integrity of a person incapable of consent. However, it is not always obvious what really constitutes mortal danger, especially in cases of end-stage renal disease. For instance, in *In re Guardianship of Pescinski*, the allegedly terminally ill kidney patient Elaine Pescinski continued to live for nearly two more years after being denied a kidney transplant from her mentally incompetent brother.[16] Moreover, as in *Little v. Little*, some courts have permitted kidney transplantation if the recipient, although in no mortal danger, would otherwise be condemned to time-consuming dialysis treatment, presumably for the rest of her life.[17] As we will argue below, this kind of extension to non-life-threatening conditions is morally unacceptable.

The last resort requirement

The next substantive requirement dictates that a mentally incompetent individual may only serve as an organ source of *last resort*. First, it must be ascertained that no alternative medical treatment exists or is expected to be available in the near future. Whereas some diseases, for which a bone marrow transplant offers a potential cure, may quickly escalate to the point that transplantation offers the only chance for survival, only in very few cases of renal disease is sustained renal dialysis not a viable long-term alternative. Using mentally incompetents as kidney donors merely to increase the comfort and quality of life of a recipient would seem difficult to justify. Indeed, only the prevention of inevitable death may warrant a rare exception to the fundamental rule that individuals with diminished or no autonomy should be excluded from intrusive medical procedures for the benefit of a third party. Moreover, organ removal from mentally incompetents is absolutely prohibited if a suitable organ from a cadaveric donor is available or is likely to become available. Although this condition seems to be universally accepted, few commentators seem to heed the implicit call to *promote post-mortem donation*. However, increasing reliance on living organ donors is problematic if insufficient effort is expended to maximize the supply of cadaveric organs. It would be all the more morally revolting to call upon mentally incompetent donors to alleviate the organ shortage if this was in no small way caused by a hopelessly inefficient regulation of *post-mortem* donation in the country at issue.

Further, it is sometimes mentioned that organ harvesting from mentally incompetents is only allowed if no compatible competent living donor is available. All reasonable steps have to be taken to find a donor who understands the risks and benefits of donation and has the autonomy to consent freely. It follows that no compatibility testing on mentally incompetent individuals should be performed until other potential living donors with the capacity to consent have been examined and found to be histoincompatible. This condition clearly aims at preventing the sacrifice of the integrity of vulnerable individuals where compatible competent donors are hesitant or unwilling to donate. Families might prefer to use a mentally incompetent individual as an organ donor instead of a family member who is more valued or considered to be more promising. That this worry is of more than theoretical import becomes painfully clear in cases on record where a competent potential donor has not even been solicited.[18] Furthermore, we should bear in mind that *competent* potential donors who are unwilling to donate may have themselves declared unfit without much difficulty, thereby *de facto* turning the mentally incompetent individual into the donor of last resort. To prevent this from happening, claims that no compatible competent donor is available need to be subjected to close scrutiny.

The expected health impact of the transplantation on recipient and source

The third cluster of substantive requirements pertains to the foreseeable physical impact of the transplantation on both recipient and donor. Organ removal from mentally incompetents should only be considered if it is very likely that the *intended recipient will benefit from the transplant*. Consequently, the donation must have the potential to save the life of the recipient, and there has to be a reasonable chance that the medical procedure is successful and the organ will not be rejected. If the expected outcome of the transplantation is below a minimum threshold of anticipated success, mentally incompetent individuals should not be volunteered to serve as organ source, because the reasonably predictable benefits will not outweigh the risks the donor will face. After all, in case of organ rejection, the recipient would not have gained anything, whereas the donor would have been

[16] *In re Guardianship of Pescinski* (1975) 226 N.W. 2d 180 (Wis Sup Ct). The case was decided by the court on 4 March 1975. Elaine Pescinski died on 5 January 1977. As mentioned in the fourth footnote to the dissenting opinion of Justice Day in *In Matter of Guardianship of Eberhardy* (1981) 102 Wis. 2d 539.

[17] *Little v. Little* (1979) 576 S.W. 2d 493 (Tex Ct of App) at 499.

[18] An egregious example involved parents petitioning for compatibility testing of their thirteen-year-old mentally incompetent boy without even considering his eleven-year-old mentally sound sister as an alternative. See M.D. Levine et al. The Medical Ethics of Bone Marrow Transplantation in Childhood. *J Pediatr* 1975; 86: 145–150: 147.

subjected to the discomfort and physical risks of the intervention and might even experience intense psychological distress. Although competent donors are in a position to accept a lower benefit-to-risk ratio, exposing incompetent people to a medical intervention with a negative risk-benefit balance is highly problematical. In addition, organ harvest from mentally incompetents may only be allowed if the *physical risks to the donor are deemed to be reasonable*. The rationale behind this requirement is that the benefits to the donor cannot possibly be expected to outweigh major health hazards. Although competent donors may, after careful deliberation, consider participating in a transplant procedure that is not in their best interest, no such intervention is allowed if the prospective donor does not have the mental ability to assess and accept this balance.

In considering what kind of medical complications a mentally incompetent donor may encounter, several types of risks should be taken into account, starting with the risk of mortality due to the surgery itself. In this respect, the collection of bone marrow is a relatively safe procedure.[19] However, since bone marrow procurement from mentally incompetents would be likely to be performed under general anesthesia, fatal complications cannot be ruled out. Estimated at 0.031%, the risk of mortality from kidney removal is considerably higher.[20] In comparison, with an incidence between 0.2% and 2%, the calculated risk of mortality from partial liver donation is already very significant.[21] Apart from this, the donor may be exposed to significant morbidity resulting from the operation. Severe peri- or postoperative complications associated with bone marrow donation are very rare.[22] In the case of kidney or partial liver donation, serious and life-threatening side-effects are more frequent, but their incidence is difficult to estimate. According to some reports, the complication rate of donor nephrectomy is as high as 35% with up to 7% major injuries.[23] Although a consensus exists that the morbidity rate of partial liver donation is significantly higher, the reported data show an immense variation.[24] Finally, organ donation may also lead to long-term health problems. Because living organ donation is a fairly recent medical procedure and follow-up studies cover only a very limited period, considerable uncertainty about the nature and prevalence of long-term risks remains. Although reports suggest that kidney and liver donors have the same life expectancy as the rest of the population and do not have a heightened risk of chronic renal or liver disease later in life, more time is needed to make conclusive assessments.[25] In case of donation of solid organs, long-term risks should certainly not be disregarded in advance.[26] As a matter of fact, dozens of kidney donors reportedly have been placed on the waiting list for kidney transplantation after they themselves suffered renal failure.[27] Moreover, renal failure would be even more problematic for a mentally incompetent person, because she will likely not be given priority on the waiting list and she will find it very difficult to comprehend and comply with regular dialysis treatment.

[19] By 2004, eleven deaths associated with bone marrow procurement had been reported worldwide, although for most of these no clear causal relation was established. See D.L. Confer. 2004. Hematopoietic Cell Donors. In *Thomas' Hematopoietic Cell Transplantation*. K.G. Blume, S.J. Forman & F.R. Appelbaum, eds. Malden, MA: Blackwell Publishing: 538–549: 543.

[20] D.L. Segev et al. Perioperative Mortality and Long-term Survival Following Live Kidney Donation. *JAMA* 2010; 303: 959–966. These figures are based on a follow-up study relating to the period 1994–2009. This study also showed that the mortality remained unchanged during those fifteen years.

[21] Merion reports a mortality risk of 0.2% to 0.5%. See R. Merion. Current Status and Future of Liver Transplantation. *Semin Liver Dis* 2010; 30: 411–421: 417. A recent review article reports a mortality risk of 0.2% to 2%. See Y. Yuan & G. Mitsukazu. Biliary Complications in Living Liver Donors. *Surg Today* 2010; 40: 411–417.

[22] The incidence of serious and life-threatening side-effects is estimated at 0.27% to 1.34%. Most of these were nerve, bone or tissue injuries sustained during the collection procedure. See Confer, *op. cit.* note 19; J. Halter et al. Severe Events in Donors after Allogeneic Hematopoietic Stem Cell Donation. *Haematologica* 2009: 94–101: 94; B.A.H. Williams, K.L. Grady & D.M. Sandiford-Guttenbiel. 1991. *Organ Transplantation*. London: Churchill Livingstone: 211. Since bone marrow regenerates within 4 to 6 weeks, no irreversible long-term damage is to be expected. *Ibid.*

[23] See J.D. Kallich & J.F. Merz. The Transplant Imperative: Protecting Living Donors from the Pressure to Donate. *J Corp Law* 1995; 20: 139–154: 148; G. Mjøen et al. Morbidity and Mortality in 1022 Consecutive Living Donor Nephrectomies: Benefits of a Living Donor Registry. *Transplantation* 2009; 88: 1273–1279: 1278; A. Spital. 2001. Ethical Issues in Living Related Donors. In *The Ethics of Organ Transplantation*. W. Shelton & J. Balint, eds. Oxford: Elsevier Science: 103. These complications include major postoperative bleeding, damage to the spleen or adrenal glands, pulmonary embolisms, and retroperitoneal infections.

[24] Yuan and Mitsukazu report a morbidity rate of 0 to 78.3%, depending on the criteria that are used. See Yuan & Mitsukazu, *op. cit.* note 21. A report of French experts indicates that the number of partial liver transplantations is in decline because of high morbidity rates: 'Après une période initiale d'enthousiasme, le nombre de procédures faites, tant en Europe qu'aux Etats-Unis, est en déclin depuis quelques années sous l'influence de la fréquence des complications graves survenant chez les donneurs. [. . .] Depuis 2006, ce type de transplantation est en déclin en France avec une baisse de 80 % enregistrée entre 2005 et 2006.' See Agence de la Biomédicine. 2009. *Recommandations formalisées d'experts sur le prélèvement et la greffe à partir de donneur vivant*. Paris: Médi-Text: 62.

[25] See D.A. Goldfarb et al. Renal Outcome 25 Years after Donor Nephrectomy. *J Urol* 2001; 166: 2043–2047; J.S. Najarian et al. 20 Years or More of Follow-Up of Living Kidney Donors. *Lancet* 1992; 340(8823): 807–810; Segev, *op. cit.* note 20.

[26] For instance, there is a possibility that a kidney donor will need a kidney transplant if, due to an accident or disease, her remaining kidney is damaged.

[27] See M.D. Ellison et al. Living Kidney Donors in Need of Kidney Transplants: A Report from the Organ Procurement and Transplantation Network. *Transplantation* 2002; 74: 1349–1351.

The exact level of risk that a mentally incompetent person may be exposed to is a topic of debate and controversy. Whereas most European regulations stipulate that organ removal should not be carried out if there is a serious risk to the health of the donor, American court decisions seem to be slightly more strict, holding that only *minimal* health risk is acceptable. In reality, however, due to the broad interpretation of what constitutes minimal risk, American courts are generally much more permissive than the transplant legislations of European countries. Apart from Belgium, Ireland,[28] Sweden,[29] and the United Kingdom,[30] removal of a non-regenerable organ from mentally incompetents is prohibited in Europe. By contrast, American courts have on several occasions authorized kidney harvesting from a mentally incompetent individual. To be frank, it might be argued that these courts have minimized the risks associated with kidney donation and exaggerated the expected benefits to the donor, in order to justify the use of mentally incompetents as kidney sources. For instance, in both *Strunk v. Strunk* and *Little v. Little*, kidney donation by a mentally incompetent person was authorized, partly because the court deemed the medical risks to be only minimal.[31] However, if we take into account the risk of mortality, severe complications, and potential long-term effects, kidney donation cannot possibly fit the conditions of minimal risk. Nevertheless, even if kidney removal involves more than minimal risk, the use of mentally incompetents could be morally acceptable if it can be convincingly established that they would receive significant psychological benefits from the transplantation.

The possibility of psychological benefits

As noted earlier, the legislations of various countries stipulate that a medical intervention involving mentally incompetents may only be performed if it would be to their direct benefit or in their best interest. However, in case of an intervention that would not have any therapeutic benefit for the incompetent person, such as organ donation, surrogate decision-makers need to focus on *possible psychological benefits*.

Studies of adult and adolescent donors have revealed several types of important psychological benefits.[32] First of all, donation may assure a continuing close relationship with the recipient and the avoidance of the intense emotional distress that the donor may experience in the event of the intended recipient's death. Secondly, psychological benefit might flow from the altruistic act itself. However, in enumerating the psychological benefits that have been reported by competent adult and adolescent donors, this argumentation conveniently overlooks the fact that many donors have expressed severe negative emotions, such as feelings of abuse, lower self-esteem, a sense of neglect and lack of appreciation, a strained relationship with the recipient and, where the transplant was not successful, feelings of anger, guilt, and blame.[33]

More importantly, the extent to which mentally incompetent persons can experience psychological benefits remains unclear. Because of their insufficiently developed cognitive and emotional capacities, most mentally incompetents can hardly be expected to identify the altruistic aspect of donation, although the contrary has routinely been suggested by American courts when authorizing kidney removal from mentally incompetents. For instance, in *Little v. Little*, the court allowed kidney removal, asserting that the mentally incompetent donor would likely receive considerable psychological and emotional benefits, such as 'heightened self-esteem, enhanced status in the family, renewed meaning in life, and other positive feelings including transcendental or peak experiences.'[34] However, it might be safely assumed that mentally incompetents will not accrue the same psychological benefits that may result from a mentally competent understanding of the transplant procedure.[35] In addition,

[28] In the absence of any specific legislation with respect to transplantation, living donation in Ireland is governed by ethical guidelines drafted for the Irish living donation programme based in the Beaumont Hospital in Dublin. These guidelines allow the removal of a non-regenerable organ from mentally incompetents under very strict conditions. Similarly, the Human Tissue Bill that is currently being drafted, also provides for the removal of a non-regenerable organ from mentally incompetents. The draft Proposal for the General Scheme of the Human Tissue Bill is available at http://www.dohc.ie/consultations/closed/human_tissue_bill/draft_proposals.pdf?direct=1 [Accessed 19 Feb 2012]. We would like to thank Dr. Siobhán O'Sullivan for providing this information.

[29] Lag (1995:831) om transplantation m.m., 8 §, available at http://www.notisum.se/rnp/sls/lag/19950831.htm [Accessed 19 Feb 2012].

[30] In the United Kingdom, under the Mental Capacity Act 2005, a court can authorize organ procurement from a mentally incompetent person on the grounds that this would be in her best interests. Although, as yet, no cases have arisen involving non-regenerable organs, nothing would prevent such cases to emerge. See J. Herring. 2010. *Medical Law and Ethics*. Oxford: Oxford University Press: 423–424; S.D. Pattinson. 2009. *Medical Law and Ethics*. London: Sweet & Maxwell: 477–478.

[31] *Strunk v. Strunk* (1969) 445 S.W. 2d 145 (Ky Ct of App) at 148–149; *Little v. Little* (1979) 576 S.W. 2d 493 (Tex Ct of App) at 499.

[32] K.D. MacLeod et al. Pediatric Sibling Donors of Successful and Unsuccessful Hematopoietic Stem Cell Transplants (HSCT): A Qualitative Study of Their Psychosocial Experience. *J Pediatr Psychol* 2003; 28: 223–231; A.F. Patenaude. Psychological Impact of Bone Marrow Transplantation: Current Perspectives. *Yale J Biol Med* 1990; 63: 515–519.

[33] See Cheyette, *op. cit.* note 13, pp. 475–485 & 500–508; P. Cohen. Donor's Dread: Why Do Children Who Help a Sick Sibling End Up Depressed? *New Scientist* 1997; 55: 20.

[34] *Little v. Little* (1979) 576 S.W. 2d 493 (Tex Ct of App) at 499.

[35] See R.A. Crouch & C. Elliott. Moral Agency and the Family: The Case of Living Related Organ Transplantation. *Camb Q Healthc Ethics* 1999; 8: 275–87: 283.

it has to be acknowledged that some of the *psychological risks* of donation may be increased for mentally incompetent donors. Thus, for instance, they might be under great stress due to their failure to understand the meaning of the medical intervention, or to adapt to the unfamiliar environment of a hospital and the strains of the whole procedure.[36]

Taking into account that kidney removal entails more than minimal health risks, that mentally incompetents are unlikely to experience the psychological benefits that have been attributed to competent donors, and that they also face increased psychological risks, it is obvious that the removal of a kidney from mentally incompetents will only very rarely be justifiable. Indeed, this kind of intervention may only be warranted if the continued survival of the intended recipient is essential to the overall well-being of the mentally incompetent person. Because it cannot be ruled out that surrogate decision-makers may be guided by their own opinions and judgments and may exaggerate even speculative psychological factors, we strongly advocate the adoption of a clear and convincing evidentiary burden of proof. First, the proposed kidney donor has to demonstrate a threshold level of cognitive and emotional capacities. Due to their immaturity or mental affliction, only few mentally incompetents will have developed 'other-regarding' interests that are strong enough to cause severe adverse reactions to the death of other people.[37] Second and most importantly, as will be discussed in more detail below, it has to be ascertained that the mentally incompetent person strongly identifies with the intended recipient. Only the prospect that the mentally incompetent person would be spared severe psychological distress and would receive continued personal companionship may represent a psychological benefit that is significant enough to outweigh the risks that may arise from kidney removal. This position was clearly articulated in *Strunk v. Strunk*, where the court established that the survival of the intended recipient – who was the mentally incompetent's only sibling, his role model, and his tie to his family, and who would be the only source of intimate communication and primary care after their parents' eventual death – was essential to the mentally incompetent's psychological stability. The court reasoned that the transplantation would be beneficial to the mentally incompetent donor, because 'Jerry was greatly dependent upon Tommy, emotionally as well as psychologically, and that his well-being would be jeopardized more severely by the loss of his brother than by the removal of a kidney.'[38]

The relationship of the mentally incompetent person with the intended recipient

Thus, inextricably bound to the requirement of psychological benefit is the condition that mentally incompetent persons may only donate to a recipient that they have an *ongoing personal relationship* with. However, if we accept that the degree of emotional intimacy is the deciding factor, a restriction to close relatives might sometimes be problematic. For one, volunteering a mentally incompetent individual to serve as a donor to a relative who is unknown, estranged or even abusive would be totally unacceptable. As *Curran v. Bosze* famously illustrated, close attachment does not always exist between biological family members.[39] On a related note, the assertion that family members possess obligations to promote the health of others, because their interests are shared,[40] must be rejected when applied to mentally incompetents. Indeed, the claim that mentally incompetents are the bearers of intra-familial obligations that may commit them to sacrifice their personal interest for the good of another family member, amounts to a license for 'compelled altruism'. Organ removal from a mentally incompetent individual needs a greater justification than the mere existence of a family tie.[41] In each case of intra-familial donation by mentally incompetents, it must be ensured that the degree of intimacy is strong enough to justify an invasion of their bodily integrity. On the other hand, intimate attachments can also exist between mentally incompetents and people with whom they are not biologically related. Because the well-being of the mentally incompetent person may be severely compromised if a close friend or more distant relative would die, the range of possible recipients may, in very exceptional circumstances and only if all other requirements are fulfilled, be extended to include people who are not biologically related to the mentally incompetent.[42]

[36] See L.E. Lebit. Compelled Medical Procedures Involving Minors and Incompetents and Misapplication of the Substituted Judgment Doctrine. *J Law Health* 1992; 7: 107–130: 119.

[37] See P. Lewis. Procedures that Are Against the Medical Interests of Incompetent Adults. *Oxford J Legal Stud* 2002; 22: 575–618: 589.

[38] *Strunk v. Strunk* (1969) 445 S.W. 2d 145 (Ky Ct of App) at 146.

[39] In *Curran v. Bosze*, bone marrow transplant compatibility testing on two 3-year-old twins was denied because the court held that they had no existing, close relationship with the intended recipient, who was their half-brother, since they were living in a separate household and had only met him twice. See *Curran v. Bosze* (1990) 566 N.E. 2d 1319 (Ill) at 1343–1344.

[40] E.g. J. Dwyer & E. Vig. Rethinking Transplantation between Siblings. *Hastings Cent Rep* 1995; 25: 7–19; L.A. Jansen. Child Organ Donation, Family Autonomy, and Intimate Attachments. *Camb Q Healthc Ethics* 2004; 13: 133–142: 136; H. Klepper. Incompetent Organ Donors. *J Soc Philos* 1994; 25: 241–255: 253.

[41] See D. Steinberg. Kidney Transplants from Young Children and the Mental Retarded. *Theor Med* 2004; 25: 229–234: 233.

[42] Cf. Jansen, *op. cit.* note 40: 139.

Who should decide?

As important as specifying which substantive requirements have to be satisfied is the procedural issue of determining who should have the power to make the assessment and decide whether organ removal may occur. The mentally incompetent person herself is in no position to make that kind of decision, because she arguably lacks the ability to adequately appraise the situation and fully comprehend the nature and consequences of her choice. The extent to which mentally incompetents should be involved in the authorization procedure is open to debate. If possible, prospective mentally incompetent donors should be informed about the significance and circumstances of the intervention, in a manner consistent with their level of maturity and cognitive ability. Subsequently, they should be consulted about their willingness to donate. If they should actively dissent to the proposed donation, the organ removal should not be carried out. Such refusal should be morally binding because little or no psychological benefits are to be expected if the mentally incompetent person opposes the donation. On the other hand, depending on her level of cognitive and moral development, a strong desire to donate may be an increasingly crucial factor in favouring organ removal.[43]

Apart from the needs to consult the prospective donor and to verify that she does not refuse, organ removal should only be allowed if the legal guardians (often the parents) give free and informed consent. In order for their permission to be valid, the guardians must have been informed about all relevant facts, including the purpose, nature, consequences, and risks involved. In balancing the risks and benefits, the guardians should decide what they deem to be in the best interest of their ward. Because guardians are normally motivated by natural bonds of affection and feelings of responsibility, they are supposed to be in the best position to consider and protect the interests of the potential donors. For this reason, some commentators argue that the decision regarding organ harvest from mentally incompetents should be left to the discretion of the guardians.[44] However, allowing guardians to grant permission for organ removal may pose severe problems if the prospective recipient is another of their children or a close relative who is in desperate need of the organ. If they are surrogate decision-makers for both the healthy incompetent child and a recipient child, guardians may consciously or subconsciously be tempted to save a competent child at the expense of the incompetent one. The possibility of a conflict of interests would leave the incompetent individual unprotected from family pressures and even from outright coercion. To prevent this from happening, custodial permission should only be a necessary but not a sufficient requirement, unlike in Belgium, where a guardian from a legal point of view may even coerce her ward to serve as her *own* organ source.

Since the request to use a mentally incompetent person as an organ source is often characterized by the despair of parents who are confronted with a competent child in urgent need of a transplant, approval by an independent body should be required. It could be argued that the decision should be left to the medical team, because it has the best understanding of the medical aspects and the expected risks and benefits to the donor. However, since the surgeons may be involved in the care of the recipient and hence may be strictly focussed on the prospect of saving her life, the interests of the donor may all too easily be neglected.[45] In order to guarantee a more independent assessment, some countries have delegated decision-making to the court, to an *ad hoc* body at the national level or to a hospital ethics committee. Courts of law have the major advantage that they are impartial and can invoke a whole range of safeguards, such as appointing a guardian *ad litem*, who may ensure that the mentally incompetent's interests are best served. However, contested court proceedings are both costly and time consuming, with a distinctive risk that the prospective recipient may die while waiting. Moreover, judges may have firm convictions about justice that do not always correspond to the perceptions of the intended donor. Hospital ethics committees can reach a decision at a lower cost and much more swiftly, but they lack the necessary independence and are already overburdened. Thus, what seems to be required is a pluridisciplinary committee (unrelated to any particular hospital and comprising physicians, ethicists, social workers, and lawyers) which would analyse, assess, and decide the thorny issues that need to be addressed in these cases. Such a committee should be enabled to investigate the facts of the case thoroughly, while at the same time attempting to reach a swift decision.

CONCLUDING REMARKS

Confronted with the numerous and highly complicated issues involved, it might seem that imposing a statutory total ban on organ harvest from mentally incompetents is the most advisable option. We do not, however, advocate such a solution, as in specific (although rare) cases it may imply a lack of respect for the interests of the individuals concerned.

[43] N. Biller-Andorno et al. Who Shall Be Allowed to Give? Living Organ Donors and the Concept of Autonomy. *Theor Med Bioeth* 2001; 22: 351–368.

[44] See, for instance, M.T. Morley. Proxy Consent to Organ Donation by Incompetents. *Yale Law J* 2002; 111: 1215–1249: 1248.

[45] S.L. Nygren. Organ Donation by Incompetent Patients: A Hybrid Approach. *Univ Chic Leg Forum* 2006; 471–502: 500.

Whereas the use of mentally incompetents as bone marrow donors seems morally permissible in view of the minimal risks involved, in our view, their use as partial liver donors ought to be uniformly rejected, given the unacceptably high level of medical risk for the donor, as mentioned earlier, which cannot possibly be outweighed by any psychological benefits. The risks associated with kidney removal are, we feel, too significant to be routinely minimized but not high enough to warrant a categorical rejection of kidney harvesting from mentally incompetents.

Thus, we have tried to argue for some guidelines that should, in our view, always be followed when envisaging the removal of a kidney from an incompetent individual. In sum, (1) the medical condition of the recipient renders the transplant absolutely necessary; (2) the prospective donor is a source of last resort, meaning that no medical alternative exists, that no cadaveric organ is available, and that no competent compatible person could donate; (3) it is very likely that the transplant will be successful, and the organ will not be rejected; (4) the foreseeable risks and medical complications for the donor have been found to be acceptable; (5) highly significant non-speculative psychological benefits for the donor are to be expected; (6) the donor and recipient are in a close relationship, whether biologically linked or not; (7) the mentally incompetent prospective donor has been involved to the greatest possible extent in the decision-making process and has not actively dissented; (8) the legal guardians have given free and informed consent; (9) the final decision is taken by a pluridisciplinary independent body.

In our view, only respecting these guidelines will ensure that a fair and adequate balance between the duties to protect vulnerable persons from harmful bodily invasions and to help sick people in desperate medical need may be reached.

Kristof Van Assche holds a doctorate in philosophy from Ghent University and is currently preparing a doctorate in law at the Faculty of Law and Criminology of the Vrije Universiteit Brussel (VUB) on legal and ethical aspects of biobanking, organ transfer, and patenting of human body material.

Gilles Genicot is a lawyer at the Liège Bar and a lecturer in Medical Law at the University of Liège (ULg), Belgium. He serves as a member of the Belgian national Advisory Committee on Bioethics.

Sigrid Sterckx, PhD, is a Professor of Ethics at Ghent University, Belgium and a part-time Professor of Ethics at the Vrije Universiteit Brussel (VUB). She is a founding member of the Bioethics Institute Ghent and a member of the Belgian national Advisory Committee on Bioethics.