



# WHEN OPPORTUNITY KNOCKS TWICE: DUAL LIVING KIDNEY DONATION, AUTONOMY AND THE PUBLIC INTEREST

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## Keywords

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## ABSTRACT

Living kidney transplantation offers the best treatment in terms of life-expectancy and quality of life for those with end-stage renal disease. The long-term risks of living donor nephrectomy, although real, are very small, with evidence of good medium-term outcomes. Who should be entitled to donate, and in which circumstances, is nevertheless a live question. We explore the ethical dimensions of a request by an individual to donate both of their kidneys during life: 'dual living kidney donation'. Our ethical analysis is tethered to a hypothetical case study in which a father asks to donate a kidney to each of his twin boys. We explore the autonomy of the protagonists, alongside different dimensions of the public interest, such as the need to protect not only the recipients, but also the donor and even the wider community.

Whilst acknowledging objections to 'dual-donation', not least by reference to the harms that the donor might be expected to endure, we suggest there is a *prima facie* case for permitting this, provided that both donor and recipients are willing and that due attention is paid to such considerations as the autonomy and welfare of all parties, as well as to the wider ramifications of acting on such a request. We argue for broader interpretations of the concepts of autonomy and welfare, recognizing the importance of relationships and the relevance of more than merely physical well-being. Equipped with such a holistic assessment, we suggest there is a *prima facie* case for allowing 'dual living kidney donation'.

## 1. INTRODUCTION

Renal Replacement Therapy (RRT) is a term used to describe treatments that at least partially substitute the role of failed kidneys and includes haemodialysis, peritoneal dialysis and renal transplantation. Transplantation is associated with better survival and quality of life compared with dialysis,<sup>1</sup> and with better outcomes for living-donor, compared with deceased-donor, transplants.<sup>2</sup> Prospective live donors are assessed according to national

and international guidelines.<sup>3</sup> The long-term risks of living donor nephrectomy, although real, are very small,<sup>4</sup> with evidence of good medium-term outcomes, at least in

<sup>1</sup> A. Laupacis, P. Keown, N. Pus, H. Krueger, B. Ferguson, C. Wong & N. Muirhead. A Study of the Quality of Life and Cost-Utility of Renal Transplantation. *Kidney Int.* 1996; 50(1): 235–242.

<sup>2</sup> Statistics and Clinical Audit: NHS Blood and Transplant Organ Donation and Transplantation Activity Report 2013/14. Available

from: [www.organdonation.nhs.uk/statistics/transplant\\_activity\\_report/current\\_activity\\_reports/ukt/activity\\_report\\_2013\\_14.pdf](http://www.organdonation.nhs.uk/statistics/transplant_activity_report/current_activity_reports/ukt/activity_report_2013_14.pdf). [cited 2015 January 25]

<sup>3</sup> United Kingdom Guidelines for Living Donor Kidney Transplantation. Compiled by a Joint Working Party of the British Transplantation Society and the Renal Association. 3rd ed. May 2011; [www.bts.org.uk/transplantation/standards-and-guidelines/](http://www.bts.org.uk/transplantation/standards-and-guidelines/); F. Delmonico & Council of the Transplantation Society. A Report of the Amsterdam Forum On the Care of the Live Kidney Donor. *Transplantation.* 2005; 79(Supplement 2): S53–S66.

<sup>4</sup> G. Mjøs, S. Hallan, A. AHartmann, A. Foss, K. Midtvedt & O. Øyen. Long-Term Risks for Kidney Donors. *Kidney Int.* 2014 Jul; 86(1): 162–167; A.D. Muzaale, A.B. Massie, M.C. Wang, R.A. Montgomery,

white populations. The quality of life of most living donors is at least equal to the general population and returns to pre-donation levels after donation.<sup>5</sup>

Who should be entitled to donate, and in which circumstances, is nevertheless a live question. In 1996, David Patterson, an inmate at California State Prison, USA, donated a kidney to his daughter, Renada Daniel-Patterson, who suffered from End-Stage Renal Disease (ESRD). In 1998, after this transplant failed, David offered to donate his second – and therefore only remaining – kidney.<sup>6</sup> The case was considered by the University of California, San Francisco's clinical bioethics committee and David's request to donate was not permitted. Renada received a kidney from her uncle, but this failed within a few years, and Renada died in 2007.<sup>7</sup>

A previous examination of the ethical dimensions of this case<sup>8</sup> focussed on issues specific to David and Renada's circumstances, including the state funding of healthcare for prisoners in a country with a private medical insurance model, the rights of prisoners, and the likelihood of rejection of a second kidney from the same donor. In this article, we aim to build on that discussion, by considering a related but different scenario, in which one individual asks to donate both of their kidneys to two recipients. The case study we describe is hypothetical, although the clinical experience of one of the authors suggests such requests do not exist in theory only. A current case in Canada, in which twin girls each require a liver transplant and the father can donate to only one, demonstrates a situation where a similar desire might exist.<sup>9</sup> We anticipate that there will be objections to the prospect of allowing such 'dual-donation', not least by reference to the harms that the donor might be expected

to endure. However, we suggest that there is a *prima facie* case for permitting the procedure, provided that certain criteria are met.<sup>10</sup> We begin by exploring the autonomy of the donor and we suggest that such a request might well be autonomous. Since autonomous requests are nonetheless bound in various ways, we consider the boundaries that might be placed around such choices by reference to the 'public interest'. Here we consider not only the welfare of the donor, but also that of the proposed recipients, and we argue that, on balance, the procedure might even contribute to the well-being of all parties. We close by reflecting on the potential wider ramifications of allowing dual-donation, by reference to collective values, including in the preservation of life. Here too we believe a tentative case can be made, and ways can be found of avoiding potentially slippery slopes. We tether our analysis to a hypothetical case, which we outline in the next section. Our case is located in England, but our arguments will have wider relevance and resonance.

## 2. AN OFFER OF DUAL-DONATION

45-year-old identical twins, James and Philip, both have ESRD secondary to X-linked Alport syndrome. They have both been on three-times-a-week haemodialysis for approximately five years, and have been active on the national deceased-donor waiting list in the UK for this time. Both have had recurrent problems whilst on dialysis, and have received a number of blood transfusions. The best option for James and Philip is to each have a Living Kidney Transplant (LKT) from a friend or relative. They have inherited their condition from their mother June, who is a carrier. In addition, June is from Trinidad and has sickle cell trait, which means she is not considered a suitable living kidney donor (LKD). Their white British father, Tom, who is 69 years old, has been retired for four years and is fit and well. No other friends or relatives are available for donation.

Tom attends the renal unit to discuss his wish to donate both his kidneys – one to each son. He reports that he has been considering this 'for years' and knows that if he donates both his kidneys he will require some form of RRT. Having attended many of his sons' clinic appointments and dialysis sessions he knows well what this involves. He states that his main priority in life is to ensure that his children are happy and healthy, and he says that he values their well-being above his own.

M.A. McBride, J.L. Wainright & D.L. Segev. Risk of End-Stage Renal Disease Following Live Kidney Donation. *JAMA*. 2014; 311(6): 579–586.

<sup>5</sup> C.R. Gross, E.E. Messersmith, B.A. Hong, S.G. Jowsey, C. Jacobs, B.W. Gillespie, et al. Health-Related Quality of Life in Kidney Donors From the Last Five Decades: Results From the RELIVE Study. *Am J Transplant*. 2013; 13(11): 2924–2934.

<sup>6</sup> D. Osborne. Convict Wants to Sacrifice his Only Kidney to Save his Dying Daughter *The Independent*. 1998 Dec 8. Available at: <http://www.independent.co.uk/news/convict-wants-to-sacrifice-his-only-kidney-to-save-his-dying-daughter-1190047.html> [cited 2015 January 25]

<sup>7</sup> M. Lagos. Woman whose Inmate Dad Donated Kidney to her Dies. *SFGate* 2007 March 20. Available at: <http://www.sfgate.com/bayarea/article/BAY-AREA-Woman-whose-inmate-dad-donated-kidney-2609092.php>. [cited 2015 January 25]

<sup>8</sup> R. Sauder & L. Parker. Autonomy's Limits: Living Donation and Health-Related Harm. *Camb Q Health Ethics*. 2001; 10(4): 399–407.

<sup>9</sup> Eleftheriou-Smith I. Parents of Twins with Alagille Syndrome in Public Plea for Liver Donor after Discovering Father is a Match – but can only Donate to one Child. *The Independent*. 2015 January 26 Available at: <http://www.independent.co.uk/news/world/americas/parents-of-twins-with-alagille-syndrome-in-public-plea-for-liver-donor-after-discovering-father-is-a-match-but-can-only-donate-to-one-child-10003178.html> [cited 2015 May 22]

<sup>10</sup> A simple utilitarian approach might bring us to such a conclusion. However, our analysis encompasses more than utilitarian concerns and we suspect it draws a more restrictive line that a utilitarian analyst might.

### 3. AN AUTONOMOUS OFFER?

Whether or not Tom's offer ought to be accepted might be said to depend, at least in part, on whether his can be considered an *autonomous* offer. Coggon has helpfully provided a tripartite typology of autonomous decision-making, by which we can distinguish autonomous choices according to whether they convey an individual's current, best, or ideal desires.<sup>11</sup> Reducing autonomous choice to one's *current* desires, and thus even to one's most fleeting whims, seems to deprive autonomy of the reflective element we might expect of true *self-rule*. The prioritization of only *ideal* desires then seems to go too far in the opposite direction: here we would only count as autonomous those choices which *should* be made, according to some objective account of the good, and this threatens to remove the *self* from self-rule. Perhaps, then, *best* desire autonomy offers the best account, since it allows the individual to choose, albeit in a suitably reflective fashion, in which there is due regard for what the individual wants to want (their second order desires).<sup>12</sup>

Of course, whichever account is preferred, there will be further criteria to be fulfilled before the individual can be considered to be making an autonomous choice. The usual criteria – which require the individual to have sufficient mental capacity, information, and freedom to decide – tend to align with our preferred account of autonomy, in which an autonomous choice is one which aligns with the individual's best desires.

Applying these observations to Tom's offer, he appears to be suitably well-informed and we have no reason to doubt that he has the requisite capacity to make this offer. But is his choice truly his own, in the sense that he has not been unduly influenced? Certainly, questions might arise as to whether Tom appears to have been pressurized (overtly or covertly). Rather than approach this case with the presumption that such interference has occurred, we suggest that we might better understand Tom's offer by putting it in (his) context – and doing so should, in turn, better enable us to assess whether this looks like an expression of Tom's best desires.

As is well known, there is growing dissatisfaction with the idea of autonomy as an isolated and individualistic concept, which presumes that we exercise our self-rule independently of others. More relational accounts suggest that autonomy is both constrained and facilitated by others. Anne Donchin has developed a critique of the atomistic concept of autonomy, which 'deprives

individuals of virtually all particularity, taking as the norm a monadic self, stripped of all social relations'.<sup>13</sup> Donchin has argued that autonomy should instead be viewed as 'a positive conception of human agency that recognizes relational experiences as an integral dimension of individuality',<sup>14</sup> acknowledging 'the social context that constructs and facilitates . . . choices'.<sup>15</sup> Similarly, Carl Elliott suggests that 'a vocabulary of rights and autonomy can be inadequate to represent the intimate bonds of family and friends, the delicate balance between sacrifice and self-interest, and the complex, often awkward relationship between doctors and organ donors or research subjects'.<sup>16</sup>

These insights suggest that Tom should not be isolated from his paternal relationship with his sons; Tom might remain an individual but his 'individual identity cannot be abstracted from its entwinement'<sup>17</sup> with the identities of these significant others. Once we appreciate this, we might also come to appreciate that Tom's choice does indeed reflect his best desires. As such, we might conclude that Tom has made an authentic, autonomous offer.

This, of course, will not be the end of the matter. Levy has referred to an individual's proclaimed 'right and capacity to make choices that advance their own significant projects'.<sup>18</sup> Here we move from considerations of autonomy to considerations of *liberty*. As we have seen, autonomy will conjure questions of capacity, but liberty will introduce different questions, regarding the rights or entitlements of individuals. No matter how autonomous a choice might be, there remains the question of *respect*: should the choice be respected, in the sense that the desire is honoured? If autonomy is tethered to ideal desires, then people's choices will certainly be limited (indeed, they will be limited from the outset). However, the extent to which individual choices should be respected will be a live issue, even if we adopt a more subjectively-oriented account of autonomy, such as one that is premised on best desires. We consider these limitations by reference to the public interest.

### 4. IN THE PUBLIC INTEREST?

Coggon and Miola have suggested that, 'Whatever the overarching normativity, liberty is the freedom to act

<sup>11</sup> J. Coggon. Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism? *Health Care Anal.* 2007; 15(3): 235–255.

<sup>12</sup> H. Frankfurt. Freedom of the Will and the Concept of a Person. *J Philos.* 1971; 68(1): 5–20; G. Dworkin. *The Theory and Practice of Autonomy*. Cambridge University Press, Cambridge; 1988.

<sup>13</sup> A. Donchin. Understanding Autonomy Relationally: Toward a Reconfiguration of Bioethical Principles. *J Med Philos.* 2001; 26(4): 365–386.

<sup>14</sup> *Ibid*: 367

<sup>15</sup> *Ibid*: 374

<sup>16</sup> C. Elliott. Doing Harm: Living Organ Donors, Clinical Research and The Tenth Man. *J Med Ethics.* 1995; 21(2): 91–96.

<sup>17</sup> A. Donchin. *op. cit.* note 12, pp 382

<sup>18</sup> N. Levy. Forced to be Free? Increasing Patient Autonomy by Constraining it. *J Med Ethics.* 2014; 40(5): 293–300.

within it. Liberty marks the bounds of the laws required to mediate the co-existence of people who should be free to act autonomously.<sup>19</sup> The boundaries that might be erected around individual choices can be conceptualized in terms of the ‘public interest’. However, determining what is – or should be – considered in the public interest is not straightforward.

Held has offered a useful typology for organizing accounts of the public interest.<sup>20</sup> First, there are *preponderance* theories. These adopt a subjective account of ‘interests’, which are to be understood in terms of individuals’ preferences; on this account, the public interest aggregates the preferences, in a utilitarian manner. Of course, this approach leaves the public interest to turn on what the majority of people happen to desire – and, as such, the minority appear doomed to lose out. The second approach is instead *unitary*, and locates the public interest in those objective interests which people should value. Yet this approach threatens to stray too far from what people actually value; specifying these ‘objective’ interests is bound to be a fraught enterprise. The final alternative strives for a degree of subjectivity, alongside a measure of objectivity, in pointing to the *common interest*, and therefore to those interests that might truly be said to be shared by everyone. But here, too, difficult questions will arise, about what these interests might be, and about the respect to be granted to different, competing interests.

So what, then, are the values that the public interest might be said to promote or protect? We can approach this question by looking at the different sorts of claims that are typically made in the name of the public interest. Ashcroft has pointed to six such claims,<sup>21</sup> which can be organized according to whose particular interests are being protected or promoted: *the individual* in question, some *other(s)*, or the wider *collective*.<sup>22</sup> We will look at each of these groups, starting with those other than the individual, with a view to exploring whether Tom’s offer to donate should be accepted.

## 5. PROTECTING THE RECIPIENT(S)?

Perhaps the most obvious arguments that could be made for accepting Tom’s offer are those which will point to the likely benefits to his sons, James and Philip. With

these transplants, James and Philip’s welfare should be improved. Welfare, however, is another complex concept; as with autonomy and the public interest itself, we can consider three ways of understanding the idea.<sup>23</sup> First, we might see welfare in terms of *desire-fulfilment*, which will invite reflection on an individual’s preferences and, therefore, on their autonomy. Alternatively, we might point to particular *mental states*, such as pleasure and the avoidance of suffering; bringing in notions like ‘quality of life’. Finally, we can see welfare in terms of particular *objective goods*: goods, such as life itself or the value in intimate relationships, which might be judged valuable in and of themselves, no matter whether individuals actually happen to want these goods or how ‘happy’ they might make them.

James and Philip’s desires – and thus their autonomy<sup>24</sup> – can be accommodated if we insist that they must agree to the offer and therefore to the transplant before it can proceed. If accepted, the offer also appears likely to improve the quality and length of their lives, especially since their prospects of receiving a transplant from other sources is slim. As of March 2014 5,881 patients were registered as active on the deceased-donor kidney transplant waiting list in the UK, and for the financial year 2013–2014, 2,142 deceased-donor kidney transplants were performed in the UK.<sup>25</sup> The short-fall between individuals requiring a renal transplant and kidneys available for donation is clear.

If all three required a transplant, James and Philip would be less likely than Tom to be offered suitable transplants from the national deceased-donor list, and they would be likely to wait longer for a suitable offer, for two main reasons. First, an individual’s likelihood of receiving a transplant from the UK’s national allocation scheme is reduced by any previous event that will have caused their immune system to encounter ‘foreign’ material and generate an immune response thereto. Through this process an individual becomes ‘sensitized’, meaning that a number of organs that may be offered to that recipient are now unsuitable. Blood transfusions, pregnancies and previous transplants are all sensitizing events. James and Philip’s previous transfusions are therefore likely to have reduced the number of deceased-donor organs suitable for them.

Secondly, James and Philip are mixed-race, and individuals from Black, Asian and Minority Ethnic (BAME) groups are less likely in practice to receive a deceased-donor transplant and are more likely to wait longer to

<sup>19</sup> J. Coggon & J. Miola. Autonomy, Liberty and Medical Decision-Making. *The Cambridge Law Journal*. Nov 2011; 70(3): 523–547.

<sup>20</sup> V. Held. *The Public Interest and Individual Interests*. Basic Books, New York. 1970.

<sup>21</sup> R. Ashcroft. From Public Interest to Political Justice. *Camb Q Health Ethics*. 2004 Winter; 13(1): 20–27.

<sup>22</sup> R. Huxtable. Autonomy, Best Interests and The Public Interest: Treatment, Non-Treatment and the Values of Medical Law. *Medical Law Review*. Jan 2014; 22(4): 459–493.

<sup>23</sup> D. Parfit. *Reasons and Persons*. Oxford University Press, Oxford; 1984; D. DeGrazia. Value Theory and the Best Interests Standard. *Bioethics*. 1995; 9(1): 50–61.

<sup>24</sup> As understood in terms of their best desires.

<sup>25</sup> Statistics and Clinical Audit: NHS Blood and Transplant *op. cit.* note 2.



receive one.<sup>26</sup> This is in part because of an increased risk of ESRD in non-white populations in the UK, and in part due to the ethnic composition of deceased-donors. Matching of a donor to a recipient is likely to be closer when the ethnicity of the donor and recipient are closer, but there is a discrepancy between supply and demand for BAME individuals: for 2013, more than 30% of people listed for a kidney transplant were from a BAME background compared to just 5.6% of deceased kidney donors.<sup>27</sup>

Although scores exist, there is no simple way to determine precisely the likelihood of an individual receiving a deceased-donor kidney transplant, but the evidence suggests that James and Philip would be waiting longer. In addition, recipient and transplant survival with LKTs remains superior to that with deceased-donor transplants,<sup>28</sup> which may be an important consideration given the ages of James, Philip and Tom. If Tom donated both his kidneys and then (if he was willing)<sup>29</sup> received a deceased-donor kidney transplant, he might die with a functioning transplant. For James and Philip, however, the longer the 'life expectancy' of the grafted kidney, the greater the time before a return to dialysis or a second transplant.

There is, therefore, a case to be made for accepting Tom's offer, in view of the benefits to his sons' physical well-being, provided they are willing to accept the offer. There is, however, the possibility that James and Philip will be at risk of harm to their psychological well-being. Qualitative research with potential and actual recipients of LKTs, in situations in which the donor has donated one kidney, suggests that recipients can experience concerns about the donor's health, feelings of guilt, and a sense of indebtedness to their donor.<sup>30</sup> One might anticipate James and Philip being especially concerned about their father, and the impact on him of accepting his offer. At the same time, however, the benefits to them remain significant, so we cannot entirely discount the possibility that they will be amenable to accepting their father's gift. It is arguable that the benefits to Tom's sons outweigh the

risks that they will experience harm. As such, so far, we have at least an arguable case that the offer can be accepted.

## 6. PROTECTING THE DONOR?

Notwithstanding any benefits to others, there is sometimes said to be a public interest in protecting the individual from him or herself, with the result that the liberty of – and thus the choices that can be made by – that individual will be constrained. Ashcroft exemplifies this by reference to the compulsory detention of a mentally disordered individual, when this is done in order to protect his or her welfare.<sup>31</sup> As with James and Philip, we can refer to Tom's desires, his mental state, and his objective good when thinking through his welfare.

There are evidently *risks* to Tom's mental state and his objective good, since donation will adversely affect his (physical) quality of life, and perhaps his life-expectancy. Feinberg distinguishes between 'direct and certain harm' and 'the risk of harm': the former includes 'cases of the direct production of harm to a person, when the harm is the certain upshot of his or another's action and its desired end', whilst the latter encompasses 'cases of the direct creation of a risk of harm to oneself in the course of activities directed toward other ends'.<sup>32</sup> Tom appears most likely to be running the 'risk of harm'; harm is not directly intended but will ensue from him donating both his kidneys.

In single kidney donation there is no physical benefit to the donor but there is a definite, albeit small, 'risk of harm' – including of death.<sup>33</sup> Traditionally the harm associated with donation is temporary (e.g. incisional pain), but it may be more permanent and significant; as such, the risk is likely only to be run if the probability of the harm materializing is sufficiently low to justify the procedure. In the case of dual-kidney donation, however, this 'risk of harm' becomes certain; the procedure would inevitably result in some harm to Tom. Whether this risk of harm should operate as a bar on Tom's choice would

<sup>26</sup> U. Udayaraj, R. Pruthib, A. Casulab & P. Roderick. UK Renal Registry 16th Annual Report: Chapter 6 Demographics and Outcomes of Patients from Different Ethnic Groups on Renal Replacement Therapy in the UK. *Nephron Clinical Practice*. 2013; 125(1–4): 111–125.

<sup>27</sup> NHS Blood and Transplant News Release 2014 Transplant and donor disparity for BAME communities 13 March. Available at: [http://www.organdonation.nhs.uk/newsroom/news\\_releases/article.asp?releaseId=359](http://www.organdonation.nhs.uk/newsroom/news_releases/article.asp?releaseId=359) [cited 2015 January 25]

<sup>28</sup> United Kingdom Guidelines for Living Donor Kidney Transplantation. *op. cit.* note 3.

<sup>29</sup> We will return to the possibility that Tom might not be willing.

<sup>30</sup> I. Sajjad, L. Baines, M. Salifu & R. Jindal. The Dynamics of Recipient-Donor Relationships in Living Kidney Transplantation. *Am J Kidney Dis*. 2007; 50(5): 834–854; M. Caletani, C. Tonkin-Crine, R. Pruthi, G. Leydon, R. Ravanani, J.A. Bradley et al. Patient Attitudes Towards Kidney Transplant Listing: Qualitative Findings from the ATTOM Study. *Nephrol Dial Transplant*. Nov 2014; 29(11): 2144–2150.

<sup>31</sup> R. Ashcroft. *op. cit.* note 19 p21.

<sup>32</sup> J. Feinberg. Chapter 20 Voluntariness and Assumptions of Risk in *The Moral Limits of the Criminal Law Volume 3: Harm to Self*. Oxford University Press; 1989.

<sup>33</sup> Mjøen et al. *op. cit.* note 4; Muzaale et al. *op. cit.* note 4; A.J. Matas, B.L. Kasiske, J.J. Snyder, M.D. Ellison, J.S. Gill & A.T. Kausz. Morbidity and Mortality after Living Kidney Donation, 1999–2001: Survey of United States Transplant Centers. *Am J Transplant* 2003; 3(7): 830–834; H.N. Ibrahim, R. Foley, L. Tan, T. Rogers, R.F. Bailey, H. Guo et al. Long-Term Consequences of Kidney Donation. *N Engl J Med*. 2009; 360(5): 459–469; D.L. Segev, A.D. Muzaale, B.S. Caffo, S.H. Mehta, A.L. Singer, S.E. Taranto et al. Perioperative Mortality and Long-Term Survival following Live Kidney Donation. *JAMA*. 2010; 303(10): 959–966.

seem to rest on the doctrine of double effect.<sup>34</sup> As such, we would first need to rely upon a distinction between a foreseen inevitable harmful consequence and an intended harmful consequence. Defenders of the doctrine would suggest that there is a valid such distinction.<sup>35</sup> Secondly, the doctrine also requires proportionality and even a degree of necessity, in the sense that running the risk is the best we can do. Here it could be argued that the risk to Tom can be reduced, by ensuring that Tom receives RRT and is placed on the transplant waiting-list.

Tom might even be able to argue that the harm-benefit ratio can be further tipped in favour of honouring his choice, since doing so respects his desires. Here we are drawn back to our earlier reflections on Tom's autonomy. Each individual will have, in Rawls' words, their own 'conception of the good' – a sense of what is valuable and to be pursued.<sup>36</sup> Subjective well-being will consist of both affective and cognitive components, which includes desire-satisfaction.<sup>37</sup> Desire-satisfaction, it has been argued, involves a realization of desires, irrespective of any associated affective satisfaction. Allowing Tom's desires to be realized could be judged valuable insofar as this involves respecting his autonomy. However, Tom could also argue that it would benefit him in other ways.

Tom could argue that his psychological well-being will be enhanced, notwithstanding any risks to his physical well-being. It seems plausible that Tom could claim that his well-being is adversely affected by witnessing his sons receiving haemodialysis. From an evolutionary perspective, Tom's choice to donate could amount to biological kin altruism:<sup>38</sup> Tom's desired outcome is the survival of his genetic progeny, an end which he might judge outweighs any costs accrued.

Indeed, ensuring the survival of his sons could contribute positively to Tom's well-being in a relational sense. Here a parallel can be drawn with a ruling from English law.<sup>39</sup> Y was a severely disabled adult, whose sister required a bone marrow transplant. Y was a suitable donor. Although there was not a close relationship between the sisters, Y reportedly took pleasure from her relationship with her mother. The court recognized that if Y's sister died as a result of not receiving the transplant,

Y's relationship with her mother would be adversely affected, in terms of the duration of visits, as her mother would have had to take on the care of Y's sister's child. Strictly-speaking, the judge was required to decide only on the basis of incapacitated Y's 'best interests'. Notably, however, the judgment afforded room to the wider familial relationships and the donation was authorized.<sup>40</sup>

These arguments can also be made a negative sense; we can point not only to the *benefits* that Tom might accrue, but also to the *harms* he might avoid, if his choice is honoured. DeGrazia argues that there exists a harm in 'confinement', in both a literal and non-literal sense i.e. harm can result from the thwarting of desires and freedoms.<sup>41</sup> Indeed, recently a call has been made to the transplant community to study the harms experienced by potential LKDs who, although willing, are not able to donate.<sup>42</sup> In this work, Allen et al. argue that the risks of donation and those of non-donation should be considered in tandem and, by extrapolation, the risk of non-donation may sometimes be 'greater' than that of donation. In Tom's case, there might be a case for considering not only the benefits and harms of donation, but also of denying him the opportunity to donate.

In sum, although there are risks to Tom if he is permitted to donate, a *prima facie* case apparently can be made for allowing him to do so, since this could also have a positive impact on his well-being. Indeed, it seems arguable that there is a 'coincidence of [the donor's] interests with the benefit to accrue to the recipient [s]'.<sup>43</sup> This cannot be the end of the matter, however, since we now need to move beyond the recipients and the donor to the wider community. Are there sufficient concerns at this level to impose a bar on Tom's choice?

## 7. PROTECTING THE COMMUNITY?

Ultimately the decision whether or not to accept Tom's offer requires consideration of the impact that this could have on the community in which Tom resides.<sup>44</sup> Identifying and specifying the collective good is not straightforward but it seems plausible to suggest that a society like England places great value on such goods as *autonomy*,

<sup>34</sup> D. Sulmasy & E. Pellegrino. The Rule of Double Effect: Clearing up the Double Talk. *Arch Intern Med.* 1999 Mar 22; 159(6): 545–550.

<sup>35</sup> *Ibid.*

<sup>36</sup> J. Rawls. *A Theory of Justice*. Harvard University Press; 1971.

<sup>37</sup> D.W. Bruckner. Subjective Well-Being and Desire Satisfaction. *Philosophical Papers.* 2010; 39(1).

<sup>38</sup> W. Hamilton. The Genetical Evolution of Social Behaviour. I–II. *J Theor Biol.* 1964; 7: 1–52; E. Madsen, R.J. Tunney, G. Fieldman, H.C. Plotkin, R.I. Dunbar, J.M. Richardson, et al. Kinship and Altruism: a Cross-Cultural Experimental Study. *Br J Psychol.* 2007; 98(Pt 2): 229–259.

<sup>39</sup> Re Y (Mental Incapacity: Bone Marrow Transplant) [1996] 2 FLR 787.

<sup>40</sup> Feinberg *op. cit.* note 31; Given Y's incapacity, we recognize the terminological difficulty of labelling this 'donation', but will retain the convention for present purposes.

<sup>41</sup> D. DeGrazia. Chapter 4 The Harms of Suffering, Confinement, and Death in *Animal Rights: A Very Short Introduction*. Oxford University Press; 2002.

<sup>42</sup> M. Allen, P. Abt & P. Reese. What are the Harms of Refusing to Allow Living Kidney Donation? An Expanded View of Risks and Benefits. *Am J Transplant* 2014; 14(3): 531–537.

<sup>43</sup> Sauder & Parker, *op. cit.* note 8, p.406

<sup>44</sup> We leave to one side how one determines the boundaries of such a community. We restrict ourselves, here, to the jurisdiction in which Tom resides, taken to be England.

health, and life.<sup>45</sup> Various laws and policies attest to the assumed value of these goods; indeed, there are also instrumental safeguards, such as the creation of specific professions which work to secure these goods: healthcare is an obvious example.

If, then, we assume that the society in question is dedicated to promoting and protecting such values as autonomy, health, and life, then how might these values be served – or threatened – by Tom's offer? In seeking to answer this question, we will explore three specific issues: the impact of donation on the collective goods; the impact of donation on those who work to protect the collective goods; and the impact of donation on the distribution of the collective goods. We will consider these issues in reverse order.

### 7.1. Distributing collective goods?

Although more can be said,<sup>46</sup> let us assume that health is a collective good, and that the 'healthcare enterprise' exists precisely in order to serve this value, whatever this 'fuzzy' value might be said to encompass.<sup>47</sup> Inevitably, more difficult questions will then arise, about how the enterprise – and the 'good' – should be shared out amongst those individuals who make up the collective. How might Tom's offer relate to the question of distribution?

If we stick with the UK context, a broadly utilitarian approach might be taken to distribution: here, the QALY (quality-adjusted life year) is used to ensure that healthcare is distributed to those most likely to benefit, in the sense that this will afford them good quality years of life.<sup>48</sup> This approach is, of course, subject to ethical complexity and controversy,<sup>49</sup> including in the field of transplantation.<sup>50</sup> If we nevertheless apply this logic, then Tom's offer could be considered favourably. Transplantation offers a net cost-benefit when compared to dialysis in a cost evaluation of RRT. The cost benefit of kidney

transplantation compared to dialysis over a period of ten years is £241,000.<sup>51</sup> The cost-benefit of dual-kidney donation in this instance is less than that associated with Tom donating a single kidney to one of his sons and remaining treatment-free. Yet, the *most* cost-effective solution would involve Tom also receiving a donated kidney. Whether a kidney would be forthcoming remains to be seen, but, in terms of distribution at least, it seems arguable that Tom's offer could be accepted.

### 7.2. Protecting the gatekeepers?

Remaining with health as a collective good, we should also consider whether Tom's offer might be considered an affront to those who strive to serve this good, i.e. healthcare professionals. Here we focus specifically on the surgeons who would be required to perform the donor nephrectomies.

Some maintain that medicine – and, by extension, surgery – has its own distinctive integrity and perhaps even a constitutive 'internal morality'.<sup>52</sup> On such accounts, surgeons should only be doing that which is compatible with the essential nature of their endeavour: they are not merely the 'puppet technicians' of the patient's will. We might well anticipate objections to Tom's offer from this perspective. Tom's request seems some distance from the traditional 'disease/treatment', 'doctor/patient' models with which surgery might usually be associated. Notwithstanding any psychological or other benefits that Tom might accrue, Tom is not (yet) a patient, nor is he an obvious beneficiary of the proposed procedure, at least in terms of his physical health.<sup>53</sup>

Yet such objections need not succeed: those accounts of the 'core' of the surgical endeavour that have been offered appear to be neither necessary nor sufficient, and they appear also to beg crucial questions.<sup>54</sup> In short, there is no obvious 'core' to the endeavour, and this should not be surprising given the intrinsic fuzziness of the ideal of

<sup>45</sup> Huxtable *op. cit.* note 21.

<sup>46</sup> J. Coggon. *What Makes Health Public? A Critical Evaluation of Moral, Legal, and Political Claims in Public Health*. Cambridge University Press, Cambridge; 2012

<sup>47</sup> K. Boyd. Disease, Illness, Sickness, Health, Healing and Wholeness: Exploring some Elusive Concepts. *Med Humanities*. 2000; 26(1): 9–17.

<sup>48</sup> Measuring Effectiveness and Cost Effectiveness: the QALY. National Institute for Health and Care Excellence 2010 Available at: <https://www.nice.org.uk/proxy/?sourceurl=http://www.nice.org.uk/newsroom/features/measuringeffectivenessandcosteffectivenessstheqaly.jsp> [cited 2015 May 22]

<sup>49</sup> G. Garbutt & P. Davies. Should the Practice of Medicine be a Deontological or Utilitarian Enterprise? *J Med Ethics*. 2011; 37(5): 267–270; T. Ottersen. Lifetime QALY Prioritarianism in Priority Setting. *J Med Ethics*. 2013; 39(3): 175–180.

<sup>50</sup> G. Persad, A. Wertheimer & E. Emanuel. Principles for Allocation of Scarce Medical Interventions. *Lancet*. 2009; 373(9661): 423–431; J. Briceño, C. Ruben & M. de la Mata. Donor-Recipient Matching: Myths and Realities. *Journal of Hepatology*. 2013; 58: 811–820.

<sup>51</sup> Cost-Effectiveness of Transplantation Factsheet 7. NHS Blood and Transplant Oct 2009; Available at: [www.organdonation.nhs.uk/newsroom/fact\\_sheets/Organ\\_Donation\\_Registry\\_Fact\\_Sheet\\_7\\_21337.pdf](http://www.organdonation.nhs.uk/newsroom/fact_sheets/Organ_Donation_Registry_Fact_Sheet_7_21337.pdf) [cited 2015 January 25]

<sup>52</sup> E. Pellegrino. The Internal Morality of Clinical Medicine: a Paradigm for the Ethics of the Helping and Healing Professions. *J Med Philos*. 2001 Dec; 26(6): 559–579; F. Miller & H. Brody. Professional Integrity and Physician-Assisted Death. *Hastings Center Report*. 1995; 25(3): 8–17.

<sup>53</sup> As such, surgeons – maybe the profession as a whole – might dispute the aforementioned suggestion that the doctrine on double effect might apply i.e. they might object that a surgeon is being required to get (morally) 'dirty hands', since he or she will be a means to the donor coming to potentially significant harm.

<sup>54</sup> R. Huxtable. Death on Demand: Proper Medical Treatment? In S. Fovargue & A. Mullock, editors. *The Power of 'Proper Medical Treatment': What Role for the Medical Exception?* Routledge. Forthcoming.



'health' that medicine purports to serve.<sup>55</sup> However, this need not mean that we should entirely discount the views of surgeons. As Freedman suggests:

the internal morality of medicine . . . rests ultimately on society's commitment to preserving and ensuring continuation to a value through allocating it to be especially safeguarded by concerned professionals in society. By adopting a profession with its central value, society has given warrant to corollaries of that value to be pursued irrespective (sometimes) of, for example, simple considerations of utility.

On this view, space should be afforded to the opinions of these 'gatekeepers' to health, but the amount of space afforded will ultimately be determined by the society, in light of the *various* values it chooses to promote.

As such, society will determine the extent to which surgeons' qualms (if present) should be heeded. Various laws and policies indicate that society wishes to afford considerable space to such professionals. Surgeons are therefore empowered as gatekeepers: they must, for example, check that patients are competent, informed and free to decide, but they are not obliged to act merely on the basis of patients' demands and they can, if conscience dictates, step back from performing certain procedures.<sup>56</sup> Yet, despite all this, the surgeon's power is not unfettered. Donchin reminds us that the 'construction of the traditional physician as a noble, paternalistic, and authoritative agent ministering to compliant patients'<sup>57</sup> no longer holds true; indeed, says Huxtable, 'health professionals' conscientious desires are, ultimately, subordinate to providing the patient with what they lawfully want or need'.<sup>58</sup>

The surgeon therefore operates within boundaries which, ultimately, are imposed by the society-at-large. Surgeons and their professional bodies will influence society's judgment, but theirs will not be the only voices, nor will the value they serve – 'health' – be the only value. One way in which society expresses all this is through the law: if a procedure is deemed lawful (subject to the satisfaction of certain criteria), then the surgeon is obliged to provide that service or, if her personal conscience is at odds with this, another surgeon must do so. But would – or should – society be willing to accede to Tom's request? We will not here consider the precise legal intricacies of Tom's offer, but we will reflect on the wider values dimensions thereof, with a view to ascertaining whether this might be an offer too far.

<sup>55</sup> Boyd *op. cit.* note 46.

<sup>56</sup> R. Huxtable. Whatever You Want? Beyond the Patient in Medical Law. *Health Care Anal.* 2008; 16(3): 288–301.

<sup>57</sup> Donchin *op. cit.* note 12 p369

<sup>58</sup> Huxtable *op. cit.* note 21 p482; Personal Beliefs and Medical Practice. General Medical Council. 2013; Available at: [www.gmc-uk.org/guidance](http://www.gmc-uk.org/guidance) [cited 2015 January 25]

### 7.3. Protecting the collective goods?

In addition to the value placed on health, (UK) society appears also to value autonomy and life, and will be mindful of the wider impact that allowing dual-donation might have on these values.

If we start with *autonomy*, it might be argued that creating the option of dual-donation would compromise the voluntariness component of autonomy. Here, we might anticipate slippery slope objections, specifically of an empirical form:<sup>59</sup> allowing Tom to donate looks likely in practice to have questionable consequences, one of which might be that the value of respect for autonomy is undermined.

One of the objections that is made against allowing the creation of a market in organs is that affording the option of sale will place pressure on some individuals to exercise the option.<sup>60</sup> By analogy, an individual could feel pressurized by the knowledge that dual-donation is an option that others have chosen to pursue. Those who opt not to donate might then experience guilt, particularly if they are proximate to the potential recipient and they witness that individual's poor health; indeed, the unexercised option might foster conflict between potential donor and potential recipient. At the same time, we might have questions about those who do opt to donate: was their decision made freely, in the absence of undue influence?

If we assume that a slippery slope objection is valid, then these concerns should give us cause to pause. Yet, these problems are not new, since they already exist in relation to single kidney donation: here too non-donors might experience guilt and donors might feel unable to decline to donate.<sup>61</sup> Indeed, perhaps these problems will be less acute in the dual-donation scenario. The significant harms that the donor might experience – and thus the gravity of their decision – could well incline those who are denied the donation towards understanding, rather than upset. Equally, the gravity of such decisions might indicate that they will not be taken lightly, but after careful reflection – and might therefore be less likely to be coerced?

We can only speculate, but, so far, we appear to have a *prima facie* case for allowing Tom's offer to be pursued. Yet, once we introduce the final value – of *life* itself – the negative case appears to gather force. It might seem odd to introduce this value here: Tom's quality of life could suffer if he makes the dual-donation, and there is also some degree of risk to his life, but we have argued that

<sup>59</sup> D. Lamb. *Down the Slippery Slope: Arguing in Applied Ethics*. Kent: Crook Helm Ltd; 1988.

<sup>60</sup> S. Rippon. Imposing Options on People in Poverty: the Harm of a Live Donor Organ Market. *J Med Ethics.* 2014; 40(3): 145–150.

<sup>61</sup> H. Maple, J Chilcot & N. Mamode. Entrapment in Living Kidney Donors. British Transplantation Society Congress 2014 Abstract Book Available at: [http://www.bts.org.uk/Documents/Congress2014/BTS2014\\_AbstractBook.pdf](http://www.bts.org.uk/Documents/Congress2014/BTS2014_AbstractBook.pdf) [cited 2015 May 22]



these risks might be acceptable. However, thus far we have presumed that Tom would *accept* RRT: what if Tom wishes to donate but declines subsequent treatment? Such a situation would, of course, affect much of our preceding analysis: now the health risks to Tom are more substantial, and his sons more likely to experience guilt. However, the other points remain: Tom might still insist that this is truly his autonomous wish, in view of the undoubted benefits to his sons, from which he will also benefit in some sense. Ordinarily, the ethic of respect for autonomy would require us not to override an autonomous refusal of treatment. What if Tom has a rational reason to not pursue dialysis after donation, such as a terminal illness that does not preclude kidney donation?<sup>62</sup> Should Tom be allowed not only to donate his two kidneys, but also to refuse RRT?

This sort of situation might be considered akin to ‘organ donation euthanasia’, whereby an individual chooses to donate their organs as a means of euthanasia i.e. their true aim is to die in view of their (current or anticipated) suffering, and this is achieved by the removal of their organs under general anaesthetic. Some argue that this practice – which is not lawful anywhere to our knowledge – should be endorsed, since it will increase the pool of donor organs and in doing so tackle some of the problems that current policies present, in terms of the timing and definition of death in the context of donation.<sup>63</sup> However, in our scenario, the better analogy is with ‘thrift euthanasia’, in which ‘an intentional act of one or more individuals. . . directly causes, or knowingly contributes to, the death of another in a manner conducive to the benefit of others’.<sup>64</sup>

We would anticipate objections – at the level of the public interest – to allowing dual-donation if the donor declines subsequent RRT, since this sort of ‘thrift euthanasia’ might be judged to involve too great an incursion into the value of life, and perhaps too proximate to euthanasia *per se*. We can well expect surgeons to object to what is being asked of them here;<sup>65</sup> and, if a compliant surgeon can be found, we can also expect questions being asked of them, perhaps even by prosecutors.

<sup>62</sup> Y.S. Rakké, W.C. Zuidema, M.T. Hilhorst, R.A.M. Erdman, E.K. Massey, M.G.H. Betjes, et al. Seriously Ill Patients as Living Unspecified Kidney Donors: Rationale and Justification. *Transplantation*. 2015 Jan; 99(1): 232–235.

<sup>63</sup> R. Truog, F. Miller & S. Halpern. The Dead-Donor Rule and the Future of Organ Donation. *N Engl J Med*. 2013; 369(14): 1287–1289; D. Sanghavi. When does Death Start? *New York Times Magazine* 2009. 16 Dec Available at: [http://www.nytimes.com/2009/12/20/magazine/20organ-t.html?pagewanted=all&\\_r=0](http://www.nytimes.com/2009/12/20/magazine/20organ-t.html?pagewanted=all&_r=0) [cited 2015 May 22]

<sup>64</sup> H. Ducharme. Thrift-Euthanasia, in Theory and in Practice: a Critique of Non-Heart Beating Organ Harvesting. In M. Freeman & A. Lewis, editors. *Law and Medicine. Current legal issues volume 3*. Oxford: Oxford University Press; 2000: 493–525.

<sup>65</sup> R. Huxtable. Whatever You Want? Beyond the Patient in Medical Law. *Health Care Anal*. 2008; 16(3): 288–301.

But if these qualms are plausible, then so too might they prove manageable. One could envisage a system to ensure that principled lines are not crossed. For example, if it is desired, dual-donation could be limited to situations in which the donor is willing to receive RRT. Dual-donors could be subjected to screening, to ensure that their decision is appropriately autonomous, and offered a medical ‘alibi’ if they decide against donation.<sup>66</sup> Equally, donation could be restricted to ‘directed donation’ where the recipients are known to the donor. Allowing donation in a case like Tom’s would certainly set a precedent, but setting such a precedent need not mean that the gates are then flung open: for example, the aforementioned case of Y has not heralded any significant shift from the primary focus being on the donor.<sup>67</sup> With individualized assessments and the limitations we sketch here, the brakes might also be applied to halt any potentially slippery slide.

In short, dual-donation would require the combination of an individual with normal kidney function who has a desire to donate to two known individuals with ESRD. Depriving the donor of the subsequent opportunity to decline RRT might be difficult to square with respect for autonomy, and perhaps the door should be open to allowing this, subject to the satisfaction of certain criteria. Quite what these criteria might be remains to be seen. At the very least, it would appear appropriate to require that donors go into the procedure prepared to become future recipients themselves, as well as preventing a loophole from opening up, through which ‘thrift euthanasia’ (and even euthanasia *simpliciter*) can slip through.

## 8. CONCLUSION

Requests for dual living kidney donation are likely to be rare, and are most likely to be associated with familial conditions, in which multiple members of one family develop renal failure, while others are disease free. We have argued that there may be a *prima facie* case for allowing such donations to occur, provided that both the donor and the recipients are willing and that due attention is paid to such considerations as the autonomy and welfare of all parties, as well as to the wider ramifications of acting on such a request. It may be that similar arguments apply to the case of sequential donation to the same recipient, such as was mooted in the case of Renada Daniel-Patterson. For now, however, we have focused on dual-donation and we have argued for broader interpretations of the concepts of autonomy and welfare, which

<sup>66</sup> C. Thiessen, Y. Kim, R. Formica, M. Bia & S. Kulkarni. Opting Out: Confidentiality and Availability of an ‘Alibi’ for Potential Living Kidney Donors in the USA. *J Med Ethics*. 2014; Nov 3 doi:10.1136/medethics-2014-102184 [Epub ahead of print].

<sup>67</sup> *Re op. cit.* note 39.

recognize the importance of relationships and the relevance of more than merely physical well-being. We suspect that, with such a holistic assessment, a case can be made for allowing dual living kidney donation.

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