Reducing barriers to living donor kidney transplantation in Ontario – adapting the Explore Transplant Education Program

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Disclosure

- The Explore Transplant Ontario adaptation project received unrestricted educational support from Astellas Pharma Canada
• Why kidney transplant; why living donor kidney transplant – **DO WE HAVE A PROBLEM??**

• Potentially modifiable barriers to KT and LDKT
  – Psychosocial barriers
  – Ethnocultural barriers

• Helping patients consider transplant – **education**
  – Explore Transplant

• Adapting Explore Transplant – Explore Transplant Ontario
Recommendations

1. All patients with end-stage renal disease should be considered for kidney transplantation provided no absolute contraindications exist (Grade A).

Renal transplantation is the treatment of choice for many patients with ESRD. Despite an increased risk of death in the early post-transplant period, transplantation improves long-term survival and quality of life compared with dialysis.\(^7\)\(^{14}\)\(^{15}\) A report from the United States Renal Data System (USRDS), in which a time-dependent non-proportional hazards model was adjusted for such covariates as age, race, gender and cause of ESRD in more than 250,000 patients initiating renal replacement therapy (RRT) between 1991 and 1996, revealed that the long-term mortality rate of patients who received a first deceased-donor renal transplant was 48–82% lower than that of patients who remained on the waiting list.\(^7\) Al-
1-YEAR RISK SUMMARY

Dialysis
6% risk of dying in next year while on Dialysis

Transplant
1% risk of dying in next year with a Kidney Transplant

Among similar people, 8 out of 100 will die in the next year on Dialysis.
Among similar people, 1 out of 100 will die in the next year with a Kidney Transplant.

You are about 6 times more likely to die on Dialysis than with a Kidney Transplant in the next year.

3-YEAR RISK SUMMARY

Dialysis
12% risk of dying in next three years while on Dialysis

Transplant
2% risk of dying in next three years with a Kidney Transplant

Among similar people, 12 out of 100 will die in the next three years on Dialysis.
Among similar people, 2 out of 100 will die in the next three years with a Kidney Transplant.

You are about 6 times more likely to die on Dialysis than with a Kidney Transplant in the next three years.

ichoosekidney: A Clinical Decision Aid for Kidney Transplantation Versus Dialysis Treatment
Rochele E. Patzer, PhD, MPH,1,2 Mohsen Beau, MPH,1 Christian R. Larsen, MD, DPH1,2 Stephen O. Pastan, MD,4 Sumit Mohan, MD, MPH1,2 Michael Patzer, BS,1 Michael Konormos, MS, CM1,2 William M. McGilton, MD, MPH1,2,3,4 Janice Lai, MD1,2,4 David Howard, PhD,1 Jennifer Garcia, PhD, MPH1,2,4,5 Kimberly Jacob-Arko, PhD, MPH1,2,4

(Transplantation 2016;100: 630–639)

http://ichoosekidney.emory.edu/
**1-YEAR RISK SUMMARY**

**Dialysis**
- 24% risk of dying in next year while on Dialysis

**Transplant**
- 7% risk of dying in next year with a Kidney Transplant

Among similar people, 24 out of 100 people will die in the next year on Dialysis.

Among similar people, 7 out of 100 people will die in the next year with a Kidney Transplant.

You are about 3 times more likely to die on Dialysis than die with a Kidney Transplant in the next year.

**3-YEAR RISK SUMMARY**

**Dialysis**
- 44% risk of dying in next three years while on Dialysis

**Transplant**
- 16% risk of dying in next three years with a Kidney Transplant

Among similar people, 44 out of 100 people will die in the next three years on Dialysis.

Among similar people, 16 out of 100 people will die in the next three years with a Kidney Transplant.

You are about 3 times more likely to die on Dialysis than die with a Kidney Transplant in the next three years.

**iChoose Kidney: A Clinical Decision Aid for Kidney Transplantation Versus Dialysis Treatment**

Rachel E. Patzer, PhD, MPH,1,2 Mohini Basu, MPH,1 Christian P. Laren, MD, DPh,1,2 Stephen O. Pastan, MD,4 Sumit Mohan, MD, MPH,1,2 Michael Patzer, BS,2 Michael Koronovsky, MS, CM,1 William M. McCullun, MD, MPH,1,2 Janice Lea, MD,2 David Howard, PhD,7 Jennifer Gardner, PhD, MPH,1 and Kimberly Jacobs Antila, PhD, MPH1

(Transplantation 2016;100: 630–639)

http://ichoosekidney.emory.edu/
Projected life expectancy after ESRD onset by recipient age and treatment modality.

Schold J D, and Meier-Kriesche H CJASN 2006;1:532-538

Which Renal Transplant Candidates Should Accept Marginal Kidneys in Exchange for a Shorter Waiting Time on Dialysis?
The Overlapping Risk Profile Between Dialysis Patients Listed and Not Listed for Renal Transplantation

J. D. Schold\textsuperscript{a,b,*}, T. R. Srinivas\textsuperscript{a}, L. K. Kayler\textsuperscript{c}
and H. U. Meier-Kriesche\textsuperscript{a}

American Journal of Transplantation 2008; 8: 58–68
According to the latest available data, 90.8% and 81.4% of kidneys transplanted into adults from living and deceased donors, respectively, were still functioning at least 5 years after transplant.

According to the latest available data, 43.2% of patients on dialysis treatments survived at least 5 years (8398 patients).

WL = 3,377 patients

Of the 20,690 patients on dialysis, more than three-quarters were receiving institutional hemodialysis, the most expensive treatment option.
Number of Kidney Transplants by Donor Type, Adult (18+), 2005 to 2014

<table>
<thead>
<tr>
<th>Year</th>
<th>Deceased</th>
<th>Living</th>
</tr>
</thead>
<tbody>
<tr>
<td>2005</td>
<td>572</td>
<td>411</td>
</tr>
<tr>
<td>2006</td>
<td>689</td>
<td>461</td>
</tr>
<tr>
<td>2007</td>
<td>727</td>
<td>458</td>
</tr>
<tr>
<td>2008</td>
<td>713</td>
<td>453</td>
</tr>
<tr>
<td>2009</td>
<td>731</td>
<td>441</td>
</tr>
<tr>
<td>2010</td>
<td>725</td>
<td>466</td>
</tr>
<tr>
<td>2011</td>
<td>758</td>
<td>438</td>
</tr>
<tr>
<td>2012</td>
<td>809</td>
<td>435</td>
</tr>
<tr>
<td>2013</td>
<td>807</td>
<td>484</td>
</tr>
<tr>
<td>2014</td>
<td>806</td>
<td>434</td>
</tr>
</tbody>
</table>

Source: Canadian Organ Replacement Register, 2015, CIHI
Figure 1  Number of donors, by donor type and year, Canada including Quebec, 2005 to 2014

<table>
<thead>
<tr>
<th>Year</th>
<th>Deceased donors</th>
<th>Living donors</th>
</tr>
</thead>
<tbody>
<tr>
<td>2005</td>
<td>411</td>
<td>504</td>
</tr>
<tr>
<td>2006</td>
<td>461</td>
<td>556</td>
</tr>
<tr>
<td>2007</td>
<td>485</td>
<td>554</td>
</tr>
<tr>
<td>2008</td>
<td>481</td>
<td>546</td>
</tr>
<tr>
<td>2009</td>
<td>487</td>
<td>516</td>
</tr>
<tr>
<td>2010</td>
<td>466</td>
<td>557</td>
</tr>
<tr>
<td>2011</td>
<td>515</td>
<td>521</td>
</tr>
<tr>
<td>2012</td>
<td>541</td>
<td>538</td>
</tr>
<tr>
<td>2013</td>
<td>553</td>
<td>585</td>
</tr>
<tr>
<td>2014</td>
<td>592</td>
<td>553</td>
</tr>
</tbody>
</table>

Source
Canadian Organ Replacement Register, 2015, Canadian Institute for Health Information.
Adult (18+) Living Donor Kidney Transplants by Year and Province, 2005 to 2014

Source: Canadian Organ Replacement Register, 2015, CIHI
Living kidney donation: outcomes, ethics, and uncertainty

Peter P Reese, Neil Boudville, Armit X Garg

Dialysis Facility and Network Factors Associated With Low Kidney Transplantation Rates Among United States Dialysis Facilities

Standardized Transplant Ratios: United States: 2007-2010

Network 6

99 facilities with no transplants

Network 1

STR=1.0

American Journal of Transplantation 2014; 14: 1562–1572
Dialysis Facility and Network Factors Associated With Low Kidney Transplantation Rates Among United States Dialysis Facilities

R. E. Patzer\textsuperscript{1,2,*}, L. Plantinga\textsuperscript{2,3}, J. Krisher\textsuperscript{4} and S. O. Pastan\textsuperscript{5,6}

American Journal of Transplantation 2014; 14: 1562–1572
Cases

- 68 yo inuit male, living in Mo x 18 mos on HD – potential live donor; T2DM, PVD, CAD
- 65yo male, on HD; t2dm, HCV – failed IFN;
- 35 yo cree female; on HD x 1 yr; T2DM, BMI 38
- 68 yo male on HD x2 yrs; T2DM, CAD, BMI 41; AC 145 cm;
- 38 yo AA female on HD x 18mos; SSD; stroke 4 mos ago; OFO
- 40 yo AA female, on HD x3 yrs; HIV+; previous infs;
• 35 yo, African Canadian male
• ESKD due to GN
• On PD x 3 yrs, recently switched to HD
• No major comorbidities
• Lives with common law partner, stable relationship

• Recurrent problems with non-adherence to dialysis, drug seeking behavior, use of recre. drugs, narcotic analgesics
• Non-adherence to HD, no-show for several appointments

• Pt. was declined to be waitlisted – he accepted
Ms C – 15 oct

- 61 yo F
- ESKD, typ1 DM
- PD since 2009
- T1DM, HTN, DLP
- Retinopathy, neuropathy, gastroparesis
- CAD, AMI 2002
- AMI 2010, PCI
- CABG 2012

- ECD 15 oct
- IGF
- NSTEMI post op
- D/C with creat N
Mr T – 15 oct

- 77 yo AA M
- ESKD since 2011
- T2 DM, HTN
- CAD – no MI
- Retinopathy – legally blind
- GERD
- Prostate CA – prostatectomy in 2006
- Lives with younger wife
- Good support
- Wants to be free from dialysis, wants to travel

- ECD/DCD 15 oct
- DGF
- d/c with creat 200, declining

Some ongoing issues, creat cca 160, says it is better now than before; made his first trip to visiting family in Florida in April
One word of caution: increasing kidney transplantation and living donor kidney transplantation

Increasing the recipient and donor pool

This can not be successful without rethinking and improving post-transplant and post-donation care
Psychosocial barriers

- Mental Health issues are frequent in patients with End Stage Renal Disease
  - ~40% of patients on dialysis experience depression (Szeifert 2011, Cukor 2007)
    - Relatively neglected
    - May be a potential barrier to transplantation
Attachment Security

- The tendency of individuals to believe that
  - they are worthy of care
  - others are trustworthy to provide it
- To value intimate relationships
- To ask for and accept care
- To acknowledge emotions in a coherent and flexible way

Courtesy of G. Rodin
Table 2. Odds ratios for being on the kidney transplant waiting list among HD patients, 18–65 years

<table>
<thead>
<tr>
<th>Final model</th>
<th>AOR (95% CI)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–45 years</td>
<td>1 (Reference)</td>
<td></td>
</tr>
<tr>
<td>46–55 years</td>
<td>0.70 (0.57–0.86)</td>
<td>0.001</td>
</tr>
<tr>
<td>56–65 years</td>
<td>0.45 (0.36–0.55)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>0.54 (0.43–0.67)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Completed high school</td>
<td>0.88 (0.71–1.09)</td>
<td>0.25</td>
</tr>
<tr>
<td>Some college or higher</td>
<td>1 (Reference)</td>
<td></td>
</tr>
<tr>
<td>Serum albumin (per 1 g/dL lower)</td>
<td>0.75 (0.62–0.90)</td>
<td>0.003</td>
</tr>
<tr>
<td>Hemoglobin (per 1 g/dL lower)</td>
<td>0.93 (0.88–0.99)</td>
<td>0.02</td>
</tr>
<tr>
<td>Dialysis vintage (months)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;6</td>
<td>0.28 (0.22–0.35)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>6–12</td>
<td>0.66 (0.50, 0.89)</td>
<td>0.006</td>
</tr>
<tr>
<td>12–24</td>
<td>1.19 (0.95, 1.50)</td>
<td>0.13</td>
</tr>
<tr>
<td>&gt;24</td>
<td>1 (Reference)</td>
<td></td>
</tr>
<tr>
<td>Comorbidities: (presence versus absence)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DM</td>
<td>0.79 (0.64–0.97)</td>
<td>0.023</td>
</tr>
<tr>
<td>CHF</td>
<td>0.74 (0.60–0.91)</td>
<td>0.005</td>
</tr>
<tr>
<td>Peripheral vascular disease</td>
<td>0.61 (0.48–0.78)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td>0.57 (0.42–0.79)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>PCS score (per 5-point lower)</td>
<td>0.91 (0.87–0.95)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>CES-D score (per 5-point higher)</td>
<td>0.91 (0.84–0.98)</td>
<td>0.013</td>
</tr>
</tbody>
</table>

Psychosocial variables are associated with being wait-listed, but not with receiving a kidney transplant in the Dialysis Outcomes and Practice Patterns Study (DOPPS)

Lilla Szeifert¹, Jennifer L. Bragg-Gresham², Jyothi Thumma², Brenda W. Gillespie³, Istvan Mucsi¹,4, Bruce M. Robinson², Ronald L. Pisoni³, Alex Disney³, Christian Combe⁶ and Friedrich K. Port⁷


35-45% of WL patients had high risk of depression
Referral to transplant WU completion, by history of psychiatric disorders

Univariable hazard ratio (95% CI) : 0.81 (0.70, 0.93)

Log Rank P = 0.003

Number at risk
No Hx of psych disorders 1326 1140 797 571 449
Hx of psych disorders 432 378 282 215 181
Multivariable adjusted likelihood of completing the transplant WU within two years after referral for patients with the history of psychiatric disorders or non-adherence

<table>
<thead>
<tr>
<th>Mental Health</th>
<th>Hazard Ratio (95% C.I.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>History of Psychiatric disorder (Yes vs. No)</td>
<td>0.81 (0.70, 0.95)</td>
</tr>
</tbody>
</table>

Adjusted for: age, sex, marital status, English communication, race, Ontario Marginalization Index and the history of: history of diabetes, coronary artery disease/myocardial infarction, heart failure, stroke and peripheral vascular disease, chronic lung disease, or non-skin cancer
Biopsy-proven acute rejection by history of MH

Biopsy-proven acute rejection by history of NA

Log Rank P = 0.15

Log Rank P = 0.04
Multivariable adjusted likelihood of BPAR for patients with a history of MH or NA

<table>
<thead>
<tr>
<th>Variables</th>
<th>Hazard Ratio (95% C.I.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>History of mental health disorder (Yes versus No)</td>
<td>1.31 (0.87, 1.99)</td>
</tr>
<tr>
<td>History of non-adherence (Yes versus No)</td>
<td>1.26 (0.76, 2.09)</td>
</tr>
</tbody>
</table>

**Adjusted for:** age, sex, race, donor type, ECD, DGF, HLA mismatch and history of diabetes
Total graft failure by history of MH

Log Rank P = 0.72

Cumulative total graft failure

Number at risk
No history of MH disorders 748 708 573 469 367 267 195 131 78
History of MH disorders 207 196 162 124 92 66 40 24 11

Months post-transplant

Total graft failure by history of NA

Log Rank P = 0.24

Cumulative total graft failure

Number at risk
No history of non-adherence 847 802 659 538 421 315 227 150 87
History of non-adherence 108 102 76 55 38 18 8 5 2

Months post-transplant
Multivariable adjusted likelihood of TGF for patients with a history of MH or NA

<table>
<thead>
<tr>
<th>Variables</th>
<th>Hazard Ratio (95% C.I.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>History of mental health disorder (Yes versus No)</td>
<td>0.96 (0.56, 1.64)</td>
</tr>
<tr>
<td>History of non-adherence (Yes versus No)</td>
<td>1.65 (0.89, 3.08)</td>
</tr>
</tbody>
</table>

*Adjusted for:* age, sex, race, donor type, ECD, DGF, HLA mismatch and history of diabetes
Ethnocultural barriers
Racial Differences in Determinants of Live Donor Kidney Transplantation in the United States

T. S. Purnell, P. Xu, N. Leca and Y. N. Hall

Patient and allograft survival of Indo Asian and East Asian dialysis patients treated in Canada

M Tonelli¹,²,³,⁴, B Hemmelgarn⁵,⁶, JS Gill⁷,⁸, S Chou⁵, B Culleton⁵, S Klarenbach¹,³, B Manns³,⁵,⁶, N Wiebe¹ and S Gourishankar¹, for the Alberta Kidney Disease Network

Kidney International (2007) 72, 499–504;

### Table 2 | Transplantation by race

<table>
<thead>
<tr>
<th></th>
<th>Any transplant</th>
<th>Deceased donor transplant only</th>
<th>Living donor transplant only</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N (%)</td>
<td>Age-adjusted HR (95% CI)</td>
<td>Adjusted¹ HR (95% CI)</td>
</tr>
<tr>
<td>East Asian</td>
<td>380 (31)</td>
<td>0.88 (0.79, 0.97)</td>
<td>0.71 (0.63, 0.79)</td>
</tr>
<tr>
<td>Indo Asian</td>
<td>203 (28)</td>
<td>0.69 (0.60, 0.80)</td>
<td>0.69 (0.60, 0.80)</td>
</tr>
<tr>
<td>White</td>
<td>4841 (25)</td>
<td>1.0</td>
<td>1.0</td>
</tr>
</tbody>
</table>

¹Adjusted for age, sex, race, smoking, diabetes, blood pressure, body mass index, and creatinine.
Table 2. Factors associated with Donor Registration (Cross-sectional study).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No. Registered (%)</th>
<th>Adjusted Prevalence Ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>49,938 (8.9%)</td>
<td>0.35 (0.35 to 0.35)</td>
</tr>
<tr>
<td>South Asian</td>
<td>47,774 (12.8%)</td>
<td>0.50 (0.50 to 0.51)</td>
</tr>
<tr>
<td>General public</td>
<td>2,676,260 (25.4%)</td>
<td>1.00 [Reference]</td>
</tr>
<tr>
<td><strong>Residence</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>2,382,847 (23.4%)</td>
<td>1.00 [Reference]</td>
</tr>
<tr>
<td>Rural</td>
<td>391,125 (29.6%)</td>
<td>1.25 (1.25 to 1.26)</td>
</tr>
<tr>
<td><strong>Age Category</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16–29 years</td>
<td>948,293 (28.8%)</td>
<td>1.00 [Reference]</td>
</tr>
<tr>
<td>30–39 years</td>
<td>558,946 (29.9%)</td>
<td>1.05 (1.05 to 1.06)</td>
</tr>
<tr>
<td>40–49 years</td>
<td>496,331 (25.1%)</td>
<td>0.87 (0.87 to 0.88)</td>
</tr>
<tr>
<td>50–59 years</td>
<td>394,863 (21.9%)</td>
<td>0.74 (0.74 to 0.75)</td>
</tr>
<tr>
<td>60–69 years</td>
<td>246,021 (19%)</td>
<td>0.64 (0.64 to 0.64)</td>
</tr>
<tr>
<td>≥ 70 years</td>
<td>129,518 (10.4%)</td>
<td>0.35 (0.34 to 0.35)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>1,250,333 (22.3%)</td>
<td>1.00 [Reference]</td>
</tr>
<tr>
<td>Women</td>
<td>1,523,639 (25.9%)</td>
<td>1.18 (1.18 to 1.19)</td>
</tr>
<tr>
<td><strong>Income Quintile</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fifth (Highest)</td>
<td>640,973 (27.8%)</td>
<td>1.16 (1.16 to 1.17)</td>
</tr>
<tr>
<td>Fourth</td>
<td>585,153 (25.1%)</td>
<td>1.04 (1.03 to 1.04)</td>
</tr>
<tr>
<td>Three (Middle)</td>
<td>553,545 (23.9%)</td>
<td>1.00 [Reference]</td>
</tr>
<tr>
<td>Two</td>
<td>522,224 (23.0%)</td>
<td>0.98 (0.97 to 0.98)</td>
</tr>
<tr>
<td>One (Lowest)</td>
<td>472,077 (21.1%)</td>
<td>0.88 (0.88 to 0.88)</td>
</tr>
</tbody>
</table>

Deceased Organ Donation Registration and Familial Consent among Chinese and South Asians in Ontario, Canada

Alvin Ho-ting Li†, Eric McArthur‡, Janet Maclean§, Cynthia Isenor§, Versha Prakash§, S. Joseph Kim*, Greg Knoll*, Baiju Shah*, Amit X. Garg*
Race/ethnicity – access to transplant, LDKT

Transplant

LDKT

Number at risk

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>White</th>
<th>Black</th>
<th>East Asian</th>
<th>Indo Asian</th>
<th>Other/unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>756</td>
<td>182</td>
<td>164</td>
<td>143</td>
<td>524</td>
</tr>
<tr>
<td>Black</td>
<td>395</td>
<td>119</td>
<td>116</td>
<td>82</td>
<td>406</td>
</tr>
<tr>
<td>East Asian</td>
<td>201</td>
<td>68</td>
<td>53</td>
<td>45</td>
<td>237</td>
</tr>
<tr>
<td>Indo Asian</td>
<td>100</td>
<td>36</td>
<td>25</td>
<td>29</td>
<td>106</td>
</tr>
<tr>
<td>Other/unknown</td>
<td>42</td>
<td>18</td>
<td>6</td>
<td>9</td>
<td>38</td>
</tr>
</tbody>
</table>

Number at risk

<table>
<thead>
<tr>
<th>Ethnicity</th>
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<tr>
<td>East Asian</td>
<td>201</td>
<td>68</td>
<td>53</td>
<td>45</td>
<td>237</td>
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<tr>
<td>Indo Asian</td>
<td>100</td>
<td>36</td>
<td>25</td>
<td>29</td>
<td>106</td>
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<tr>
<td>Other/unknown</td>
<td>42</td>
<td>18</td>
<td>6</td>
<td>9</td>
<td>38</td>
</tr>
</tbody>
</table>

Log Rank P < 0.001
LD transplant versus having a potential LD at referral

Log Rank P < 0.001

Cumulative transplantation probability

Years from referral date

Number at risk

No LKD at referral

LD transplant

Having a potential LD at referral

Number at risk

No LKD at referral

LD transplant

LKD at referral

Number at risk

585

354

141

38

823

416

155

39
Psychosocial and ethno-cultural barriers to living donor kidney transplantation

I. Mucsi, A.D. Waterman, S.J. Kim, J.S. Zaltzman, K.P. Fung, D. Buchman, R. Nissim and M. Novak

This study will investigate readiness to accept living donor kidney transplant (LDKT) and also psychosocial and ethno-cultural barriers to accepting LDKT among patients with chronic kidney disease (CKD) – referred for pre-transplant assessment
CAPTURING THE PATIENT PERSPECTIVE

ASSESSING PATIENT REPORTED MEASURES
Pan-Canadian Practice Guideline: Screening, Assessment and Management of Psychosocial Distress, Major Depression and Anxiety in Adults with Cancer

Version 2, 2015

30/07/15
Screening for depression: only one piece of the puzzle

M. Novak¹,²
I. Mucsi³,⁴
and D.C. Mendelssohn⁵

¹Psychonephrology Unit, Department of Psychiatry, University Health Network, University of Toronto, Toronto, ON, Canada,
²Institute of Behavioral Sciences, Semmelweis University, Budapest, Hungary,
³Division of Nephrology, McGill University Health Centre, Montreal, QC, Canada,
⁴Semmelweis University, Budapest, Hungary and
⁵Humber River Regional Hospital and University of Toronto, Toronto, ON, Canada

Correspondence and offprint requests to: David C. Mendelssohn; Email: dmendelssohn@hrrh.on.ca; dmendy@gmail.com

Keywords: depression, distress, patient-reported outcomes
Brief communication: patient satisfaction with the use of tablet computers: a pilot study in two outpatient home dialysis clinics

Kara Schick-Makaroff and Anita Molzahn
Study Questionnaires

- TRANSPLANT DECISION MAKING SURVEY
- ILLNESS INTRUSIVESNESS RATING SCALE
- EXPERIENCE OF CLOSE RELATIONSHIP SCALE
- KIDNEY DISEASE QUALITY OF LIFE
- FATIGUE SEVERITY SCALE (FSS)
- MOS SOCIAL SUPPORT
- SHORT LITERACY SURVEY
- SOCIO-DEMOGRAPHIC & CULTURAL QUESTIONNAIRE
- PATIENT RESPONSE QUESTIONNAIRE
- DART (PHQ-9, GAD, ESAS, SDI)
3. Which of the following statements best describes in general how safe you feel in your home or neighbourhood?

- I feel very safe in my home or neighbourhood
- I feel somewhat safe in my home or neighbourhood
- I do not feel safe at all in my home or neighbourhood
- Not applicable
- Prefer not to answer
Did you find the task of completing the questionnaires ON THE TABLET COMPUTER too difficult or tiring?

Did you need someone’s help to complete the questionnaire?

- No
- Yes

- Not at all
- Very little
- Somewhat
- A great extent
- Someone completed it for me
Sample Question from DART
(PHQ-9, GAD, ESAS, SDI)

Please select the number that best describes how you feel NOW:

0 1 2 3 4 5 6 7 8 9 10

No Pain

Worst Possible Pain

No Tiredness
(Thiredness = lack of energy)

Worst Possible Tiredness

No Drowsiness
(Drowsiness = feeling sleepy)

Worst Possible Drowsiness
Proportion of patients with distress (n=64)
## Factors associated with distress (any)

|                | Odds Ratio | Std. Err. | z     | P>|z| | [95% Conf. Interval] |
|----------------|------------|-----------|-------|------|----------------------|
| income_cat     | .4552638   | .1885658  | -1.90 | 0.057| .202164              |
| gender_used    | .5135771   | .35992    | -0.95 | 0.342| .1300395             |
| ethnicity_bin  | 4.331028   | 2.887063  | 2.20  | 0.028| 1.172681             |
| comorbidity_cat| 1.511797   | 1.909273  | 0.33  | 0.743| .127203              |
| _cons          | .8879505   | 1.811041  | -0.06 | 0.954| .0163042             |
**Tx knowledge vs having a living donor identified**

- **Tx knowledge low**
  - LD yes
  - LD no

- **Tx knowledge high**
  - LD yes
  - LD no

**Tx knowledge vs LD readiness**

- **Tx knowledge low**
  - LD late
  - LD early

- **Tx knowledge high**
  - LD late
  - LD early
Tx knowledge vs LD donor identified

| LD_ready_bin_log | Odds Ratio | Std. Err. | z    | P>|z|  | [95% Conf. Interval] |
|------------------|------------|-----------|------|------|----------------------|
| TDMS_Score_9     | 4.480295   | 3.368067  | 1.99 | 0.046| 1.026632  19.55232  |
| gender_used      | 0.4858262  | 0.3510951 | -1.00| 0.318| 0.1178522  2.002738 |
| comorbidity_cat  | 0.2490567  | 0.3794517 | -0.91| 0.362| 0.0125727  4.933661 |
| ethnicity_bin    | 1.236509   | 0.8572366 | 0.31 | 0.759| 0.3177484  4.81184  |
| education_3      | 3.371607   | 2.082988 | 1.97 | 0.049| 1.004528   11.31648 |
| _cons            | 0.0813949  | 0.2263812 | -0.90| 0.367| 0.0003493  18.96784 |
Reducing barriers to living donor kidney transplantation in Ontario – adapting the Explore Transplant Education Program
Road to Transplant Requires:

- Learn about transplant as an option
- Begin evaluation
  - (be identified and accept)
- Attend transplant appointments
- Get listed for transplant
- Complete yearly re-evaluation
- Find a matching kidney
- Receive a deceased or living donor transplant
Patient- and Provider-Reported Information about Transplantation and Subsequent Waitlisting

Megan L. Salter,† Babak Orandi,† Mara A. McAdams-DeMarco,‡ Andrew Law,‡† Lucy A. Meoni,§∥ Bernard G. Jaar,§∥∥ Stephen M. Sozio,§ Wen Hong Linda Kao,§§ Rulan S. Parekh,|| and Dorry L. Segev‡‡

doi: 10.1681/ASN.2013121298

Number at risk

<table>
<thead>
<tr>
<th></th>
<th>Both</th>
<th>Provider only</th>
<th>Patient only</th>
<th>Neither</th>
</tr>
</thead>
<tbody>
<tr>
<td>Listed for KT (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time to Listing (years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Both: 218
- Provider only: 108
- Patient only: 32
- Neither: 30

2016-06-17
Renal Transplant Symposium 2016
Living Donor Kidney Transplantation: Improving Education Outside of Transplant Centers about Live Donor Transplantation—Recommendations from a Consensus Conference

Amy D. Waterman, Marie Morgievich, David J. Cohen, Zeeshan Butt, Harini A. Chakker, Carrie Lindover,
# Making House Calls Increases Living Donor Inquiries and Evaluations for Blacks on the Kidney Transplant Waiting List

James R. Rodrigue,
Matthew J. Paek,
Ogo Egbuna,
Amy D. Waterman,
Jesse D. Schold,
Martha Pavlakis,
and Didier A. Mandelbrot

## Table 3. LDKT readiness stage, knowledge, concerns, and willingness by intervention group over time

<table>
<thead>
<tr>
<th></th>
<th>House calls</th>
<th>Group-based</th>
<th>Individual counseling</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline 1 wk 6 wk</td>
<td>Baseline 1 wk 6 wk</td>
<td>Baseline 1 wk 6 wk</td>
<td></td>
</tr>
<tr>
<td>LDKT readiness stage, %</td>
<td>Baseline 1 wk 6 wk</td>
<td>Baseline 1 wk 6 wk</td>
<td>Baseline 1 wk 6 wk</td>
<td></td>
</tr>
<tr>
<td>Pre-Contemplation</td>
<td>24 4 2</td>
<td>24 9 11</td>
<td>37 12 12</td>
<td>0.001</td>
</tr>
<tr>
<td>Contemplation</td>
<td>33 10 2</td>
<td>31 23 23</td>
<td>31 33 33</td>
<td></td>
</tr>
<tr>
<td>Preparation</td>
<td>32 46 24</td>
<td>33 46 32</td>
<td>22 44 41</td>
<td></td>
</tr>
<tr>
<td>Action</td>
<td>9 32 54</td>
<td>10 20 32</td>
<td>8 9 12</td>
<td></td>
</tr>
<tr>
<td>Maintenance</td>
<td>2 8 2</td>
<td>2 2 2</td>
<td>2 2 2</td>
<td></td>
</tr>
<tr>
<td>LDKT knowledge, mean</td>
<td>9.9 12.9 13.2</td>
<td>9.7 12.0 12.0</td>
<td>9.4 11.1 11.3</td>
<td>0.007</td>
</tr>
<tr>
<td>LDKT concerns, mean</td>
<td>38.9 32.4 31.5</td>
<td>38.9 34.3 34.5</td>
<td>39.9 37.7 38.6</td>
<td>0.005</td>
</tr>
<tr>
<td>Willingness to talk to others, mean</td>
<td>3.7 5.2 6.1</td>
<td>3.9 4.7 5.1</td>
<td>3.4 4.0 3.9</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Transplantation 2014;00: 00Y00
## Transplant Education Practices in Dialysis Centers

<table>
<thead>
<tr>
<th>Practice</th>
<th>Providers engaging in this practice: (N=1544)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orally recommend patients learn more about transplant themselves</td>
<td>72%</td>
</tr>
<tr>
<td>Orally recommend being evaluated for transplant</td>
<td>69%</td>
</tr>
<tr>
<td>Refer patients to an external transplant educational program</td>
<td>44%</td>
</tr>
<tr>
<td>Distribute transplant center phone numbers</td>
<td>37%</td>
</tr>
<tr>
<td>Detailed discussion about advantages/risks of DDKT</td>
<td>21%</td>
</tr>
<tr>
<td>Detailed discussion about advantages/risks of LDKT</td>
<td>21%</td>
</tr>
</tbody>
</table>
What is Explore Transplant?

- Comprehensive education program that helps kidney patients make informed transplant decisions
  - Video, print resources with patient and donor stories
  - Discussion of risks/benefits of transplant and living donation
- Individually-tailored conversations based on what is important to patient
- Educational materials for dialysis patients, family members & living donors
Explore Transplant

Ontario Adaptation

• Review, update and adapt Explore Transplant content to Canadian healthcare system

• Include Ontario physicians, patients and living donors in videos
Engagement from all 6 Ontario transplant programs
1. Is getting dialysis the same as having a working kidney?
No. Dialysis is a life-sustaining treatment where a machine filters wastes out of the blood. A normal working kidney can remove wastes from a person’s body 24 hours a day; dialysis can only do 10 to 15% (about one tenth) of the work of a normal kidney.

2. Who can get a transplant?
All kidney patients should talk to their doctor to see if they might be able to get a transplant. Many patients with diabetes and high blood pressure have kidney failure and still can get a transplant. Many older patients (even above the age of 70 years) can get a transplant. Patients may not be able to get a transplant if they have cancer or serious heart disease.

3. Is it better to have a transplant early?
Yes. Kidney transplants before starting dialysis or within the first years of dialysis are usually the most successful. Having a kidney transplant early can also prevent dialysis-related health problems.

4. Can a person live longer with a transplant compared to staying on dialysis?
Yes. Patients who have a transplant often live longer than patients who stay on dialysis. This is because dialysis treatments are hard on a person’s body and can cause other medical problems.

5. How long does a transplant last?
Kidney transplants are very successful. About 90 out of every 100 people find that their kidney transplants are still working after one year. Transplanted kidneys often last for 10 to 20 years. If a transplant fails, a patient can begin or return to dialysis or try to have another transplant.

6. How does a person’s life change if he or she gets a transplant?
Most patients say that getting a kidney transplant improves the quality of their lives. Recipients of a transplant say that they feel better, have more energy to spend time with their family, do their hobbies, travel and go back to work. Recipients also say they have more time, since they do not have to spend hours on dialysis each week.
TO ACCESS ONTARIO TRANSPLANT CENTRES:

University Health Network (UHN) – Kidney Transplant Program
Toronto, Ontario
(416) 340-4800, ext. 6385
www.uhn.ca/MOT/PatientsFamilies/Kidney_Transplant_Program/Pre_Transplant

St. Michael’s Hospital – Renal Transplant Program
Toronto, Ontario
(416) 867-3710
www.stmichaelshospital.com/programs/renaltransplant/

St. Joseph’s Healthcare
Hamilton, Ontario
(905) 522-1155, ext. 35170
www.stjoes.ca/health-services/kidney-urinary-services/kidney-transplant-inpatient-unit-clinic

London Health Sciences Centre – Kidney Transplant
London, Ontario
(519) 685-8500
www.lhsc.on.ca/Patients_Families_Visitors/Rehabilitation-options/transplant/index.htm

Kingston General Hospital – Nephrology, Renal and Kidney Care
Kingston, Ontario
(613) 549-6666, ext. 3527
www.kgh.on.ca/internal-medicine-care/neph/renal-and-kidney-care/nephrology/about

The Ottawa Hospital – Nephrology Programs
Ottawa, Ontario
(613) 738-8400, ext. 82228
www.ottawahospital.on.ca/wps/portal/Base/TheHospital/ClinicalServices/DeptPgrmC/Departments/Nephrology
Next steps

- Pilot training – MAY 10, UHN
- Pilot study of ETO – MSH-UHN AMO Innovation fund
- Provincial implementation study (Dr. A. Garg) of a multifaceted intervention to increase living donor kidney transplant – SPOR-CAN-SOLVED-CKD
Special thanks to:

Kidney recipients and living donors who shared their stories.

The family and friends who supported them.
Also special thanks to the dialysis and transplant professionals for their contribution from:

- Kidney Foundation of Canada
- Kingston General Hospital, Kingston, Ontario
- London Health Sciences Centre, London, Ontario
- St. Joseph`s Healthcare, Hamilton, Ontario
- St. Michael`s Hospital, Toronto, Ontario
- The Ottawa Hospital, Ottawa, Ontario
- University Health Network, Toronto, Ontario
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University of Toronto Transplantation Institute
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Ms. Dorothy Wong Ms. Heather Ford

Current and past students in my group:

- Aarushi Bansal
- Amanda Sissons
- Candice Richardson
- Dmitri Belenko
- Eleanor Warsmann
- Evan Tang
- Eszter Mucsi
- Franz Marie Gumabay
- Kefan Bei
- Luca Ugenti
- Luke Dingwell
- Michael Jeannette
- Nathaniel Edwards
- Priscilla Yung
- Sarah Cao
- Yalinie Kulandaivelu