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Should Past Recipients of a Kidney Be Allowed To Have Another? Surveys of Preferences of Individuals with and without End Stage Renal Disease

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Should past recipients of a kidney be allowed to have another? Surveys of preferences of individuals with and without end stage renal disease

Marco D. Huesch[*] Richard L. Brady[†]

Abstract

We surveyed the preferences of individuals for allowing repeat renal transplantation before first time grafts. In a pilot survey without medical context, 71% (74%) of 151 individuals preferred no repeat participation of prior winners in a second raffle under a stakeholder (spectator) framing. Of 65 dialysis patients with end-stage renal disease, 88% preferred to allow repeat kidney grafts. Of 1,203 individuals without end-stage renal disease, 74% preferred to allow repeat kidney grafts as a spectator, 61% if as a stakeholder, but only 29% when asked about arbitrarily named candidates. 'Fairness' was the most common stated rationale in all surveys. Ethical guidelines currently do not support consideration of past resource use in future allocations. Given the source of many kidney grafts, public preferences may need to be considered.

Keywords: distributive justice, absolute scarcity, framing effects, medical ethics, transplantation

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1 Introduction

Decisions on how to distribute absolutely scarce medical resources are difficult for society as a whole, patients and their physicians. Kidney transplants for patients with end-stage renal disease (ESRD) are a leading example (Curtis, 2006; Marsden, 2003; Hippen, Thistlethwaite, and Ross, 2011). Waiting lists for a transplant are long and growing (OPTN, 2011; Reese et al, 2010), as yearly transplants are less than a fifth of the number waiting (OPTN, 12). Many patients die while waiting (USRDS, 2012; CKDPC, 2010). Indeed, half of transplant candidates aged 60 years or older on entry into the waiting list will die before receiving a deceased donor transplant (Schold et al, 2009).

Worse, half of ESRD patients who do receive a cadaveric organ will see this graft fail in about a decade (OPTN, 2011), and hence many patients are awaiting a repeat graft (Coupel et al, 2003; Izquierdo et al, 2010). A retransplant is neither technically difficult nor controversial (NKF, 2013). Cost-effectively, kidney transplants dominate dialysis (NKF, 2013), while repeat kidney transplantation compares favorably with other common therapies (Hornberger, Best, and Garrison, 1997). Yet little research has examined attitudes to the perceived fairness of repeated kidney transplantation (Piccoli et al, 2004).

In the United States and Europe, kidney re-transplantation status does not currently affect the waiting-time oriented prioritization of renal grafts, independently of its impact on sensitization (OPTN, 2011; Mayer and Persijn, 2006). Past use of medical resources is considered an ethically unacceptable criterion for future allocation (CEJA, 1995), as theories of justice do not offer compelling arguments to choose between primary and repeated claimants (Ubel, Arnold, and Caplan, 1993). While this said to result in equality of opportunity (Daniels, 2008; Donabedian, 1971), egalitarianism alone is insufficient

(Persad, Wertheimer, and Emanuel, 2009), and not always easily implementable (Rid, 2009; Keren and Teigen, 2010). Clearly, someone must go without - at least temporarily - when someone else has a second opportunity at a kidney.

Bioethicists argue that only differences in intervention efficacy should be considered Ubel, Arnold, and Caplan, 1993), but survey evidence is mixed (Huesch, 2012). In hypothetical scenarios, primary recipients were favored for organ donations compared to those waiting to be retransplanted (Chan, Cheung, and Yip, 2006; Ubel and Loewenstein, 1995), although few appeared willing to completely abandon the retransplant candidates (Ratcliffe, 2000). In practice, graft efficacy differences are not large, slightly in favor of retransplants in the US (OPTN, 2012), and internationally slightly in favor of primary transplants with shrinking differences (Izquierdo et al, 2010).

If both primary and secondary kidney graft candidates were considered equally deserving, then risk-averse decision-makers would favor random allocations across all candidates. Waiting time prioritization as performed today does not reflect equal claims as disproportionately fewer retransplant surgeries are performed compared to the number of retransplant candidates (OPTN, 2012). Older patients, more likely to have experienced prior graft failure, face far bleaker odds of a graft (Schold et al, 2009).

On the other hand, if the two types were not considered equally deserving, then neither random allocations nor the current waiting time prioritizations would be favored. Requiring re-accrual of waiting time seniority (OPTN, 2011), is a bias against retransplant candidates. Performing approximately one in nine transplant surgeries on retransplant candidates is a bias against primary candidates (OPTN, 2012).

The objective of this analysis was therefore to understand the perceived fairness of allowing repeat transplants before primary transplants. Accordingly, we surveyed the attitudes of members of the public and of dialysis patients towards the fairness of allowing repeat kidney transplantation.

2 Method

We analyzed three separate convenience sample sets of survey data (see Supplementary Material for all survey instruments). This study and the survey protocols were approved by Duke University's Social Science Institutional Review Board (for the Qualtrics and Clear Voice panel surveys). The DaVita survey was approved by Duke University Health System's Institutional Review Board and was separately and additionally approved by DaVita Clinical Research, Late Stage Group, Investigator Driven Trials.

2.1 Survey without medical context

First, we conducted an anonymous online survey from an extensive national panel maintained by Qualtrics who were compensated by the authors for access to the panel and for administration of the survey. Rolling recruitment continued until our target of 150 participants had been reached or exceeded. A total of 151 participants were compensated by Qualtrics by receiving redeemable online currency for the time spent completing the survey.

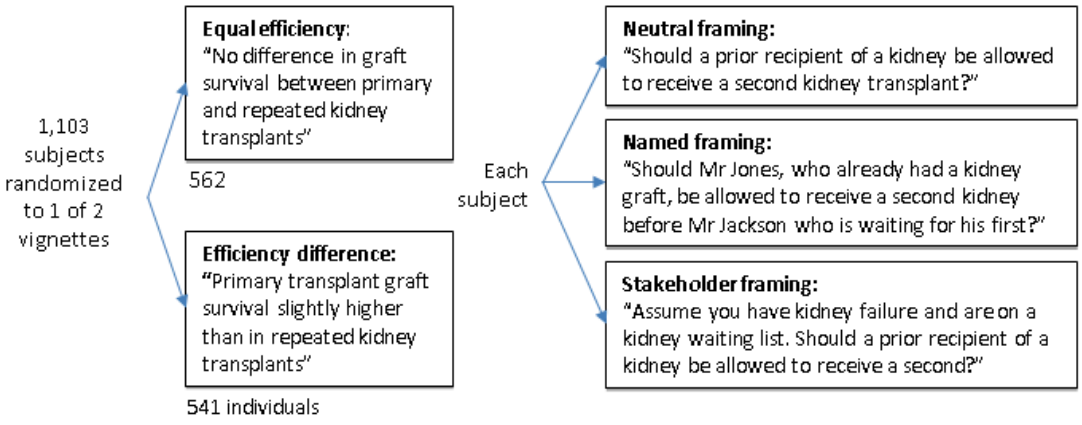
Participants designated their preferences and stated their free text rationales for a choice between two back-to-back raffle designs that involved 10 hypothetical participants. The only difference between the two designs is that the winner of the first raffle did or did not participate in the second. In the first raffle of each design, each hypothetical participant has a 1 in 10 chance of winning a $100 prize. Allowing participation of the winner would result in an identical second raffle. However, choosing to exclude the prior winner would result in each remaining participant having a 1 in 9 chance of winning $100 in the second raffle. The expected payoff in either hypothetical design is equivalent, but the variance is lower in the exclusion design reflecting the less risky nature of sampling without replacement. Each subject was asked to state their preference over raffle designs both as a hypothetically implicated *stakeholder* (him or her and nine other players) and as a hypothetically impartial *spectator* (10 other players not including subject). The order of the two framings was presented randomly across subjects.

2.2 Survey in individuals without end-stage renal disease

Second, we conducted an online survey from an extensive national compensated panel maintained by Clear Voice Research which was compensated by the authors for access to the panel and administration of the survey. Of 453,121 total possible panelists, we targeted a subgroup of 171,173 (38%) meeting age, health, and ethnicity characteristics and oversampling older panelists with chronic conditions (see Supplementary Table S1). Of these, Clear Voice Research randomly invited 29,148 to participate in the survey and rolling recruitment continued until our target of 1,100 respondents had been reached or exceeded. A total of 1,103 responses were obtained.

All subjects received information on ESRD and treatment options and were randomized to receive one of two vignettes. The "Equal efficiency" one stated that no difference in graft survival rates existed between primary and repeated transplants. The "Efficiency difference" one stated that a transplanted kidney would survive slightly longer in a patient receiving a primary transplant than in a patient receiving a second transplant. The difference in the vignettes reflects prior theoretical and empirical evidence that subjects may prefer equity in distribution of healthcare resources even at small costs in efficacy (Ubel and Loewenstein, 1995; Ratcliffe, 2000).**Error! Bookmark not defined.,Error! Bookmark not defined.** Both vignettes stated that the waiting list for donor kidneys was long, and that a patient receiving a second kidney graft likely meant that a patient in need of a primary graft would go without.

Figure 1: Randomization of subjects to vignettes and presentation of framings



Each subject was asked their preference for allowing repeat kidney grafts under three different framings presented in random order (Figure 1). In the *neutral* framing each

subject was asked whether a prior recipient of a graft should be allowed to receive a second kidney transplant. In the *named individual* framing each subject was asked if an arbitrarily named 'Mr Jones' should be allowed to receive a second kidney transplant before an arbitrarily named 'Mr Jackson' with identical health status waiting for a primary graft.

Under a *stakeholder* framing the subject was instructed to assume he or she had kidney failure and was on the waiting list to receive a transplant. The subject was then again asked whether a prior recipient of a graft should be allowed to receive a second kidney transplant. After each answer of 'yes' or 'no' a different web-based screen allowed panelists to choose one of six possible researcher-selected reasons for their choice.

2.3 Survey of dialysis patients

Third, an in-person survey eliciting preferences for allowing repeated renal transplantation grafts among ESRD patients was conducted at a dialysis clinic operated by DaVita. The authors compensated DaVita Clinical Research for administrative expenses involved in the study. A DaVita-employed research associate trained in clinical research and certified by DaVita's Clinical Research division conducted in-person interviews with dialysis patients receiving care at DaVita Durham over an eight-hour period spanning two days and two daytime shifts. The DaVita research associate received additional compensation from the authors on the basis of a small fee per recruited patient from DaVita Clinical Research for his research assistance, beyond his regular compensation for patient care at the dialysis center.

Of all 68 patients receiving hemodialysis on those days, one declined participation, and two were unable to respond due to intercurrent medical conditions. The remaining 65 gave informed consent to an anonymous survey not impacting their current/future treatment. Subjects were individually interviewed in private during their dialysis treatment and were asked whether someone who had already had a kidney transplant once should be allowed to receive another one.

The DaVita research associate read the survey to patients and then captured verbal responses by hand. Each patient viewed completed responses for confirmation and was not compensated for their participation. Interviewees were explained that the question was to be answered in general terms, as opposed to applying to them individually. Subjects were advised that the answers were anonymous without impact on their own treatment or treatment options.

2.4 Analytic Strategy

Statistical analyses were limited to testing the significance of differences in the proportions of respondents preferring to allow or disallow repeated kidney grafts using χ-squared tests. We tested whether different framings of the question led to differences in response by the same subject using McNemar tests of symmetry. Finally, a Kruskal-Wallis test was used to understand whether there were any significant differences between survey respondents randomized to the Equal efficiency vignette or the Efficiency difference vignette. Analysis was performed using Stata/SE software, version 10.1 (Stata Corp; College

Station, Texas). All analyses were 2-tailed. No adjustments for multiple comparisons were made (Rothman, 1990). We considered all *P*-values <.05 to be statistically significant.

3 Results

3.1 Survey without medical context

The survey without medical context showed a strong preference for exclusion of a prior winner in a subsequent raffle (Table 1). In the stakeholder framing, 71% of the respondents preferred the exclusion design (p<.001) while 74% preferred exclusion under the spectator framing (p<.001).

Table 1: Context-free pilot survey on inclusion/exclusion of prior winners in a repeat raffle

	Question framing (no., %)	
Choice	Spectator	Stakeholder
Include 1st winner to take part in 2nd raffle, because of	38 (25.2)	44 (29.1)
Statistical reasons†	11 (7.3)	21 (13.9)
Fairness reasons‡	11 (7.3)	7 (4.6)
Unclear or no reason given	16 (10.6)	17 (11.3)
Exclude 1st winner to take part in 2nd raffle, because of	110 (72.8)	107 (70.9)
Statistical reasons†	83 (55.0)	78 (51.7)
Fairness reasons‡	19 (12.6)	14 (9.3)
Unclear or no reason given	12 (7.9)	17 (11.3)
Missing response	3 (2.0)	0 (0.0)
Total	151	151

N = 151 individuals, each asked twice under different questionnaire framing. Sub-totals of counts of rationales may exceed sub-totals of counts of choices as subjects appealing to both statistical reasoning as well as fairness reasoning are counted in both rows.
† Coded as use of any of the following: expected value, expected return, average return, better off, expected payout, expected winnings, expected payoff, expectation, odds, better shot, probability, distribution, fewer people, more likely, likelihood, better opportunity.
‡ Coded as use of any of the following: fair, unfair, equity, equitable, right thing to do, appropriate, moral, share.

Of the 148 subjects who completed the survey under both framings, 20% did not change their preference for inclusion while 67% did not change their preference for exclusion (Supplementary Table S2). A McNemar test of symmetry (χ^2 = 0.47, 1 d.o.f.; p =.49) indicated no significant difference in the proportion of subjects choosing inclusion between the two framings.

3.2 Survey in individuals without end-stage renal disease

A total of 562 (51%) of 1,103 respondents in the Clear Voice survey were randomized to the Equal Efficiency vignette. Under the neutral framing (Table 2, first column), there was a strong preference for allowing repeat grafts (74%, p<.001). Fairness towards the repeat graft candidate or the primary graft candidate were the most common stated rationales.

In the framing which named individuals this preference was reversed (Table 2, center column). Here 72% of respondents chose not to allow Mr. Jones a second graft while Mr. Jackson had not received his first (p<.001). Of the 561 subjects who fully completed the survey, 26% preferred allowing repeat grafts under both framings while 24% preferred not allowing repeat grafts under both framings (Table 3a). A significant plurality (48%,

p<.001) of the respondents switched preferences from 'allow' to 'do not allow' across the two framings.

Table 2: Preferences, rationales for allowing 2nd kidney grafts in 'equal efficiency' vignette of survey of individuals without end-stage renal disease

	Question framing (no., %)		
Choice	"Should 2nd grafts be allowed?"	"Should Mr Jones receive a 2nd graft before Mr Jackson receives a 1st graft?"	"You have ESRD. Should 2nd grafts be allowed?"
Allow, because	414 (73.7)	155 (27.6)	345 (61.4)
It's not fair to exclude anyone	191 (34.0)	55 (9.8)	177 (31.5)
We owe it to them to make it right	25 (4.4)	28 (5.0)	25 (4.4)
Someone else would be just as sick or old	9 (1.6)	7 (1.2)	17 (3.0)
He/she could get same out of life as another	127 (22.6)	49 (8.7)	83 (14.8)
The kidney will do just as well/last just as long	17 (3.0)	7 (1.2)	13 (2.3)
No reason given	44 (7.8)	9 (1.6)	30 (5.3)
Missing	1 (0.2)	0 (0.0)	0 (0.0)
Do not allow, because	148 (26.3)	406 (72.2)	217 (38.6)
It's not fair to others who never received one	113 (20.1)	329 (58.5)	174 (31)
Doctors have done their best already	5 (0.8)	13 (2.3)	10 (1.8)
Someone else is probably younger/less sick	5 (0.8)	10 (1.8)	3 (0.5)
Someone else could get more out of extra life	9 (1.6)	12 (2.1)	8 (1.4)
The kidney won't do as well/last as long	2 (0.4)	8 (1.4)	7 (1.2)
No reason given	14 (2.5)	34 (6.0)	15 (2.7)
Missing	0 (0.0)	0 (0.0)	0 (0.0)
No preference selected	0 (0.0)	1 (0.2)	0 (0.0)
Total	562	562	562

N = 562; vignette stated that graft failure would not differ across candidate types.

Under the stakeholder framing which supposed the respondent had ESRD and was himself or herself on the waiting list for a donor kidney (Table 2, right column), there was a strong preference for allowing repeat grafts (61%, p<.001). A McNemar test showed a significantly larger proportion of respondents (Table 3b) preferred to allow a 2nd graft under this framing than under the framing which named graft candidates (p<.001).

Table 3a: Within-subject changes in survey (neutral versus named framings) in 'equal efficiency' vignette of survey of individuals without end-stage renal disease

		Framing: "Should Mr Jones receive a 2nd graft before Mr Jackson receives a 1st graft?"		
		Allow	Do not allow	Total
Framing: "Should 2nd grafts be allowed?"	Allow	144 (25.7)	269 (47.9)	413 (73.6)
	Do not allow	11 (2.0)	137 (24.4)	148 (26.4)
	Total	155 (27.6)	406 (72.4)	561

N = 561 (excludes blank responses), equal efficiency vignette. Number (percentage) displayed

Of the 541 panelists in the Clear Voice survey who were randomized to the Efficiency Difference vignette (Supplementary Table 3), results were qualitatively similar to those randomized to the Equal Efficiency vignette albeit with slightly more support for 'do not allow' under each framing. A Kruskal-Wallis test grouping the 1,102 completed responses by vignette viewed revealed no significant difference between the two vignettes in their responses under the general framing (p = 0.53) nor the framing which assumed the respondent had ESRD (p=0.38) either in preferences or stated rationales.

Table 3b: Within-subject changes in survey (named versus stakeholder framings) in 'equal efficiency' vignette of survey of individuals without end-stage renal disease

		Framing: "Suppose you have ESRD. Should 2nd grafts be allowed?"		
		Allow	Do not allow	Total
Framing: "Should Mr Jones receive a 2nd graft before Mr Jackson receives a 1st graft?"	Allow	136 (24.2)	19 (3.4)	155 (27.6)
	Do not allow	208 (37.1)	198 (35.3)	406 (72.4)
	Total	344 (61.3)	217 (38.7)	561

N = 561 (excludes blank responses), equal efficiency vignette. Number (percentage) displayed

3.3 Survey of dialysis patients

Of the DaVita dialysis patients a slight majority was male (58%), median age was 57 years (interquartile range [IQR]: 49 to 64 years; range: 27 to 93), median time on dialysis was 3 years (IQR: 1.5 to 8 years; range: 1 month to 20 years), and 4.6% of interviewees were past recipients of renal grafts. A total of 34% were currently on the kidney transplantation waiting list with median waiting time of 1 year (IQR: 1.6 to 3 years; range: 1 month to 6 years).

The results of the in-person survey administered to DaVita dialysis patients were similar to but stronger than the Clear Voice survey results under the stakeholder framing. A total of 57 (88%) preferred to allow repeat kidney grafts ($p<.001$), while 6 (9%) stated that someone who had already had one transplant should not be allowed to receive one and 2 declined to state a preference. The Da Vita survey was not adequately powered to detect bivariate differences in response by age, gender, retransplant or waiting list status.

In unreported analysis, a multivariable logistic regression of gender, length of treatment, age, and waiting list status on response choice had pseudo R^2 of 0.29 and a C-statistic of 0.88. Entered continuously, only age was significantly associated with response choice with increasing age reduced the odds of choosing to allow second grafts (odds ratio 0.87; 95% CI 0.77-0.98).

4 Discussion

Our study found that subjects preferred to exclude prior winners from further opportunities to win, in a hypothetical pair of raffles without medical context. In contrast, we found that subjects without ESRD preferred to allow repeat kidney grafts when asked in neutral terms. These preferences were expressed after receiving unambiguous briefing information about the opportunity costs of giving a scarce organ to any one candidate. The study demonstrated a smaller majority in favor of allowing repeat kidney grafts when subjects were asked to suppose that they had ESRD and were on a waiting list. In the latter framing considerations of equity may have been balanced with considerations of one's own future needs (Huesch and Brady, 2010).

We found a marked preference reversal when subjects without ESRD were asked to choose between two named individual candidates. A significant majority of respondents preferred not to allow the named secondary candidate to have a repeat graft before the named primary candidate. These results were unexpected, and not easily linked to prior empirical evidence of an 'identifiable victim effect' (Jenni and Lowenstein, 1997), and a 'rule of rescue' favoring repeated interventions on patients especially when these are identified individuals (Ubel, Arnold, and Caplan, 1993; McKie and Richardson, 2003). We

conjecture that framing the question in such a way that both options were an identifiable individual blunted the effect of the 'rule of rescue'.

Results were similar regardless of the vignette's claims of similar or worse graft failure rates among retransplants; implying that subjects did not noticeably trade off equity in distribution for graft efficiency (Bleichrodt, Doctor, and Stolk, 2005). Finally, regardless of transplant or waiting list status, subjects with ESRD overwhelmingly supported allowing retransplants, in line with current organ transplant guidelines. Prior research differs as to how closely patients agree (Louis, Sankar and Ubel, 1997) or disagree (Geddes et al, 2005) with such guidelines. Had a 'present bias' existed in these choices (Loewenstein and Prelec, 1993), towards shorter waiting times, patients might have been expected to prefer not to allow repeat transplants since these would delay their own surgeries. Instead, our findings are consistent with ESRD patients' considering their own ultimate future needs which may include a repeat graft.

Kidney organ allocation rules currently *seek* to offer equality of opportunity to repeat and first-time kidney graft candidates, conditional on same medical need. In particular, kidney re-transplantation status does not currently affect the waiting-time oriented prioritization of renal grafts, independently of its impact on sensitization(OPTN, 2011; Mayer and Persijn, 2006).

In the US, these rules are administered by the United Network for Organ Sharing, the private organization that managed organ waiting lists in the US. The rules implement the federal Department of Health and Human Services' Final Rule. These rules impact large numbers of patients. At the end of 2012, more than 94,000 patients with ESRD were waiting for a kidney graft, yet in 2011 a little less than 17,000 kidney transplants took

place. Median waiting times for a kidney are between 3-5 years and for adults the percentage of patients still waiting for a transplant two years following registration ranges from 70-80% (OPTN, 2012). With a graft, survival is 85% through 5 years (OPTN, 2012). Without a graft, patients face a 20% chance of death each year on dialysis (USRDS, 2012; CKDPC, 2010).

Given absolute scarcity, indivisibility, and higher demand than supply, such *aggregate* outcomes would be expected even under the best possible *individual* allocation regime. They could be acceptable if the current allocation rule were egalitarian, and consistent with egalitarian preferences in society.

Yet our study suggests that these attributes may not be met. The current system does not appear truly egalitarian, as certain subsets of patients such as the aged are far less likely to receive a deceased donor transplant (Schold et al, 2009), while failed transplant candidates must re-earn seniority on the waiting list (OPTN, 2011). The surveyed preferences of the participants in this study were not consistently egalitarian either. While majorities of individuals without ESRD state that repeat kidney transplants should be allowed, a large majority stated that a named individual who had already had a graft should not have one before another named individual who'd not yet had one.

If societal preferences were indifferent between primary and repeat candidates, then equality of opportunity might be better served through lotteries. Probabilistic allocations have the added virtue of dominating deterministic allocations for risk-averse individuals (Taylor, Tsui, and Zhu, 2003). On the other hand, if societal preferences were towards favoring first time or favoring repeat transplants, then the current waiting time prioritization ill serves either preference. Requiring re-accrual of waiting time seniority is a

bias against retransplant candidates. Performing approximately one in nine transplant surgeries on retransplant candidates (OPTN, 2012), is a bias against primary candidates.

This study had a number of important limitations. The results were limited by its reliance on convenience samples which can only imprecisely represent national preferences for the allocation of scarce medical resources. This limitation renders these findings more hypothesis-generating than hypothesis-confirming. This is especially germane in our small study of dialysis patients. However, patients' preferences are arguably important inputs in the allocation process (Ahn and Hornberger, 1996; Freeman et al, 2009).

A related limitation is that the preferences of the general public were also elicited in a process which abstracted from many important clinical and other factors which impact the allocation decision. The views of transplant surgeons, nephrologists and other medical providers, care-givers and relatives were not captured. Yet it is members of the general public that form the pool of potential cadaveric organs, and as such are interested parties. To the extent that the supply of donor organs critically depends on the public's trust that equitable measures will be used in the distribution (Guttman, 1996), surveys such as ours may help to inform organ allocation procedures.

Our study has also ignored black market, price-based mechanisms which allocate kidneys to a subset of privileged patients. The World Health Organization estimates 5% of the 66,000 kidney transplants performed globally involve the sale/purchase of a human organ (Shimazono, 2005). Such black markets interact indirectly with ethical transplant centers in purchasers' home countries due to the need for after-care (Ambagtsheer et al, 2012). More directly, given the long and growing waiting lists in developed countries for

kidney transplants, future use of such black markets by developed world patients may increase.

Finally, as opposed to absolute scarcity, relatively scarce resources have their supply is limited only by decisions on how many financial inputs to apply (Kock, 1996). An ICU bed or chemotherapy is a relatively scarce resource often in short supply in the short run. The consequences for hospitalized patients of a full ICU include changes in treatment goals e.g. to comfort care (Stelfox et al, 2012). Decisions of how to deal with chemotherapy availability resemble the ethical difficulties faced with dealing with absolutely scarce and indivisible resources (Rosoff et al, 2012). Nevertheless, our study is silent as to the ethics of, and preferences for, allocating relatively scarce resources. Further elucidation of such preferences seems desirable.

Donor kidneys are absolutely scarce and indivisible; their allocation is a difficult and often controversial decision (ASTS, 2008). Current guidelines strive for equality of opportunity between those who have not, and those who have already received a kidney graft. This study suggests that such egalitarianism is not consistently reflected in the preferences of those with and without end stage renal disease. Members of the general public are the ultimate sources of cadaveric and living donor kidneys. Future studies and more public discussion on the perceived fairness of allowing retransplants ahead of primary transplant candidates nevertheless seems warranted; incorporating the resulting preferences into organ allocation rules seems desirable.

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Supplemental Material

Table S1: Within-Subject Preference Changes in Context-Free Survey (Spectator versus Stakeholder Framings)

Table S2: Clear Voice Target Group Demographics and Response Summary

Table S3: Preference, Rationale for Allowing 2nd Kidney Grafts in 'Efficiency Difference' Vignette

Appendix Material: Survey Instruments

Table S1: Within-Subject Preference Changes in Context-Free Survey (Spectator versus Stakeholder Framings)

		Framing: "Suppose 10 people are taking part in two raffles. Should the first winner be allowed to take part in the 2nd raffle?"		
		Allow	Do not allow	Total
Framing: "Suppose you and 9 other people are taking part in two raffles. Should the first winner be allowed to take part in the 2nd raffle?"	Allow	30 (20.3)	11 (7.4)	41 (27.7)
	Do not allow	8 (5.4)	99 (66.9)	107 (72.3)
	Total	38 (25.7)	110 (74.3)	148

N = 148 (excludes blank responses), each asked 2 times under different framing

Table S2: Clear Voice Target Group Demographics and Response Summary

Group description (age, ethnicity, medical condition)	Available (no., % total enrolled)[a]	Targeted (no., % available)	Invited	Final responses (no., %)	Response rate (%)[b]
35-54, African American	10 402 (2.3)	50 (4.5)	1 100	51 (4.6)	4.6
Hispanic	4 860 (1.1)	50 (4.5)	1 100	53 (4.8)	4.8
Asian/Pacific Island/Native Am	3 800 (0.8)	50 (4.5)	1 100	53 (4.8)	4.8
Diabetic	3 114 (0.7)	50 (4.5)	1 100	52 (4.7)	4.7
Hypertension	4 986 (1.1)	50 (4.5)	1 100	50 (4.5)	4.5
Heart Disease/Heart Ailment	1 139 (0.3)	50 (4.5)	530	51 (4.6)	9.6
35-54[c]	71 542 (15.8)	250 (22.7)	5 000	258 (23.4)	5.2
55+, African American	4 995 (1.1)	50 (4.5)	1 100	50 (4.5)	4.5
Hispanic	906 (0.2)	50 (4.5)	906	23 (2.1)	2.5
Asian/Pacific Island/Native Am	946 (0.2)	50 (4.5)	945	47 (4.3)	5.0
Diabetic	3 643 (0.8)	50 (4.5)	1 100	51 (4.6)	4.6
Hypertension	6 044 (1.3)	50 (4.5)	1 100	51 (4.6)	4.6
Heart Disease/Heart Ailment	2 249 (0.5)	50 (4.5)	967	52 (4.7)	5.4
55+[c]	52 547 (11.6)	250 (22.7)	12 000	260 (23.6)	2.2
Total	171 173 (37.8)	1 100	29 148	1 102 (100)	3.8

[a] Percentage of total 453,121 panelists enrolled at the time of survey

[b] Number of responses/number of invited panelists

[c] Any ethnicity, with or without any medical condition

Table S3: Preference, Rationale for Allowing 2nd Kidney Grafts in 'Efficiency Difference' Vignette

Choice	Question framing (no., %)		
	"Should 2nd grafts be allowed?"	"Should Mr Jones receive a 2nd graft before Mr Jackson receives a 1st graft?"	"You have ESRD. Should 2nd grafts be allowed?"
Allow, because	386 (71.3)	131 (24.2)	315 (58.2)
It's not fair to exclude anyone	159 (29.4)	39 (7.2)	150 (27.7)
We owe it to them to make it right	41 (7.6)	36 (6.7)	37 (6.8)
Someone else would be just as sick or old	11 (2)	7 (1.3)	20 (3.7)
He/she could get same out of life as someone else	109 (20.1)	28 (5.2)	61 (11.3)
The kidney will do just as well/last just as long	16 (3.0)	7 (1.3)	13 (2.4)
No reason given	50 (9.2)	14 (2.6)	34 (6.3)
Missing	0 (0.0)	0 (0.0)	0 (0.0)
Do not allow, because	154 (28.5)	406 (75)	225 (41.6)
It's not fair to others who've never received one	103 (19)	298 (55.0)	171 (31.6)
Doctors have done their best already	7 (1.3)	16 (3.0)	8 (1.5)
Someone else is probably younger and less sick	2 (0.4)	10 (1.8)	3 (0.6)
Someone else could get more out of the extra life	12 (2.2)	14 (2.6)	4 (0.7)
The kidney won't do as well/last as long	18 (3.3)	43 (7.9)	20 (3.7)
No reason given	12 (2.2)	24 (4.4)	19 (3.5)
Missing	0 (0.0)	1 (0.2)	0 (0.0)
No preference selected	1 (0.2)	4 (0.7)	1 (0.2)
Total	541	541	541

N = 541, no overlap with "Equal efficiency" sample. Each asked 3 times under different framing. Vignette stated that a graft would fail slightly earlier in a secondary graft candidate.

Survey 1: Qualtrics panel survey instruments

Stakeholder framing

Suppose you and 9 others will take part in a pair of raffles. You prefer which design?

Design A:

In one raffle you have a 1/10 chance to win $100, followed by another raffle in which you again have a 1/10 chance to win $100.

Design B:

In one raffle you have a 1/10 chance to win $100. If you didn't win, you have another raffle in which you now have a 1/9 chance to win $100.

Briefly, any reason why?

Spectator framing

Suppose 10 other people — not including you — will take part in a pair of raffles. You prefer which design?

Design A:

In one raffle everyone has a 1/10 chance to win $100, followed by another raffle in which everyone again has a 1/10 chance to win $100.

Design B:

In one raffle everyone has a 1/10 chance to win $100. For the nine who didn't win, they have another raffle in which everyone now has a 1/9 chance to win $100.

Briefly, any reason why?

Survey 2: Clear Voice panel survey introductions and instruments

Equally Efficient introduction (randomly shown to approximately half of participants)

How do you feel about the rules of organ transplantation? Let's start with some detail about why people need kidney transplants:

People whose kidneys have failed will die without dialysis or a kidney transplant. Dialysis washes the blood several times a week in a clinic for a few hours at a time.

On the other hand, a kidney transplant is an operation in which a person receives a new kidney to take over the work of cleaning the blood. Transplantation is a better option than dialysis: better quality of life and better chance of survival.

But there's a long waiting list for a transplant. Many people on the waiting list will die while getting dialysis, before ever getting a transplant.

Even those who do get a transplant may end up having that new kidney fail after a few years. They will then need dialysis again, or need another transplant.

Today, we want to get your opinion on the rules for those seeking another kidney transplant after their first one failed. Here's a little more detail that might be useful:

A transplanted kidney will do just as well in someone who's getting their first one as in someone who's getting their second one if the patients are otherwise the same (same medical status, blood type, etc.).

But remember, there is a waiting list for kidneys. If someone gets a second kidney transplant, it means that someone else missed out that time. The person who missed out was probably waiting for their first kidney, and is now going to have to wait longer for their turn.

So, how do you feel about allowing a second chance at a kidney transplant to those whose first kidney transplant failed? *We are going to ask you this a few different ways. Each time, please assume the described scenario is true for you:*

Survey 2: (continued) Clear Voice panel survey introductions and instruments

Efficiency Difference introduction (randomly shown to approximately half of participants)

How do you feel about the rules of organ transplantation? Let's start with some detail about why people need kidney transplants:

People whose kidneys have failed will die without dialysis or a kidney transplant. Dialysis washes the blood several times a week in a clinic for a few hours at a time.

On the other hand, a kidney transplant is an operation in which a person receives a new kidney to take over the work of cleaning the blood. Transplantation is a better option than dialysis: better quality of life and better chance of survival.

But there's a long waiting list for a transplant. Many people on the waiting list will die while getting dialysis, before ever getting a transplant.

Even those who do get a transplant may end up having that new kidney fail after a few years. They will then need dialysis again, or need another transplant.

Today, we want to get your opinion on the rules for those seeking another kidney transplant after their first one failed. Here's a little more detail that might be useful:

A transplanted kidney will do a little better (last longer before failing) in someone who's getting their first one than in someone who's getting their second one if the patients are otherwise the same (same medical status, blood type, etc.).

And remember, there is a waiting list for kidneys. If someone gets a second kidney transplant, it means that someone else missed out that time. The person who missed out was probably waiting for their first kidney, and is now going to have to wait longer for their turn.

So, how do you feel about allowing a second chance at a kidney transplant to those whose first kidney transplant failed? *We are going to ask you this a few different ways. Each time, please assume the described scenario is true for you:*

Survey 2: (continued) Clear Voice panel survey introductions and instruments

Spectator I framing – asked to each subject after viewing one of previous introductions

You don't have kidney failure and you don't know anyone who does.

Should people be allowed to get a second kidney transplant?

Which best describes the reason for your choice?

__ Yes, because it's not fair to exclude anyone

__ Yes, because we owe it to them to make it right

__ Yes, because someone else would be just as sick or just as old

__ Yes, because the person getting the kidney could get more or just the same out of life as someone else

__ Yes, no reason given

__ Yes, because the kidney will do just as well/last just as long

__ No, because it's not fair to other who've never received a kidney

__ No, because doctors have done their best already

__ No, because someone else is probably younger and less sick

__ No, because someone else could get more out of the extra life

__ No, because the kidney won't do as well/last as long

__ No, no reason given

Spectator II framing – asked to each subject after Spectator I framing

You don't have kidney failure and you don't know anyone who does.

Should Mr. Jones, whose first kidney transplant failed, be allowed to get another before Mr. Jackson whose never received one and has the same health and medical status?

Which best describes the reason for your choice?

__ Yes, because it's not fair to exclude anyone

__ Yes, because we owe it to them to make it right

__ Yes, because someone else would be just as sick or just as old

__ Yes, because the person getting the kidney could get more or just the same out of life as someone else

__ Yes, no reason given

__ Yes, because the kidney will do just as well/last just as long

__ No, because it's not fair to other who've never received a kidney

__ No, because doctors have done their best already

__ No, because someone else is probably younger and less sick

__ No, because someone else could get more out of the extra life

__ No, because the kidney won't do as well/last as long

__ No, no reason given

Survey 2: (continued) Clear Voice panel survey introductions and instruments

Stakeholder framing – asked to each subject after Spectator II framing

You have kidney failure, are currently being treated with dialysis, and are on the waiting list to receive a kidney transplant.

Should people be allowed to get a second kidney transplant?

Which best describes the reason for your choice?

__ Yes, because it's not fair to exclude anyone

__ Yes, because we owe it to them to make it right

__ Yes, because someone else would be just as sick or just as old

__ Yes, because the person getting the kidney could get more or just the same out of life as someone else

__ Yes, no reason given

__ Yes, because the kidney will do just as well/last just as long

__ No, because it's not fair to other who've never received a kidney

__ No, because doctors have done their best already

__ No, because someone else is probably younger and less sick

__ No, because someone else could get more out of the extra life

__ No, because the kidney won't do as well/last as long

__ No, no reason given

Survey 3: DaVita survey instrument administered to DaVita dialysis patients

Your opinion is important to us, but you don't have to take part in this survey.

Please do not write your name or any other identifying information on this form.

(All participants will remain completely anonymous. We will not contact participants further. Your responses have no impact on future eligibility to receive any medical treatments or procedures.)

Thank you for answering these questions. There is no right or wrong answer.

Q1: What is your gender? Male / Female *(please circle one)*

Q2: What is your age? _____*(years)*

Q3: Which type of treatment are you currently receiving?

Hemodialysis / Peritoneal Dialysis *(please circle one)*

Q4: How long have you been receiving dialysis treatment? _____*(years)*

Q5: Are you the past recipient of a kidney transplant?

Yes / No *(please circle one)*

Q6: Are you currently on the kidney donation waiting list?

Yes / No *(please circle one)*

Q7: In your opinion, should someone who has already had a kidney transplant once be allowed to receive another one?

Yes / No *(please circle one)*

Why? _____