

REVIEW

Could minors be living kidney donors? A systematic review of guidelines, position papers and reports

Kristof Thys,¹ Kristof Van Assche,² H el ene Nobile,^{1,3} Marion Siebelink,⁴ Isabelle Aujoulat,⁵ Paul Schotsmans,¹ Fabienne Dobbels⁶ and Pascal Borry¹

1 Centre for Biomedical Ethics and Law, University of Leuven, Belgium

2 Research Group on Law, Science, Technology and Society, Vrije Universiteit Brussel, Belgium

3 German Institute of Human Nutrition (DIfE), Potsdam-Rehbr ucke, Germany

4 University of Groningen, University Medical Centre Groningen, The Netherlands

5 Institute of Health & Society, Universit e Catholique de Louvain, Belgium

6 Centre for Health Services and Nursing Research, University of Leuven, Belgium

Keywords

kidney donation, living donation, pediatric donation and transplantation.

Correspondence

Fabienne Dobbels, Centre for Health Services and Nursing Research, University of Leuven, Kapucijnenvoer 35/4, BE - 3000 Leuven, Belgium.

Tel.: (+32) 16 33 69 61;

fax: (+32) 16 33 69 70;

e-mail: Fabienne.Dobbels@med.kuleuven.be

Conflicts of interest

The authors have declared no conflicts of interests.

Received: 17 October 2012

Revision requested: 5 January 2013

Accepted: 10 March 2013

Published online: 8 April 2013

doi:10.1111/tri.12097

Introduction

Kidney transplantation is the preferred treatment option for many patients suffering from acute or chronic kidney disease. Several studies indicate that successful kidney transplantation is associated with a lower risk for morbidity and mortality [1,2] and a higher quality of life compared with long-term dialysis treatment [3–5]. Especially in pediatric patients, there is a growing awareness of the negative consequences of long-term dialysis on their physical and psychosocial well-being, including an increased risk for comorbidity [6–8], lower self-esteem, more emotional and school problems, and less participation in family activities

Summary

The purpose of this study is to systematically review guidelines, position papers, and reports on living kidney donation by minors. We systematically searched the databases such as Medline, Embase, ISI Web of knowledge, Google scholar as well as the websites of various bioethics committees, transplant organizations and societies. Guidelines were included if they provided recommendations for or against living kidney donation by minors. Data were analyzed using qualitative content analysis. We included 39 documents in this study. Twenty seven of these endorse an absolute prohibition of living kidney donation by minors, because of concerns regarding the decision-making capacity of minors, the impartiality of parental authorization, the best interests of the minor, and the necessity of the donation. Twelve guidelines, however, would exceptionally allow living kidney donation by minors, provided that adequate safeguards are put in place, including an assessment of the minor's autonomy and maturity, authorization by an independent body, assuring that the anticipated psychosocial benefits outweigh the medical and psychosocial risks for the donor and the restriction to situations of last resort. A more adequate medical and psychosocial follow-up of living kidney donors may likely contribute to a more unified approach towards living kidney donation by minors.

[9–11]. Because of the lack of available deceased donors, living-donor kidney transplantation has become increasingly common, in some countries even outnumbering kidney transplantations from deceased donors.

As a rule, only adults are considered as living kidney donors. However, in several countries, also minors have exceptionally been accepted as living kidney donors. In the US, for example, 52 minors less than 18 years donated a kidney between 1988 and 2012 [12]. More than half of these donations were directed towards adult recipients, and in only a minority of cases, the recipient was an identical twin [13]. Other cases have been reported in European countries and Canada [14].

The desirability of an absolute prohibition on living kidney donation by minors has been the subject of considerable scholarly debate. Proponents of a ban warn that living kidney donation cannot be in the minor's best interests, as it concerns an intrusive medical procedure for the therapeutic benefit of someone else. Moreover, it is argued that allowing kidney donation by minors may result in abuse of power by proxy decision-makers [13]. In contrast, critics stress that a prohibition insufficiently takes into account minors' ability to make deliberate decisions concerning their own health [14–17]. It is argued that their decision-making capacity is increasingly being recognized in many health areas, including consent to medical treatment and research participation [18], genetic testing [19], reproductive health services [20], and postmortem organ donation [21]. It is also suggested that a prohibition is based on an overly narrow interpretation of the minor's best interests that only considers medical interests, disregarding potential psychosocial benefits as a consequence of donation [13,22]. Other commentators argue that intra-familial obligations to support the well-being of the family as a unit may necessitate living kidney donation by minors for the benefit of a relative [23,24].

Studies on the attitudes of health care professionals also reveal a mixed picture. A survey showed that US kidney transplant centers and transplant physicians are generally opposed to living kidney donation by minors, because of concerns on minors' ability to provide informed consent and the increased risk for them to need a kidney transplantation themselves in the case of a hereditary disease. However, more physicians would be willing to consider donation by a minor in specific situations, for example when the waiting time for the recipient is increasing, when donor and recipient are identical twins or when their own children would be in need of an organ [25,26].

To our knowledge, no studies have systematically analyzed the guidelines and recommendations of national and international expert committees and organizations on living kidney donation by minors. An overview of the recommendations and arguments of expert organizations may help us to better understand current attitudes and to critically re-evaluate the practice of living kidney donation by minors. Therefore, the aim of this systematic review is to critically evaluate the viewpoints of guidelines, position papers, and reports in favor or against living kidney donation by minors.

Methods

Data sources

We systematically searched the databases such as Medline, Embase, and ISI Web of Science. We used standardized search strings that combined the keywords 'living donor',

'living donation', 'kidney donor', 'kidney donation', 'renal donor', 'renal donation', 'organ donor', and 'organ donation' with the keywords 'guideline', 'report', 'recommendation', 'statement', and 'position'. Additionally, we looked for gray literature by consulting the search engine Google scholar and by visiting the websites of various national bioethics committees (listed on the website of the WHO [27]), transplant organizations, international transplant societies and organizations (listed on the website of the Global Observatory on Donation and Transplantation [28]). We also consulted the reference lists within the retrieved documents in order to retrieve additional guidelines ('snowballing'). We did not restrict our search based on publication year. We ended our search for relevant publications on June 27th 2012. Title and abstract screening, as well as full text analyses were performed independently by two teams of authors.

Study selection

The selection and screening of the documents was carried out in accordance with the PRISMA guidelines [29]. We only included guidelines, position papers and reports, giving recommendations or opinions on living kidney donation by minors. We included documents that were written in English, French, German, Spanish, Italian, Dutch or Danish. Legal documents and documents that only discuss donation of regenerative cells, tissues and organs or donation by anencephalic infants were excluded from our study. The retrieved documents are listed in Table 1.

Data extraction and content analysis

From every included document we retrieved the quotes that contained recommendations or opinions on living kidney donation by minors and each quote was assigned one or more codes. We set up a pilot study with three documents that were analyzed independently by four authors using the technique of open coding [30]. After comparison of these open codes, all authors agreed on a preliminary coding scheme in which axial codes were identified through a process of data comparison [30]. This scheme was regularly refined during the process of analysis. Ultimately, the results were organized in four thematic categories, representing the main concerns and safeguards related to living kidney donation by minors. An overview of these categories is presented in Table 2.

Results

Figure 1 presents an overview of the selection and screening procedure. Ultimately, we retrieved 39 documents that met our inclusion criteria. The retrieved documents were published between 1993 and 2012 and originated from 29

Table 1. Overview of guidelines by source.

| Author | Region | Title | Year of publication | Living kidney donation by minors legally allowed in country? |
|---|------------------|--|---------------------|--|
| National Bioethics Committees (<i>n</i> = 14) | | | | |
| Belgian Advisory Committee on Bioethics | Belgium | Advies nr. 11 van 20 December 1999 betreffende het wegnemen van organen en weefsels bij gezonde levende personen, met het oog op transplantatie | 1999 | No |
| Belgian Advisory Committee on Bioethics | Belgium | Advies nr. 50 van 9 mei 2011 betreffende bepaalde ethische aspecten van de wijzigingen door de wet van 25 februari 2007 aangebracht aan de wet van 13 juni 1986 betreffende het wegnemen en transplanteren van organen | 2011 | No |
| French Biomedicine Agency | France | Recommandations formalisées d'experts sur le prélèvement et la greffe à partir de donneur vivant | 2009 | No |
| Danish Council of Ethics | Denmark | Levende donorer: En redegørelse om nyredonation og knoglemarvsdonation | 1999 | No |
| Italian National Bioethics Committee | Italy | Il problema bioetico del trapianto di rene da vivente non consanguineo | 1997 | No |
| Italian National Bioethics Committee | Italy | La donazione da vivo del rene a persone sconosciute (c.d. donazione samaritana) | 2010 | No |
| Commission Consultative Nationale d'Ethique pour les Sciences de la Vie et de la Santé (C.N.E.) | Luxembourg | Avis 1999.1: Convention pour la protection des droits de l'homme et de la dignité de l'être humain à l'égard des applications de la biologie et de la médecine: Convention sur les droits de l'homme et la biomédecine | 1999 | No |
| Commission Consultative Nationale d'Ethique pour les Sciences de la Vie et de la Santé (C.N.E.) | Luxembourg | Avis 1999.2 concernant la signature par le Luxembourg du Protocole sur la transplantation d'organes et de tissus d'origine humaine | 1999 | No |
| Swiss National Advisory Commission on Biomedical Ethics | Switzerland | On the regulation of living donation in the transplantation law | 2003 | No |
| The Central Ethics Committee of the Swiss Academy of Medical Science | Switzerland | Medical-ethical guidelines for organ transplantation | 1995 | No |
| The Central Ethics Committee of the Swiss Academy of Medical Science | Switzerland | Lebendspende von soliden Organen. Medizinisch-ethische Richtlinien und Empfehlungen | 2008 | No |
| Nuffield Council of Bioethics | United Kingdom | Human tissue: ethical and legal issues | 1995 | Yes |
| Nuffield Council of Bioethics | United Kingdom | Human bodies: donation for medicine and research | 2011 | Yes |
| National Independent Scientific Advisory Committees (<i>n</i> = 2) | | | | |
| Health Council of the Netherlands | The Netherlands | New Options for Organ Donation | 2003 | No |
| National Health and Medical Research Council | Australia | Organ and Tissue Donation by Living Donors – Guidelines for Ethical Practice for Health Professionals | 2007 | No (Except for Australian Capital Territory) |
| National and International Transplant and Nephrology Organizations and Societies (<i>n</i> = 12) | | | | |
| British Columbia Transplant Society | British Columbia | Clinical Guidelines for Living Donor Kidney Transplantation Program | 2009 | No |
| Consiglio Superiore di Sanità | Italy | Parere in merito a Casi di donatore 'samaritano' di rene | 2010 | No |
| Saudi Centre for Organ Transplantation | Saudi Arabia | Guidelines for Renal Transplantation in Saudi Arabia | 2006 | No |
| Spanish Society of Nephrology (SEN) and National Transplant Organization (ONT) | Spain | Recomendaciones SEN-ONT sobre Trasplante Renal de Donante Vivo | 2010 | No |

Table 1. continued

| Author | Region | Title | Year of publication | Living kidney donation by minors legally allowed in country? |
|---|----------------|---|---------------------|--|
| British Transplantation Society | United Kingdom | Recommendations on the use of living kidney donors in the United Kingdom | 1986 | Yes |
| Joint Working Party of the British Transplantation Society and the Renal Association | United Kingdom | United Kingdom Guidelines for Living-Donor Kidney Transplantation | 2011 | Yes |
| Ad hoc Clinical Practice Guidelines Subcommittee of the Patient Care and Education Committee of the American Society of Transplant Physicians | United States | The evaluation of living renal transplant donors: clinical practice guidelines | 1996 | Yes |
| Sistema de Procura de Órganos y Tejidos | Venezuela | Recomendación Rec - RCIDT - 2007 Sobre Guías de Calidad y Seguridad de Células y Tejidos Humanos para Trasplante | 2007 | No |
| Sistema de Procura de Órganos y Tejidos | Venezuela | Recomendación Rec - RCIDT - 2008 Sobre Guías de Calidad y Seguridad de Células y Tejidos Humanos para Trasplante | 2008 | No |
| European Association of Urology | Europe | EAU guidelines on renal transplantation | 2009 | – |
| European Dialysis and Transplantation Association and European Renal Association | Europe | European Best Practice Guideline for Transplantation | 2000 | – |
| The Transplantation Society | International | TTS Amsterdam Forum on the Care of the Live Kidney Donor: Data and Medical Guidelines | 2004 | – |
| National Pediatric Associations (<i>n</i> = 1) | | | | |
| Ethics Committee of the American Academy of Pediatrics | United States | Minors as living solid-organ donors | 2008 | Yes |
| National and International Medical Associations (<i>n</i> = 5) | | | | |
| Österreichisches Bundesinstitut für Gesundheitswesen | Austria | Positionspapier des am ÖBIG eingerichteten Transplantationsbeirates | 2005 | No |
| Ständige Kommission Organtransplantation der Bundesärztekammer | Germany | Positionen zur Lebendorganspende | 2008 | No |
| Council of Ethical and Judicial Affairs of the American Medical Association | United States | Report of the Council on Ethical and Judicial Affairs: The Use of Minors as Organ and Tissue Donors | 1993 | Yes |
| Council of Ethical and Judicial Affairs of the American Medical Association | United States | Report of the Council on Ethical and Judicial Affairs: transplantation of organs from living donors (Opinion 2.15) | 2005 | Yes |
| World Medical Association | International | WMA Statement on Human Organ Donation and Transplantation | 2006 | – |
| Intergovernmental Organizations and Agencies (<i>n</i> = 3) | | | | |
| Council of Europe | Europe | Guide to Safety and Quality Assurance for the Transplantation of Organs, Tissues, and Cells | | – |
| World Health Organization | International | WHO Guiding Principles on Human Cell, Tissue, and Organ Donation | | – |
| World Health Organization | International | Third WHO Global Consultation on Organ Donation and Transplantation: Striving to Achieve Self-Sufficiency, March 23–25, 2010, Madrid, Spain | | – |
| Conference Proceedings and Working Group Meetings (<i>n</i> = 3) | | | | |
| National Conference on the Nondirected Live-Organ Donor | United States | The nondirected live-kidney donor: ethical considerations and practice guidelines: A National Conference Report | 2002 | Yes |
| Live Organ Donor Consensus Group | International | Consensus statement on the live organ donor | 2000 | – |
| Working Group on Incentives for Living Donation | International | Incentives for Organ Donation: Proposed Standards for an Internationally Acceptable System | 2011 | – |

Table 2. Comprehensive scheme of codes.

| | Concerns | Proposed safeguards |
|--|--|--|
| The decision-making capacity of minors | Minors may be unable to understand and balance the risks and benefits [32–34,42–45,51,58,61,62,64,68]; Minors may be unable to make an autonomous decision on living kidney donation [32–35,39,45,51,58,61,62,64,65,68]. | Assessment of the minor's maturity and autonomy [32,34,43,44,51,58,61,62,64,68]; Additional psychological or psychiatric consultations [44,58,61]. |
| Parental authorization | Parents experience a conflict of interests when considering living kidney donation by one of their children for the benefit of another child [32,42,44,45,58,61,65,68]. | Authorization of the donation by an independent body [32,43,44,51,61–63,68]. |
| The best interests of the minor | Living kidney donation is not for the therapeutic benefit of the donor and involves more than minimal risks [32,34,42,45,58,62–64]; There is uncertainty about the long-term health risks for minor donors [58,68]; Living kidney donation may result in psychosocial harm [32,34,58]. | Minimization of medical risks [58,64,68]; Long-term medical follow-up should be guaranteed [58]; Anticipated psychosocial benefits should significantly outweigh the foreseeable health and psychosocial risks for the donor [32,43,44,58,61,62,68]; Minimization of psychosocial risks (through education) [58]; Long-term follow-up of psychosocial outcomes [58]; Restriction to recipients with whom the potential donor has a close emotional bond [32,34,44,58,61,62,65]. |
| The necessity of the minor's donation | Minors could be considered potential living kidney donors even when there is no desperate medical need, competent donors are available and/or there is no reasonable chance of success [32,34,39,42–44,57,58,61]. | Only acceptable as a means of last resort [32,43,44,58,61,68]; Reasonable probability of success [58,61,68]. |

organizations. They were published by national bioethics committees ($n = 13$) [31–43], national independent scientific advisory committees ($n = 2$) [44,45], national and international transplant or nephrology organizations and societies ($n = 12$) [46–57], national pediatric associations ($n = 1$) [58], national and international medical associations ($n = 5$) [59–63], intergovernmental organizations and agencies ($n = 3$) [64–66] or were published as conference proceedings or working group meeting reports ($n = 3$) [67–69].

Attitudes on living kidney donation by minors

The majority of documents ($n = 27$) [31,33,35–42,45–50,52–57,59,60,66,67,69] consider age less than 18 years as an absolute contra-indication for living kidney donation. Six of these 27 documents specifically focus on nondirected donation (i.e. donation that is not intended 'for a specific person or to a member of a specific group of people' [70]) and do not necessarily endorse a ban on directed donation by minors [35,36,47,50,67,69]. Twelve documents [32,34,43,44,51,58,61–65,68], however, would allow living kidney donation by minors in exceptional circumstances and subject to appropriate safeguards. The American Medical Association, for example, expressed the view that minors 'need not be prohibited from acting as sources of organs, but their participation should be limited' [61].

In the following analysis, we will highlight the concerns about living kidney donation by minors. These concerns focus on four different aspects: the decision-making capac-

ity of minors, the parental authorization for donation, the best interests of the minor, and the necessity of the minor's donation. In relation with each category of concern, we will also present the safeguards that have been proposed to overcome these concerns in the 12 documents that exceptionally would allow living kidney donation by minors.

The decision-making capacity of minors

Several documents question the capacity of minors to understand and balance the risks and benefits at stake and to make an autonomous decision. A document of the Nuffield Council of Bioethics recommends that 'where children are concerned, a cautious view should be taken regarding the quality of their understanding of the explanation of any procedure' [42]. A guideline from the British Transplantation Society and Renal Association states that 'there are genuine concerns about autonomy and the validity of consent from minors in this situation' [51].

Several documents highlight the risk of family pressure when the intended recipient is a close relative of the minor donor [34,35,39,45,58,61,64,65,68]. This pressure may vary from subtle forms of emotional manipulation to outright coercion, compromising a voluntary choice of the donor. A guideline from the Danish Council of Ethics mentions the possibility of large impact of parental preferences on the minor's decision: 'The minor child's motive may be [...] to prove to themselves and their parents that she is able to make a mature and adult decision' [34]. A guideline from the Italian national bioethics committee issues a similar

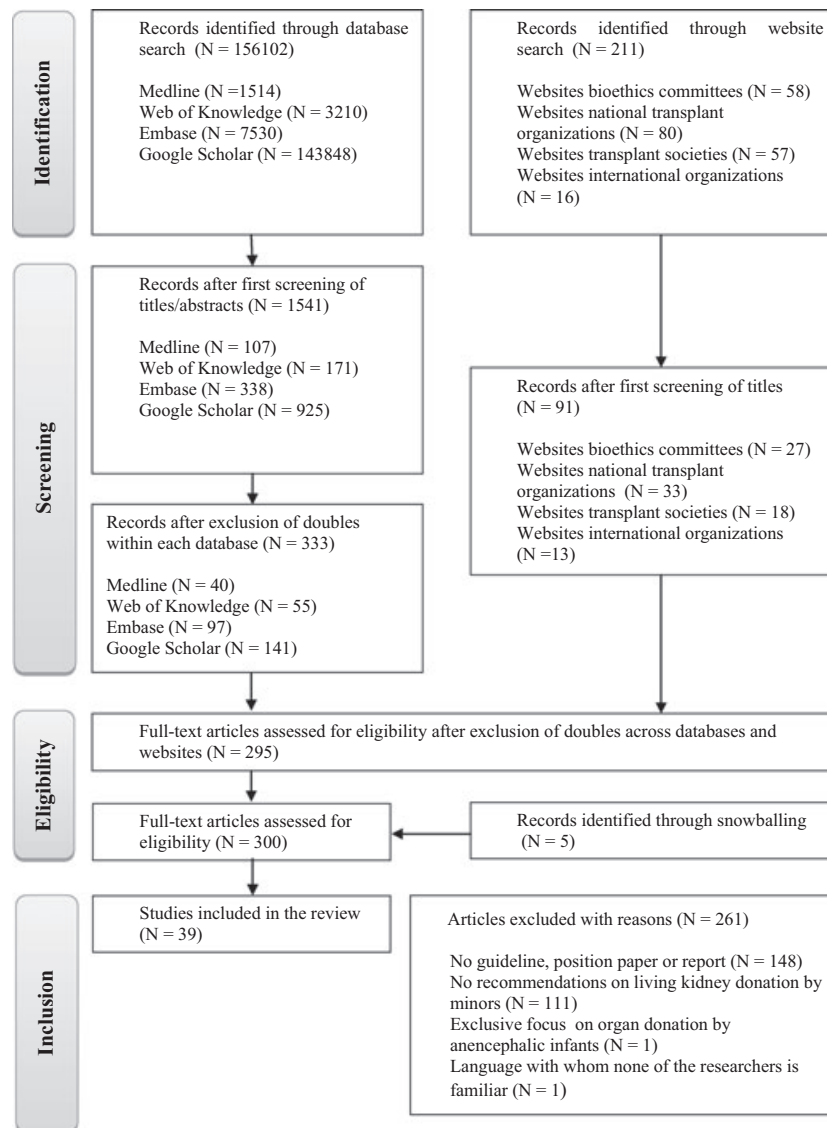


Figure 1 Prisma flow diagram.

warning with regard to potential pressure by the intended recipient [35].

To address this concern, several guidelines that do not endorse a total ban state that living kidney donation by minors may be justified when the potential donor is sufficiently mature and autonomous [32,43,44,58,61,62]. A report from the Council of Ethical and Judicial Affairs of the American Medical Association (CEJA) [62], recommends that ‘if a child is capable of making her own medical treatment decisions, she should be considered capable of deciding whether to be an organ or tissue donor’ [61]. Some members of the Belgian Advisory Committee on Bioethics explained that the donor ‘should have reached the age in which she is able to make a well-considered moral deliberation’; at the same time stating that this ability may already

be present at the age of 12. Three of these guidelines [44,58,61] recommend that, next to the standard social and medical evaluation, potential minor donors should undergo additional psychological or psychiatric consultations.

Moreover, two reports from the CEJA [61,62], also allow for living-kidney donation by nonmature minors in the case when there is parental approval and court authorization and the ‘transplantation presents a ‘clear benefit’ to the minor donor’ [61].

Parental authorization

Eight documents [32,42,44,45,58,61,65,68] warn that parental authorization for living kidney donation by one of their children may be compromised because of the conflict

of interests when they are at the same time responsible for the care of the intended recipient. For instance, a CEJA report states that ‘in their desire to save a seriously ill child, parents may temporarily subordinate the welfare of another child who is a potential source’ [61].

Guidelines that do not favor a total ban agree that consent from the minor’s parents or legal guardian is a necessary condition to allow the donation [32,43,44,58,61,62,64,65,68]. The ethics committee of the American Academy of Pediatrics (AAP), for example, holds that this decision ‘is too momentous to be left to minors alone, but should reflect a shared decision between minor and parent(s)’.

However, recognizing that parental judgment may be clouded because of the conflict of interests, several of these guidelines emphasize that final approval by an independent body should be sought to guarantee that the donation would indeed be in the minor’s best interests. While some guidelines hold that court approval should preferably be sought [43,44,51,61], others argue that authorization can best proceed by consulting a specialized multidisciplinary team, like a national or institutional ethics committee [32,62,63,68]. The AAP guideline states, however, that a positive judgment from the donor advocacy team is generally sufficient and ‘hospital ethics committee and psychiatric consultations should be considered for more complex cases, such as when the minor donor has cognitive disabilities or when there are procedural questions given the child’s age’ [58].

The best interests of the minor

Many guidelines express severe doubts as to whether living kidney donation can ever be in the minor’s best interests, given the medical and/or psychological risks that minors may face as a result of donation.

Medical risks

Several guidelines state that minors should not be exposed to surgical procedures that involve more than minimal risk and that are not for their own health benefit. For instance, a document from the Nuffield Council of Bioethics questions whether ‘with the exception of trivial procedures [...], children under the age of 18 should be regarded as competent to consent to the donation of tissue where this is not part of their medical treatment’ [42].

Some documents [34,58,65,68] also mention long-term risks of living with a solitary kidney. Considerable worry is expressed about the ‘lack of long-term data on the safety of pediatric donation’ [58] and the ‘inadequacy of our knowledge regarding the minor’s lifetime with a solitary kidney’ [68].

Some of the guidelines that do not endorse a prohibition argue that living donation by minors could be acceptable if

the health risks for the donor can be minimized. Accordingly, the consensus statement on the live kidney donor recommends that this could only be allowed when ‘the surgical risk for the donor is extremely low’ [68]. Similarly, the AAP guideline explains that ‘the risks of certain solid-organ donations such as that of a kidney are known to be smaller than others, such as that of the liver, suggesting that minors should be restricted to serve as living kidney donors’ and not as liver donors [58].

Psychosocial risks

Two documents [34,58] also discuss the psychosocial risks that may result from donation. The AAP guideline refers to similar risks in donation by adults, who may ‘feel lower self-esteem, a sense of neglect, and lack of appreciation after the donation as the attention refocuses on the recipient’ [58]. A guideline of the Danish Council of Ethics also mentions the possibility of future regret: ‘Every young person is a potential parent. You can give a kidney only once to a family member, discarding the possibility of later being able to do the same for your own child’ [34].

The guidance document from the AAP states that living kidney donation by minors may be acceptable when due care is taken to minimize these psychosocial risks. It considers family education as a crucial factor in this process [58]. Moreover, this guideline recommends to provide follow-up psychological support and to establish donor registries in order to collect ‘long-term follow-up data on pediatric donors’ [58].

Hypothetical psychosocial benefits

Five guidelines that exceptionally would allow living kidney donation by minors [32,43,44,58,61] argue that this procedure should only be allowed if a clear psychosocial benefit is to be expected, such as the development of greater self-esteem [58,61], a ‘continued emotional bond’ [61] between donor and recipient, the benefit of living ‘in an intact family’ [61,71], the ‘prevention of adverse reaction to the death of a sibling’ [61] and the prevention of future guilt [32]. A CEJA report states that ‘if there is good reason to believe that the potential donor would suffer greater psychological harm from the death of the potential recipient than medical harm from the removal of an organ for transplantation, it may be appropriate to proceed’ [62].

Five guidelines [32,34,44,58,61] state that, next to the individual benefits for the donor and the recipient, also benefits for the family as a unit should be taken into account. The Danish Council of Ethics stated that ‘the minor child should not only be respected as an isolated individual, but also as a person whose values and actions are intimately linked to family values and actions’ [34]. The CEJA warns, however, that ‘psychological benefits to the

family should not be confused with psychological benefits to the child, as they are not necessarily the same' [61].

In order to maximize the possibility of psychological benefits for the donor (and the family), it is sensible to restrict living kidney donation by minors to recipients with whom they have a close emotional bond [32,34,44,58,61,62,65]. Two guidelines [44,65] argue that kidney donation by minors should only be considered when the recipient is an identical twin.

A report from the Health Council of the Netherlands states that 'donation from a minor to an adult [...] can never or seldom be justified' [44]. Yet, some documents would exceptionally also allow donation to adult family members. The AAP states that 'there may be rare cases in which it is morally appropriate for a donation to be considered from a minor donor to an adult family member' [58]. A CEJA report even states that 'there may be some circumstances in which a strong emotional relationship exists with a relative who is not part of the immediate family or even a nonrelative' [61].

The necessity of the minor's donation

Several guidelines express concern about the possibility that minors are considered as potential living donors, even in the absence of an urgent need for transplantation, without a reasonable chance that the transplantation will be successful or despite the fact that other means to help the recipient (like competent living donors, deceased donors or substitute treatments) are available. The AAP guideline clarifies that living kidney donation by minors could not be justified unless the intended recipient is not likely 'to survive the wait to receive a deceased donor organ, despite being an excellent candidate for transplantation' [58], for example when 'the potential kidney recipient has exhausted sites for dialysis access or is highly sensitized to most potential donors, but not the identified child donor' [58]. A report from the Dutch Health Council also refers to the likely availability of sufficient potential adult donors that would eliminate the need for donation by minors: 'it would be extraordinary if a minor would be the only suitable donor within a family, considering the broader possibilities of unrelated donation' [44].

To address this concern, several guidelines that do not endorse a complete ban on living kidney donation by minors stipulate that this procedure should only be allowed as a means of last resort. The CEJA holds for example that minors can only be living kidney donors when the transplantation is 'necessary with some degree of medical certainty to prevent an extremely poor quality of life' [61] and 'all other available sources of organs, both donor pools and competent adult family members, must be medically inappropriate or significantly inferior to the minor' [61]. Simi-

larly, the AAP requires that 'all other opportunities for transplantation have been exhausted, no potential adult living donor is available and timely and/or effective transplantation from a deceased donor is unlikely' [58].

Discussion

Our review showed that 27 out of 39 guidelines endorse a prohibition of living kidney donation by minors. In contrast, 12 guidelines exceptionally allow living kidney donation by minors, provided that adequate safeguards are present. These include an assessment of the minor's decision-making capacity and best interests by an independent competent body.

With regard to the minor's decision-making capacity, these 12 guidelines emphasize the need to protect minors from external pressure. However, they do not provide recommendations for the assessment of their psychosocial maturity. This is rather unfortunate given that, although most children from the age of 14 are cognitively able to make rational and informed treatment decisions [70,71], their decision-making capacity may be compromised because of increased susceptibility to peer pressure, risk-taking behavior, and impulsivity [72,73] as a result of their psychosocial development stage.

Minors' best interests include both self-regarding and other-regarding interests [74]. Self-regarding interests are minors' interests in their own well-being, and include the potential psychosocial benefits that they may experience as a consequence of altruistic behavior, such as increased self-esteem, self-worth, and improved relationship with the recipient [75,76]. Other-regarding interests are minors' interests in the well-being of the intended recipient, 'at least partly as an end in itself' [74]. The best interests standard has been primarily applied to sibling relationships, particularly identical twins, because of their strong emotional bond and the additional graft survival advantage to the recipient. Minor-to-adult donations will be harder to justify considering the increasing possibility of finding an adult kidney donor.

The application of the best interests standard to the context of living kidney donation by minors has been sharply criticized. First, limited empirical evidence is available on long-term psychosocial outcomes in minor donors and their recipients. Although adult kidney donors generally report psychosocial benefits as a consequence of donation, it is uncertain whether these would also be observed in minors [74,77]. Moreover, living kidney donation by minors might have disturbing psychological effects in the recipients, including feelings of indebtedness towards the donor, which are likely to have a negative impact on pediatric recipients' self-managed care and compliance [78].

Second, critics have argued that courts and ethics committees are insufficiently qualified to adequately appreciate the medical risks for the minor donor, particularly the long-term risks, and are therefore in no position to substitute the medical judgment of transplant physicians [79]. Currently, we have no clear view of the long-term medical implications of donor nephrectomy in minors. In one study, a significant decline of renal function was observed in several patients 25 years after unilateral nephrectomy [80]. Moreover, the risk of sibling donors and recipients developing future diabetes cannot be excluded. Furthermore, living with a solitary kidney may restrict minors from performing certain physical activities and making future lifestyle and career choices [79]. A clearer view of the long-term medical outcomes of living kidney donation will likely contribute to a more unified approach towards living kidney donation by minors.

Similar to guidelines, transplant legislations also differ in their approach to living kidney donation by minors. In Europe, the Convention on Human Rights and Biomedicine [81] and its Additional protocol concerning the Transplantation of Organs and Tissues of Human Origin [82], hold that persons not able to consent should not be considered as suitable donors of nonregenerative tissues and organs. However, it is left to domestic law to specify at what age persons should be considered competent to consent to living kidney donation. In Norway, this may already be the case for minors older than 12. In several countries that have not ratified this convention including Ireland, Sweden, and the United Kingdom, minors who are not able to consent may also be legally considered as potential living kidney donors. Outside of Europe, in South Korea and some Canadian provinces, minors above a certain age may be considered competent to consent to living kidney donation. In India, Israel, Japan, the US, and one Australian territory, minors who are not able to consent may also be legally considered as potential living kidney donors. Invariably, strict procedural and substantive requirements are imposed. Procedural requirements include parental authorization, absence of refusal by the minor and final approval by an independent competent body. Substantive requirements include nonavailability of a suitable deceased-donor organ or compatible adult living donor, life-saving potential of the transplantation, close degree of consanguinity, and conformity with the best interests of the minor.

This study is subject to some limitations. First, it is possible that we did not retrieve some relevant guidelines, despite our systematic approach. Second, we did not distinguish guidelines according to their level of sectorial or geographical impact. Third, most included documents provide general guidelines on living kidney donation by competent donors, and thus do not give extensive argumentation with regard to the issue of donation by minors.

Funding

The authors have declared no funding.

References

1. Wolfe RA, Ashby VB, Milford EL, *et al.* Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. *N Engl J Med* 1999; **34**: 1725.
2. Ojo AO, Hanson JA, Meier-Krische HU, *et al.* Survival in recipients of marginal cadaveric donor kidneys compared with other recipients and wait-listed transplant candidates. *J Am Soc Nephrol* 2001; **12**: 589.
3. Sayin A, Mutluay R, Sindel S. Quality of life in hemodialysis, peritoneal dialysis, and transplantation patients. *Transplant Proc* 2007; **39**: 3047.
4. Fujisawa M, Ichikawa Y, Yoshiya K, *et al.* Assessment of health-related quality of life in renal transplant and hemodialysis patients using the SF-36 health survey. *Urology* 2000; **56**: 201.
5. Jofre R, Lopez-Gomez JM, Moreno F, Sanz-Guajardo D, Valderrabano F. Changes in quality of life after renal transplantation. *Am J Kidney Dis* 1998; **32**: 93.
6. Chavers BM, Li S, Collins AJ, Herzog CA. Cardiovascular disease in pediatric chronic dialysis patients. *Kidney Int* 2002; **62**: 648.
7. Mitsnefes M, Stablein D. Hypertension in pediatric patients on long-term dialysis: a report of the North American Pediatric Renal Transplant Cooperative Study (NAPRTCS). *Am J Kidney Dis* 2005; **45**: 309.
8. McDonald SP, Craig JC. Long-term survival of children with end-stage renal disease. *N Engl J Med* 2004; **350**: 2654.
9. Riaño-Galán I, Málaga S, Rajmil L, *et al.* Quality of life of adolescents with end-stage renal disease and kidney transplant. *Pediatr Nephrol* 2009; **24**: 1561.
10. Goldstein SL, Graham N, Burwinkle T, Warady B, Farrah R, Varni JW. Health-related quality of life in pediatric patients with ESRD. *Pediatr Nephrol* 2006; **21**: 846.
11. Gerson A, Hwang W, Fiorenza J, *et al.* Anemia and health-related quality of life in adolescents with chronic kidney disease. *Am J Kidney Dis* 2004; **44**: 1017.
12. U.S. Organ Procurement and Transplantation Network. Living donors recovered in the U.S. by donor age. <http://optn.transplant.hrsa.gov/latestData/rptData.asp> (last accessed on 14 September 2012).
13. Delmonico FL, Harmon WE. The use of a minor as a live kidney donor. *Am J Transplant* 2002; **2**: 333.
14. Webb NJA, Fortune PM. Should children ever be living kidney donors? *Pediatr Transplant* 2006; **10**: 851.
15. Cheyette C. Organ harvests from the legally incompetent: an argument against compelled altruism. *BCL Rev* 1999; **41**: 465.
16. Brierley J, Larcher V. Organ donation from children: time for legal, ethical and cultural change. *Acta Paediatr* 2011; **100**: 1175.

17. Delpin ES. Additional guidelines on the use of minors as living kidney donors. *Am J Transplant* 2003; **3**: 1182.
18. Alderson P. Competent children? Minors' consent to health care treatment and research. *Soc Sci Med* 2007; **65**: 2272.
19. Borry P, Stultiëns L, Nys H, Cassiman JJ, Dierickx K. Presymptomatic and predictive genetic testing in minors: a systematic review of guidelines and position papers. *Clin Genet* 2006; **70**: 374.
20. Dickens BM, Cook RJ. Adolescents and consent to treatment. *Int J Gynaecol Obstet* 2005; **89**: 179.
21. Siebelink MJ, Geerts EAHM, Albers MJII, Roodbol PF, van de Wiel HBM. Children's opinions about organ donation: a first step to assent? *Eur J Pub Health* 2011; **22**: 529.
22. Schenberg BA. Harvesting Organs from Minors and Incompetent Adults to Supply the Nation's Organ Drought: a Critical Review of the Substituted Judgment Doctrine and the Best Interest Standard. *Ind Health L Rev* 2007; **4**: 319.
23. Dwyer J, Vig E. Rethinking transplantation between siblings. *Hastings Cent Rep* 1995; **25**: 7.
24. Morley MT. Proxy consent to organ donation by incompetents. *Yale LJ* 2002; **111**: 1215.
25. Spital A. Should children ever donate kidneys?: views of US transplant centers. *Transplantation* 1997; **64**: 232.
26. Joseph JW, Thistlethwaite JR Jr, Josephson MA, Ross LF. An Empirical Investigation of Physicians' Attitudes Toward Intrasibling Kidney Donation by Minor Twins. *Transplantation* 2008; **85**: 1235.
27. World Health Organization. <http://www.who.int/ethics/regions/en> (last accessed on 25 April 2012).
28. Transplant Observatory. <http://www.transplant-observatory.org> (last accessed on 25 April 2012).
29. Liberati A, Altman DG, Tetzlaff J, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *J Clin Epidemiol* 2009; **62**: e1.
30. Corbin J, Strauss A. *Basics of qualitative research: grounded theory procedures and techniques*. London: Sage Publications, 1990.
31. Belgian Advisory Committee on Bioethics. Advies nr. 11 van 20 December 1999 betreffende het wegnemen van organen en weefsels bij gezonde levende personen, met het oog op transplantatie. 1999. <http://www.health.belgium.be/eportal/Healthcare/Consultativebodies/Comitees/Bioethics/Opinions/index.htm> (last accessed on 14 March 2012).
32. Belgian Advisory Committee on Bioethics. Advies nr. 50 van 9 mei 2011 betreffende bepaalde ethische aspecten van de wijzigingen door de wet van 25 februari 2007 aangebracht aan de wet van 13 juni 1986 betreffende het wegnemen en transplanteren van organen. 2011. <http://www.health.belgium.be/eportal/Healthcare/Consultativebodies/Comitees/Bioethics/Opinions/index.htm> (last accessed on 14 March 2012).
33. French Biomedicine Agency. Recommandations formalisées d'experts sur le prélèvement et la greffe à partir de donneur vivant. 2009. <http://www.agence-biomedecine.fr/Recommandations-formalisees-d> (last accessed on 14 March 2012).
34. Danish Council of Ethics. Levende donorer: En redegørelse om nyredonation og knoglemarvsdonation. 1999. <http://etiskraad.dk/upload/publikationer/organdonation-og-obduktion/levende-donorers/kap01.htm> (last accessed on 14 March 2012).
35. Italian national bioethics committee. Il problema bioetico del trapianto di rene da vivente non consanguineo. 1997. http://www.governo.it/bioetica/pareri_abstract/abstract_trapianto_rene_non_consang_6.pdf (last accessed on 14 March 2012).
36. Italian national bioethics committee. La donazione da vivo del rene a persone sconosciute (c.d. donazione samaritana). 2010. http://www.governo.it/bioetica/pareri_abstract/abstract_donatori_rene.pdf (last accessed on 14 March 2012).
37. Commission Consultative Nationale d'Ethique pour les Sciences de la Vie et de la Santé. Avis 1999.1: Convention pour la protection des droits de l'homme et de la dignité de l'être humain à l'égard des applications de la biologie et de la médecine: Convention sur les droits de l'homme et la biomédecine. 1999. http://www.cne.public.lu/publications/avis/1999_1.pdf (last accessed on 14 March 2012).
38. Commission Consultative Nationale d'Ethique pour les Sciences de la Vie et de la Santé. Avis 1999.2 concernant la signature par le Luxembourg du Protocole sur la transplantation d'organes et de tissus d'origine humaine. 1999. http://www.cne.public.lu/publications/avis/1999_2.pdf (last accessed on 14 March 2012).
39. Swiss National Advisory Commission on Biomedical Ethics. Opinion no. 6/2003. On the regulation of living donation in the transplantation law. 6/2003 ed. 2003. <http://www.bag.admin.ch/nek-cne/04229/04232/index.html?lang=en> (last accessed on 14 March 2012).
40. The Central Ethics Committee of the Swiss Academy of Medical Science. Lebendspende von soliden Organen. Medizinisch-ethische Richtlinien und Empfehlungen. 2008. <http://www.samw.ch/de/Ethik/Richtlinien/Aktuell-gueltinge-Richtlinien.html> (last accessed on 25 April 2012).
41. The Central Ethics Committee of the Swiss Academy of Medical Sciences. Medical-ethical guidelines for organ transplantation. 1995. <http://www.samw.ch/en/Ethics/Guidelines/Archive.html> (last accessed on 25 April 2012).
42. Nuffield Council on Bioethics. Human Tissue: ethical and Legal Issues. Nuffield Council on Bioethics. 1995. <http://www.nuffieldbioethics.org/human-tissue> (last accessed on 25 April 2012).
43. Nuffield Council on Bioethics. Human bodies: donation for medicine and research. Nuffield Council on Bioethics. 2011. <http://www.nuffieldbioethics.org/donation> (last accessed on 25 April 2012).
44. Health Council of the Netherlands. New Options for Organ Donation. The Hague. 2003. <http://www.gezondheidsraad.nl/en/publications/new-options-organ-donation> (last accessed on 25 April 2012).

45. National Health and Medical Research Council. Organ and Tissue Donation by Living Donors - Guidelines for Ethical Practice for Health Professionals. 2007. <http://www.nhmrc.gov.au/guidelines/publications/e71> (last accessed on 25 April 2012).
46. British Columbia Transplant Society. Clinical Guidelines for Living Donor Kidney Transplantation Program. 2009. http://www.transplant.bc.ca/Clinical_Guidelines_for_Transplantation/living_donor_kidney_master.pdf (last accessed on 14 May 2012).
47. Consiglio Superiore di Sanità. Parere in merito a Casi di donatore 'samaritano' di rene. 2010. <http://www.trapianti.salute.gov.it> (last accessed on 14 May 2012).
48. Saudi Centre for Organ Transplantation. Guidelines for Renal Transplantation in Saudi Arabia. 2006. <https://scot.org.sa/en/en/research-a-scince/guidelines/121-guidelines-for-renal-transplantation-in-saudi-arabia-2006.html> (last accessed on 14 May 2012).
49. Fresnedo GF, Valentín MO. Recomendaciones de la Sociedad Española de Nefrología (S.E.N.) y de la Organización Nacional de Trasplantes (ONT) sobre trasplante renal de donante vivo. *Revista Nefrología* 2010; 30. <http://www.ont.es/infesp/DocumentosDeConsenso/Guias%20SEN.pdf> (last accessed on 14 May 2012).
50. Sells RA, Johnson RWG, Hutchinson I. Recommendations on the use of living kidney donors in the United Kingdom. *BMJ* 1986; **293**: 257.
51. Joint Working Party of the British Transplantation Society and Renal Association. United Kingdom Guidelines for Living Donor Kidney Transplantation. 2011. <http://www.bts.org.uk/Documents/Guidelines/Active/UK%20Guidelines%20for%20Living%20Donor%20Kidney%20July%202011.pdf> (last accessed on 14 May 2012).
52. Kasiske BL, Ravenscraft M, Ramos EL, Gaston RS, Bia MJ, Danovitch GM. The evaluation of living renal transplant donors: clinical practice guidelines. Ad hoc clinical practice guidelines subcommittee of the patient care and education committee of the American Society of Transplant Physicians. *J Am Soc Nephrol* 1996; **7**: 2288.
53. RED/Consejo Iberoamericano de donación y trasplantes. Recomendación REC-RCIDT-2007 (7) sobre guías de calidad y seguridad de células y tejidos humanos para trasplante. 2nd edn. 2008. <http://incort.gob.do/Publicaciones/tabid/250/Default.aspx> (last accessed on 14 May 2012).
54. RED/Consejo Iberoamericano de donación y trasplantes. Recomendación REC-RCIDT-2008 (7) consideraciones bioéticas sobre la donación y el trasplante de órganos, tejidos y células. 2nd edn. 2008. <http://incort.gob.do/Publicaciones/tabid/250/Default.aspx> (last accessed on 14 May 2012).
55. Kälble T, Alcaraz A, Budde K, *et al.* EAU Guidelines on Renal Transplantation. 2012. <http://www.uroweb.org/gls/pdf/Renal%20Transplantation%202010.pdf> (last accessed on 14 May 2012).
56. European Renal Association – European Dialysis and Transplant Association. Section II: evaluation and selection of donors. *Nephrol Dial Transplant* 2000; **15**: 39.
57. Delmonico F. A report of the Amsterdam forum on the care of the live kidney donor: data and medical guidelines. *Transplantation* 2005; **79**: S53.
58. Ross LF, Thistlethwaite JR Jr. Minors as living solid-organ donors. *Pediatrics* 2008; **122**: 454.
59. Österreichisches Bundesinstitut für Gesundheitswesen. Lebendspende: Positionspapier des am ÖBIG eingerichteten Transplantationsbeirates. 2012. <http://www.goeg.at/de/Bereich/Lebendspende.html> (last accessed on 20 May 2012).
60. Ständige Kommission Organtransplantation der Bundesärztekammer. Positionen zur Lebendspende. Wildbad Kreuth. 2003. <http://www.baek.de/downloads/positionenlebendorganspende20040206.pdf> (last accessed on 14 May 2012).
61. Council on Ethical and Judicial Affairs of the American Medical Association. Report 3 – I-93. The Use of Minors as Organ and Tissue Donors. 1993. http://www.ama-assn.org/resources/doc/ethics/ceja_3i93.pdf (last accessed on 08 June 2012).
62. Council on Ethical and Judicial Affairs of the American Medical Association. Report 5 – A-05. Transplantation of Organs from Living Donors. 2005. <http://www.ama-assn.org/resources/doc/ethics/ceja-5a05.pdf> (last accessed on 08 June 2012).
63. World Medical Association. WMA Statement on Human Organ Donation and Transplantation. 2006. <http://www.wma.net/en/30publications/10policies/t7> (last accessed on 08 June 2012).
64. Council of Europe. *Guide to Safety and Quality Assurance for Organs, Tissues and Cells*. 2nd edn. Strasbourg Cedex. 2004. http://www.coe.int/t/dg3/health/Source/GuideSecurity2_en.pdf (last accessed on 08 June 2012).
65. World Health Organization. WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation. 2010. http://www.searo.who.int/LinkFiles/BCT_WHO_guiding_principles_organ_transplantation.pdf (last accessed on 14 May 2012).
66. World Health Organization. Third WHO global consultation on organ donation and transplantation: striving to achieve self-sufficiency, March 23-25, 2010, Madrid, Spain. *Transplantation* 2011; **91**: S39.
67. Adams PL, Cohen DJ, Danovitch GM, *et al.* The nondirected live-kidney donor: ethical considerations and practice guidelines: a National Conference Report. *Transplantation* 2002; **74**: 582.
68. Abecassis M, Adams M, Adams P, *et al.* Consensus statement on the live organ donor. *JAMA* 2000; **284**: 2919.
69. Working Group on Incentives for Living Donation. Incentives for organ donation: proposed standards for an internationally acceptable system. *Am J Transplant* 2012; **12**: 306.

70. Dorn LD, Susman EJ, Fletcher JC. Informed consent in children and adolescents: age, maturation and psychological state. *J Adolesc Health* 1995; **16**: 185.
71. Kuther TL. Medical decision-making and minors: issues of consent and assent. *Adolescence* 2003; **38**: 343.
72. Gardner M, Steinberg L. Peer influence on risk taking, risk preference, and risky decision making in adolescents and adulthood: an experimental study. *Dev Psychol* 2005; **41**: 625.
73. Halpern-Felsher B, Cauffman E. Costs and benefits of a decision: decision-making competence in adolescents and adults. *J Appl Dev Psychol* 2001; **22**: 257.
74. Crouch R, Elliott C. Moral agency and the family: the case of living related organ transplantation. *Camb Q Healthc Ethics* 1999; **8**: 275.
75. Schover LR, Stroom SB, Boparai N, Duriak K, Novick AC. The psychosocial impact of donating a kidney: long-term follow-up from a urology based center. *J Urol* 1997; **157**: 1596.
76. Johnson EM, Anderson JK, Jacobs C, et al. Long-term follow-up of living kidney donors: quality of life after donation. *Transplantation* 1999; **67**: 717.
77. Jansen LA. Child organ donation, family autonomy, and intimate attachments. *Camb Q Healthc Ethics* 2004; **13**: 133.
78. Aujoulat I, Schwering KL, Reding R. Living-related donation: a challenge to adolescent transplant recipients who transit from parental care to self-managed care. *Child Care Health Dev* 2012; **38**: 146.
79. Salvatierra O. Transplant physicians bear full responsibility for the consequences of kidney donation by a minor. *Am J Transplant* 2002; **2**: 297.
80. Davis CL. Evaluation of the living kidney donor: current perspectives. *Am J Kidney Dis* 2004; **43**: 508.
81. Council of Europe. Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: convention on Human Rights and Biomedicine. CETS No. 164. Oviedo; 1997. <http://conventions.coe.int/Treaty/en/Treaties/Html/164.htm> (last accessed on 13 February 2013).
82. Council of Europe. Additional Protocol to the Convention on Human Rights and Biomedicine concerning Transplantation of Organs and Tissues of Human Origin. Strassbourg; 2002. <http://conventions.coe.int/Treaty/Commun/QueVoulezVous.asp?NT=186&CL=ENG> (last accessed on 13 March 2013).