Organ Offers and Utilization - Would Greater Transparency Improve Equity?

Sumit Mohan, MD, MPH
Associate Professor of Medicine & Epidemiology
Columbia University Irving Medical Center, NY
Disclosure

- Member, UNOS Data Advisory Committee
- Member, SRTR Visiting Committee
- Member, ASN Quality Committee
- Deputy Editor, Kidney International Reports
- Scientific Advisory Board, Angion Pharmaceuticals
Learning Objectives

• 1. Kidney offers are frequently being declined without patient participations
• 2. Declined offers adversely impacts equity and patient outcomes
• 3. Engaging patients in decisions will improve equity and utility
Medical Paternalism

Medical paternalism is a set of attitudes and practices in medicine in which a physician determines that a patient's wishes or choices should not be honored.

- These practices were current through the early to mid 20th century, and were characterized by a paternalistic attitude, surrogate decision-making and a lack of respect for patient autonomy.

- It is almost exclusively undertaken with the intention of benefiting the patient, although this is not always the case.
BACKGROUND
Comparison of 5-year survival rates by diagnosis
Comparing Graft survival rates with dialysis survival rates

Donor reference population: All deceased kidney donors recovered for transplant in 2016. Based on OPTN data including primary, adult, deceased donor, kidney alone transplants, as of April 20, 2018.

USRDS 2017 ADR

https://www.usrds.org/2017/view/v2_05.aspx
Patient preferences

prioritize wait time over posttransplant outcomes when selecting a transplant center

Only published national survey identifying patient centered criteria on selecting a transplant center
Over 500 respondents for survey conducted in 2017

Husain SA et al. Am J Transplant. 2018
Transplant centers don’t call patients with offers

Deceased Candidates receiving offers

- 2012: 627
- 2013: 740
- 2014: 767
- 2015: 778

% kidneys offered to a deceased patient

- 2012: 14%
- 2013: 16%
- 2014: 17%
- 2015: 18%

Median of 4 post-death offers (range 1-385, IQR 2-12).
Most (60.4%) offers to deceased candidates occurred >1 month after candidate death

Husain SA et al. Am J Transplant. 2018
King et al. in review

Graph showing the percentage of centers receiving HCV NAT+ offers over time from June 15 to June 19. The x-axis represents the months and years (June 15 to June 19), and the y-axis represents the percentage of centers. The graph tracks the percentage of centers receiving HCV NAT+ offers, those not receiving offers, and centers with no response. The number of centers performing HCV NAT+ kidney transplants is also shown on the right y-axis.
Lousy kidneys are better than dialysis

Patients want centers with shorter wait times

Communicate poorly with patients and dialysis units

Evidence adoption is slower than perceived
Weekend effect for organ acceptance

Odds of being hard to place

- Mean Sequence number of acceptance
- Odds of being hard to place
- Odds after excluding bypasses

Monday: 1
Tuesday: 1.03
Wednesday: 1.02
Thursday: 1.03
Friday: 1.16
Saturday: 1.19
Sunday: 1.15

Mean Sequence number:
- Monday: 120
- Tuesday: 125
- Wednesday: 130
- Thursday: 135
- Friday: 140
- Saturday: 145
- Sunday: 150
# Reasons for deceased donor kidney offer refusal

*No change over the spectrum of KDPI*

*Excludes discards*

<table>
<thead>
<tr>
<th>KDPI Decile</th>
<th>Patient Related</th>
<th>Organ or Donor Quality</th>
<th>Logistical</th>
<th>Immunologic or Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>All</td>
<td>232 193 (2.6)</td>
<td>8 416 474 (92.6)</td>
<td>49 492 (0.5)</td>
<td>388 920 (4.3)</td>
</tr>
<tr>
<td>0-10</td>
<td>11 047 (4.2)</td>
<td>229 852 (87.1)</td>
<td>1533 (0.6)</td>
<td>21 383 (8.1)</td>
</tr>
<tr>
<td>11-20</td>
<td>20 011 (4.5)</td>
<td>394 126 (87.9)</td>
<td>2718 (0.6)</td>
<td>31 300 (7.0)</td>
</tr>
<tr>
<td>21-30</td>
<td>16 232 (2.8)</td>
<td>522 603 (90.7)</td>
<td>2945 (0.5)</td>
<td>34 531 (6.0)</td>
</tr>
<tr>
<td>31-40</td>
<td>21 722 (3.7)</td>
<td>540 643 (91.6)</td>
<td>2844 (0.5)</td>
<td>25 340 (4.3)</td>
</tr>
<tr>
<td>41-50</td>
<td>20 244 (2.6)</td>
<td>726 831 (92.9)</td>
<td>5408 (0.7)</td>
<td>30 045 (3.8)</td>
</tr>
<tr>
<td>51-60</td>
<td>23 576 (2.4)</td>
<td>917 430 (92.0)</td>
<td>7213 (0.7)</td>
<td>48 827 (4.9)</td>
</tr>
<tr>
<td>61-70</td>
<td>29 091 (2.4)</td>
<td>1 118 833 (93.5)</td>
<td>5124 (0.4)</td>
<td>43 836 (3.7)</td>
</tr>
<tr>
<td>71-80</td>
<td>28 914 (2.0)</td>
<td>1 337 402 (93.3)</td>
<td>8687 (0.6)</td>
<td>57 896 (4.0)</td>
</tr>
<tr>
<td>81-90</td>
<td>33 078 (2.3)</td>
<td>1 379 845 (93.8)</td>
<td>7396 (0.5)</td>
<td>51 413 (3.5)</td>
</tr>
<tr>
<td>91-100</td>
<td>26 841 (2.1)</td>
<td>1 194 896 (94.3)</td>
<td>5042 (0.4)</td>
<td>40 826 (3.2)</td>
</tr>
<tr>
<td>Unknown</td>
<td>1437 (2.4)</td>
<td>54 010 (90.7)</td>
<td>582 (1.0)</td>
<td>35 235 (5.9)</td>
</tr>
</tbody>
</table>

*Husain SA et al. JAMA Netw Open 2019*
Time to first offer

Proportion of kidneys accepted without a decline

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>0.05</th>
<th>0.1</th>
<th>0.15</th>
<th>0.2</th>
<th>0.25</th>
<th>0.3</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>29</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Median days to first offer

Overall

Husain SA et al. JAMA Netw Open 2019
Evidence that offer declines are not related to organ quality

- More declines on weekends
- Declines attribute to organ quality regardless of KDPI
- Matchrun sequence number is not predictive of outcomes
- Majority of organs are declined at least once
ORGAN OFFERS: Outcomes and consequences
<table>
<thead>
<tr>
<th>Category, Specific Outcome</th>
<th>n, 1000</th>
<th>%a</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney transplanted</td>
<td>49</td>
<td>0.7</td>
</tr>
<tr>
<td>Donor-related refusal</td>
<td>3232</td>
<td>45.0</td>
</tr>
<tr>
<td>Donor age or quality</td>
<td>2194</td>
<td>30.7</td>
</tr>
<tr>
<td>Organ-specific donor issue such as testing unavailable or unacceptable, or abnormal biopsy</td>
<td>265</td>
<td>3.7</td>
</tr>
<tr>
<td>Other, e.g., donor blood type, donor size or weight, donor social history</td>
<td>772</td>
<td>10.8</td>
</tr>
<tr>
<td>Transplant center bypassed for prespecified criteria</td>
<td>3167</td>
<td>44.0</td>
</tr>
<tr>
<td>Not offered because minimal acceptance criteria not met</td>
<td>949</td>
<td>13.3</td>
</tr>
<tr>
<td>Directed donation</td>
<td>765</td>
<td>10.7</td>
</tr>
<tr>
<td>Other, e.g., offer not made due to expedited placement attempt</td>
<td>1453</td>
<td>20.3</td>
</tr>
<tr>
<td>Recipient-related refusal</td>
<td>141</td>
<td>2.0</td>
</tr>
<tr>
<td>Patient ill, unavailable, refused, or temporarily unsuitable</td>
<td>130</td>
<td>1.8</td>
</tr>
<tr>
<td>Multiple organ transplant or different laterality required</td>
<td>9</td>
<td>0.1</td>
</tr>
<tr>
<td>Other, e.g., patient’s condition improved or already transplanted</td>
<td>2</td>
<td>0.03</td>
</tr>
</tbody>
</table>
Association Between Declined Offers of Deceased Donor Kidney Allograft and Outcomes in Kidney Transplant Candidates

S. Ali Husain, MD, MPH\textsuperscript{1,2}; Kristen L. King, MPH\textsuperscript{1,2}; Stephen Pastan, MD\textsuperscript{3}; Rachel E. Pazter, PhD\textsuperscript{4,5}; David J. Cohen, MD\textsuperscript{1}; Jai Radhakrishnan, MD\textsuperscript{1}; Sumit Mohan, MD, MPH\textsuperscript{1,2,6}

» Author Affiliations  |  Article Information

Real consequences of declining a kidney offer

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total</th>
<th>Died While on Waiting List</th>
<th>Received Allograft From DD</th>
<th>Received Allograft From LD</th>
<th>Removed From Waiting List</th>
<th>Remaining on Waiting List</th>
</tr>
</thead>
<tbody>
<tr>
<td>Started dialysis between wait-listing and event, No. (%)&lt;sup&gt;d&lt;/sup&gt;</td>
<td>14,953 (5.3)</td>
<td>750 (2.9)</td>
<td>2,059 (2.5)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>950 (3.1)</td>
<td>2,190 (3.7)</td>
<td>9,004 (11.0)</td>
</tr>
<tr>
<td>Days between listing and first offer, median (IQR)</td>
<td>48 (13-232)</td>
<td>78 (17-401)</td>
<td>79 (16-426)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>34 (11-103)</td>
<td>62 (16-302)</td>
<td>30 (9-104)</td>
</tr>
<tr>
<td>Days between first offer and event, median (IQR)&lt;sup&gt;d&lt;/sup&gt;</td>
<td>526 (193-1041)</td>
<td>651 (304-1117)</td>
<td>422 (106-909)</td>
<td>188 (83-403)</td>
<td>690 (326-1192)</td>
<td>650 (276-1255)</td>
</tr>
<tr>
<td>No. of offers before event, median (IQR)&lt;sup&gt;d&lt;/sup&gt;</td>
<td>16 (5-40)</td>
<td>16 (6-41)</td>
<td>17 (6-44)</td>
<td>7 (3-16)</td>
<td>15 (6-37)</td>
<td>21 (8-51)</td>
</tr>
<tr>
<td>Days between first and last offers, median (IQR)</td>
<td>386 (122-829)</td>
<td>390 (140-764)</td>
<td>420 (103-907)</td>
<td>144 (40-350)</td>
<td>392 (149-775)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>490 (191-984)</td>
</tr>
</tbody>
</table>

Husain SA et al. JAMA Netw Open 2019
Adjusted odds ratio for death on the waitlist after receipt of at least 1 deceased donor kidney offer

Husain SA et al. JAMA Netw Open 2019
Probability of transplantation within 3 years of waitlisting for Candidates listed in 2015. Adjusted for candidate and allocation factors.

- 58 centers (30%) below the nationwide PrTx
- 55 centers (28%) above the nationwide PrTx
- 81 centers (42%) not significantly different from nationwide PrTx

King et al. in review
Adjusted for:
- blood group
- dialysis vintage
- PRA
- age at listing
- sex
- race
- diabetes
- obesity

By OPTN Region

3 Year Cumulative Probability of Transplant by Region

King et al. in review
Contribute
Disparities

Drive
Variations in probability of transplantation

Decrease
efficiency of allocation
Transparency of offers
Challenges of disclosure

• Real time is unrealistic for every organ offer
• Patients are incapable of understanding complex decision
  – (medical paternalism at it’s best)
Benefits of disclosure to utility

Force communication with waitlisted patients which will improve patient engagement, improve primary nephrologist engagement, and improved allocation efficiency.

More objective evaluation of organ offers: improved understanding of patient preferences, evaluate organ utility for a given patient, and reasons for offer decline shared with patient.

Increased transparency of organ offer acceptance patterns: market pressure to be more accommodating, lower variation in probability of transplantation within a DSA.

Improved outcomes: fewer discards and more appropriate allocation of organs; subsets of patients may get organs earlier than they would have.
Benefits of disclosure to equity

Fewer declined offers
- Decrease opportunities for implicit bias
- Organ evaluation with the intended recipient in mind
- Greater awareness of patient preferences

Improved communication
- Increases accountability
- Improved documentation of reasons for decline
- *will improve ability to study the problem*

Transplant center changes
- Re-evaluation of filter settings
- Eliminating “internal holds”
- Greater scrutiny of declined offers
Summary

• The vast majority of organ offers are declined for reasons other than organ quality
• Nearly ¾ of patients have received an offer for an organ that was declined on their behalf and subsequently transplanted lower on the waitlist
• Nearly a third of patients with an organ offer either die or are delisted without a transplant.
• Variations in probability of transplantation are being associated with variations in organ offer acceptance
• We don’t call patients when they get an offer
• We aren’t as accepting of new evidence that would
Conclusions

• Changing center level behavior to put patients first requires transparency and awareness of center level practices that disadvantages them.

• This includes transparency with respect to:
  – Patient selection
  – Organ offer filters
  – Organ acceptance
  – informing patients when they receive an offer that is declined for them
Indirect evidence that offer declines are not related to organ quality

- More declines on weekends
- Declines attribute to organ quality regardless of KDPI
- Matchrun sequence number is not predictive of