



Published in final edited form as:

*Am J Transplant.* 2011 November ; 11(11): 2317–2321. doi:10.1111/j.1600-6143.2011.03726.x.

## Rational Rationing or Discrimination: Balancing Equity and Efficiency Considerations in Kidney Allocation

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### Abstract

After six years of deliberation, the Organ Procurement and Transplantation Network recently released a concept document proposing changes to the kidney allocation algorithm, sparking a heated debate about priority-setting of scarce health resources and discrimination. Proponents of the proposal argue that it will result in an additional 15,223 life years following transplant annually for recipients, yet the benefit will not be equally distributed and will likely benefit younger patients. Critics argue the new model will promote age discrimination and may lead to a further decrease in live kidney donation. If true, these concerns could undermine fairness and damage public trust in the organ allocation system. We address these objections and consider their merit, highlighting both benefits and shortcomings of the proposal. We argue that, despite weaknesses of the proposal and the importance of maintaining consistency in patient and provider expectations over time, the proposal represents a needed first step in balancing equity and efficiency.

### Keywords

Kidney transplantation; allocation; ethics; age discrimination

### Introduction

Nearly 85,000 people are waitlisted for a kidney transplant in the United States, with the median waiting time exceeding three years (1). Kidney transplantation is the most cost-effective treatment for ESRD and leads to improved survival and quality of life (2, 3). Although demand for kidneys has increased annually, the supply of deceased and live kidney donations has declined since 2007 and 2004, respectively, exacerbating the shortage and the need for rationing (4). While domestically, health care is implicitly rationed based on price and availability, kidney transplantation presents a rare and salient example of natural scarcity requiring explicit rationing of life-saving treatment.

After six years of deliberation, the Organ Procurement and Transplantation Network (OPTN) recently released a concept document proposing changes to the kidney allocation

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#### DISCLOSURES:

The authors of this manuscript have no conflicts of interest to disclose as described by the American Journal of Transplantation. KL is in the 18–49 age group that would be advantaged by the proposed changes whereas DWH is in the >50 age group that would be disadvantaged. The authors have no other disclosures.

algorithm, sparking a heated debate about priority-setting of scarce health resources and discrimination (5, 6). This proposal aims to address three main concerns about the existing allocation system: (1) waste (discarding of potentially usable kidneys); (2) inefficiency (mismatch in lifespan of kidney and recipient); and (3) inequity (variability in access to transplantation according to blood group, race/ethnicity, pediatric candidate, geography, and pre-sensitization) (6). If adopted, the proposal would institute three major changes: (1) utilize a kidney donor profile index (KDPI) to estimate the expected function of a kidney transplanted into an average recipient; (2) allocate the best 20% of kidneys (KDPI $\leq$ 20%) to the 20% of candidates with the highest estimated post-transplant survival (EPTS); and (3) allocate the remaining 80% of kidneys by age-matching whereby candidates within 15 years of the donor (older and younger) are given priority. These are marked deviations from the current algorithm where priority is largely assigned by time on the waiting list (i.e. first come, first served). This paper will not address the accuracy of the OPTN modeling, rather it will address underlying ethical concerns and implications stemming from changing the current allocation algorithm.

Proponents of the proposal argue that it will result in an additional 15,223 life years following transplant annually for recipients, significantly increasing the average lifespan per transplanted organ from 4.9 to 5.4 years. However, benefit will not be equally distributed. Patients aged 18 to 49 years and patients with glomerulonephritis would receive a greater proportion of deceased-donor kidneys and kidneys with a lower KDPI. These gains would come at the expense of patients over the age of 50 years, diabetics, and presensitized patients. Critics argue the new model will promote age discrimination and may lead to a further decrease in live kidney donation. If true, these concerns could undermine fairness and damage public trust in the organ allocation system (7). Below, we address these objections and consider their merit, highlighting both benefits and shortcomings of the proposal. Finally, we argue that, despite weaknesses of the proposal and the importance of maintaining consistency in patient and provider expectations over time, the proposal represents a needed first step in balancing equity and efficiency.

### **Age discrimination versus. fair innings**

Some bioethicists and transplant experts have suggested that the proposal amounts to age discrimination, disadvantaging patients who could benefit significantly from transplantation due to a morally and often clinically irrelevant factor such as age (7, 8). The Institute of Medicine defines disparities as an unfair treatment of patients on the basis of irrelevant traits, such as race or ethnicity, and discrimination as a provider supplying lesser care due to clinically irrelevant characteristics, such as race/ethnicity or gender (9). Critics of the proposal argue that, similar to race, age is clinically irrelevant, because many healthy 50 year olds could benefit equally from the 20 years of extra life. Thus, reducing the proportion of organs allocated to older adults is discriminatory.

Age, however, does not meet the IOM criteria like racial or gender discrimination because age is a medically relevant trait for promoting efficiency, and potentially, equity. According to OPTN estimates, age-matching and allocating the top 20% of kidneys to correspondingly high EPTS patients is likely to reduce inefficiency by increasing the probability that patients don't outlive their transplants and vice versa, prioritizing younger patients as a result (6). Age may also not meet IOM criteria because, unlike race or gender which are largely immutable criteria characterizing a person over the lifecycle, older age is considered to be a stage that, if lucky, all persons will experience. In fact, given shorter life expectancy and earlier onset of ESRD among racial minorities, disproportionate allocation of organs to older patients may be seen as disadvantaging minorities.

Some ethicists, relying on a conditional “fair innings” approach, suggest that prioritizing younger patients may enhance equity. They argue that prioritizing younger patients is more equitable, not because they are likely to benefit most, rather because they have not yet experienced their “fair innings”, meaning they have not yet had the opportunity to reach the same point in life as the older patient (10). “Fair innings” enhances equity by affording all patients the opportunity to achieve “...as much of a normal lifespan as possible...”, equalizing the opportunity of reaching a normal life expectancy *for patients of all age groups* (6). This approach is consistent with prior OPTN policies prioritizing pediatric (<18 years) patients, balancing the impact of organ failure on physical and mental development, and fair-innings considerations. While fair-innings cannot serve as a tiebreaker because no two candidates are identical, we suggest that fair innings should be considered together with criteria such as quality of life and prognosis.

Still, some have expressed efficiency concerns about preferentially allocating organs to younger patients who may be poor stewards of their organs (i.e. less compliant). For example, they question whether priority should be given to a teenager whose compliance is less predictable and whose social contributions and obligations may be less than a 50 year-old firefighter with a family of four. Common metrics such as social support, psychological profile, history of noncompliance, and current substance abuse are used to predict compliance and apply to all patients regardless of age. Compliance is a concern for patients of any age, including those with self-inflicted disease and/or organ failure (e.g. alcoholic cirrhosis, smoking-related cancer, etc.). The public and health care professionals have resisted using blame (let alone potential for abuse) as a legitimate criterion for allocation of resources, so long as the patient is willing to change the behavior or health care in general. Thus, concerns about non-compliance in younger patients should not drive allocation decisions.

### **Potential reduction in live donor kidney transplants in younger patients**

Critics argue that prioritizing younger patients may reduce the overall supply of organs because many potential live donors, who are more likely to donate to younger patients, may forgo donation due to the higher likelihood that younger ESRD patients will receive a high quality deceased donor kidney (8).

Ross and Thistlethwaite hypothesized that the decline in live donation to pediatric candidates between 2004–2006 resulted from national allocation policy changes that increased the priority of younger patients (<18 years) on the deceased donor waiting list (11). They suggested that relatives and friends of young patients who often donate decided against or postponed donating given the high likelihood that young patients would receive a good quality deceased donor kidney in a relatively short period of time and because of concern that they might need a second transplant sometime in the future. This raises two important questions: first, is it likely that the proposal’s attempt to prioritize younger patients will amount to an overall decrease in the total organ supply? Second, if likely, does this unintended consequence constitute an ethical reason not to prioritize younger patients?

The evidence presented is only a temporal correlation, thus it remains uncertain whether prioritization of younger patients will, in fact, lead to a decrease in organ availability. Modeling performed by the OPTN does not have sufficient data on live donation to include the impact of changes in the allocation of deceased donor kidneys on live kidney donation and collection of this data in future might be of value as further changes in allocation are considered. Even if parents or siblings are postponing donation to the future (at which point the minor will likely be in an older age bracket), it is possible that the organ pool will remain stable over the long-run, though it may be affected in the short-term. Furthermore, because

LDKT can be performed preemptively and has a longer half-life than even the best deceased donor kidney transplant (12), many donor-recipient pairs have much to gain from LDKT and may still opt for this option.

The unintended consequence of a decrease in live kidney donation in young patients does not present adequate justification to drop the proposed allocation changes. Not all patients have access to a live donor and so would not be equally affected, furthering the argument that effects on live donation that only would affect a subset of candidates should not determine a policy that affects all candidates (13).

### **Increased dependence on less available live donors for older patients**

Critics also argue that prioritizing younger patients may make older patients, who are potentially less likely to receive a live donor, more vulnerable and dependent on live donors as the availability of deceased donor kidneys decreases (14). Weng et al suggest that older candidates are currently less likely to have an available and willing live donor, although this may be a rational response to the existing allocation policies, and may be responsive to change (14). Since 1990, the proportion of 50–64 years olds receiving deceased donor transplants increased from 23 to 39%, and the proportion for those over 65 years old increased from 3–15% (6). During this time, older patients received a larger proportion of kidneys from younger donors due to low donation rates in older adults, lower utilization of kidneys from older donors, and higher demand from older patients due to population aging (6). Systemic barriers, such as reluctance among surgeons to transplant older or ECD kidneys for fear of lowering patient and graft survival rates (quality metrics used by payers), and reluctance among Organ Procurement Organizations (OPOs) to procure such kidneys due to difficulty in organ placement leading to prolonged cold ischemia times have resulted in high discard rates and more organs from young donors going to older patients (6, 15). Thus, for older candidates, waiting for a deceased donor as opposed to pursuing living donation may have been a rational response to the existing allocation policies, since chances were that they would receive an organ from a young donor and would not have a prolonged wait.

Decreasing the availability of kidneys (particularly younger kidneys) may force older patients to seek donors, potentially posing a unique set of obstacles. Donors may be reluctant to donate to older patients due to social perceptions that intergenerational transfers flow from older to younger (16). However, in many cultures the expectation that children will help their parents and grandparents in later life is equally strong, particularly with relation to time transfers and social support, and domestically, with respect to financing of public programs such as Medicare and Social Security (16). There is little evidence that live donors face a higher risk of kidney failure or other morbidity, and as such, there is no practical or ethical reason to think that donation should occur in one intergenerational direction over another (17). Potential repugnance with intergenerational transfers from young to old may be responsive to changes in incentives, in this case a greater relative need for older patients. Furthermore, repugnance associated with younger to older intergenerational transfers (particularly those related to medical need) may be, in part, attributed to a belief in “fair innings”, suggesting broader support for this ethical approach. On the other hand, it is hoped that utilization of the KDPI and changes in the allocation priorities will increase the retrieval and utilization of usable ECD kidneys in more appropriate older patients, thereby reducing the wastage and making more deceased donor kidneys available to older patients.

Even in the unlikely case that prioritizing younger patients will limit the organ supply, placing the collective burden of maintaining high donation rates on a single group, in this

case younger patients merely because they are easily identifiable is ethically problematic. Pinpointing a specific group as one that, if prioritized, might lead to systemic negative externalities places an undue burden on these patients. This is particularly troubling in LDKT because deprioritized patients are in a sense being punished for the action (or inaction of others), in that they themselves are not donors, but merely related to the donors. For example, since wives are often living donors, it seems reasonable that more wives might donate if husbands were deprioritized, resulting in positive systemic externalities. There may be many other groups that would respond similarly, but are difficult to identify (e.g. people with three siblings under the age of 30, people with large social networks, etc.). Deprioritizing a group merely because they are easily identifiable and because of their instrumental value in preserving the organ supply seems arbitrary and unfair, and should not be a criterion for organ allocation.

## Rationing, discrimination, and kidney allocation: Lessons for the health care system

Despite the negative public response to perceived rationing in the *Patient Protection and Affordable Care Act*, Americans have confronted rationing in the context of kidney transplantation. Resource allocation in transplantation may serve as an example for other areas of health care in that it has established a federal process inclusive of multiple stakeholders to explicitly ration based on well-defined criteria that have generally been accepted by the American public. Though rationing of health care has largely been obscured in policy debates by expanding supply through the continued increase in federal and private spending, this strategy is unsustainable and has resulted in skyrocketing health care costs over the past half-century (18). Worth noting, however, is that age-based rationing of health resources has been done with other public programs, such as SCHIP and Medicare, both of which have age-based eligibility requirements.

Public resources and public trust are essential to the functioning and sustainability of a deceased organ sharing network, because ESRD *patients* must be willing to be evaluated and waitlisted for life-saving treatment using common metrics and without using alternate sources (e.g. the black market), and *donors* must believe that organs donated into the system will be distributed fairly and efficiently (19). Organs donated from non-directed altruistic live donors and from deceased donors are entrusted into a public pool and therefore are public resources. Fairness, predictability, and transparency are critical to ensuring continued public participation. The transparent and iterative deliberative process of amending the algorithm for kidney allocation that balances equity and efficiency is central to public acceptance of rationing, and provides an important example for the broader health care system.

Unavoidably, in a zero-sum game, some will gain at the expense of others. The real question is: are proposed changes to allocation are system-enhancing by improving efficiency and equity, or are they discriminatory? Though the proposal may not adequately address disparities, it is difficult to argue that it increases discrimination using the Institute of Medicine definition that disparities indicate an unfair treatment of patients on the basis of irrelevant traits (9). Older patients will likely receive organs from older donors and may have to wait longer. Some also suggest that older patients are also more likely to die on the waiting list, and as a result should be given preference. While this may be true, urgency is currently not the central criteria in kidney allocation (in contrast to liver allocation). Instead, waiting time and suitability play a more significant role, and in this sense, the OPTN proposal does not introduce a new problem. It does attempt to equalize the opportunity for reaching a normal life expectancy *for patients of all age groups*. Older patients are closer to

normal life expectancy than younger, and as a result, have already enjoyed a longer life than younger patients.

## Persistent Disparities

Though the OPTN proposal presents a compelling approach to improving efficiency and enhancing equity, it does not go far enough in addressing racial/ethnic, geographic, or sensitization disparities. For example, while the median wait time for patients listed in 2010 is projected to reach 3.6 years, estimates range from 2.3 years for whites to 3.7 years for African Americans (20). Geographic disparities persist. Nationwide median wait times for adults transplanted in 2008 was 2.1 years while in a number of states the median exceeded three years, including Alabama and California, where median waits were 7.2 and 9.3 years, respectively (20). The proposal does not address the political or economic incentives, such as CMS quality ratings leading OPO and transplant centers to differentially reject organs that may be of use to some patients. The OPTN should also consider how to better match presensitized patients, perhaps incorporating paired donation. Given the iterative nature of the allocation algorithm, future steps should aim at increasing supply and redistributing across regions.

## Conclusions

The proposed changes in the allocation of deceased donor kidneys are likely to improve efficiency by matching the expected life span of the recipient and the kidney allograft by utilizing the KDPI and a change in allocation priorities. Better estimating a match between donor and graft longevity will hopefully reduce waste as more ECD and older kidneys are retrieved and allocated to older recipients (21). We believe that the fair innings argument provides a sound rationale for the proposed changes and balances equity and efficiency in a way that does not amount to age discrimination. Although a decline in live donations to young patients is possible, we believe this is unlikely because of the continued survival advantage of live donor kidneys and the need for second transplants. Furthermore, the burden of a potential future decline in organ donations should not be placed on a single subset of the patient population, and should not determine allocation policies that affect all patients. Older patients will need to pursue live donation more often or utilize more ECD kidneys, and while that may shift current norms, it does not constitute age discrimination.

## Acknowledgments

Funding Sources: The authors gratefully acknowledge support from the Julie Henry Research Fund and the Center for Transplant Outcomes and Quality Improvement in the Transplant Institute at Beth Israel Deaconess Medical Center (KL and DWH); and from the National Institute on Aging, through Grant Number T32 AG000186-22 to the National Bureau of Economic Research (KL).

## Abbreviation

**SCHIP** State Children's Health Insurance Program

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