#### Where do we go from here?

A path to reduce the demand for transplant tourism

BC Kidney Days 2012 October 19, 2012

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## Reality #1: Organ trafficking is bad





#### **Vendor Characteristics**

Table 1: Demographics of vendors and control donors

	Kidney	Control	
	vendors	donors	
Parameter	(n = 104)	(n = 184)	p-Value
Nephrectomy	$33.89 \pm 30.0$	$32.01 \pm 29.71$	0.601
duration (Months)			
Age (years)	$30.55 \pm 8.17$	$30.65 \pm 7.85$	0.919
Male:Female	85:19 (4.5:1)	149: 35 (4.2:1)	
Age males (years)	$30.8 \pm 8.0$	$30.75 \pm 7.2$	0.895
Age females (years)	$29.2 \pm 8.9$	$29.98 \pm 8.6$	0.660
Occupation			
White collar job	0 (0%)	20 (11.0%)	0.0001
Self-employed	12 (11.5%)	36 (19.5%)	0.079
Skilled worker	10 (9.6%)	89 (48.3%)	0.0001
Housewife	10 (9.6%)	20 (11.0%)	0.738
Student	0 (0%)	2 (1.0%)	0.286
Laborer	0 (0%)	9 (4.8%)	0.020
Bonded labor	67 (64%)	0 (0%)	0.0001
Unemployed	5 (4.8%)	8 (4.3%)	0.857
Monthly income \$ US	3		
< 50	89 (85%)	0 (0%)	0.0001
50–100	10 (10%)	6 (3%)	0.020
100-200	4 (4%)	97 (53%)	0.0001
> 200	1 (1%)	81 (44%)	0.0001

- Vendors' self-reported co-morbidities
  - jaundice 7.8%
  - malaria 5.7%
  - stone disease in 2%
  - UTI in 5%

#### Vendor outcomes

Table 2: Postnephrectomy complaints and complications

Complaint	Kidney vendors (n = 104)	Control donors (n = 184)	p-Value
Physical weakness	71 (68.3%)	4 (2.1%)	0.0001
Fatigue	11 (10.5%)	0 (0%)	0.0001
Fever	35 (33.7%)	4 (2.1%)	0.0001
Pain at site of surgery	61 (58.7%)	20 (11%)	0.0001
Urinary tract symptoms	50 (48.1%)	6 (3.2%)	0.0001
Dyspepsia	14 (13.4)	4 (2.1%)	0.0001
Loss of appetite	10 (9.6%)	0 (0%)	0.0001
Depression	5 (4.8%)	1 (0.5%)	0.010

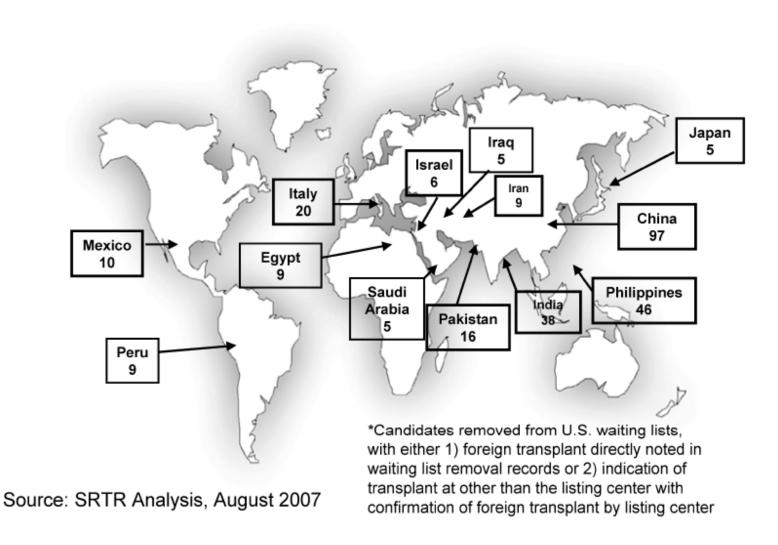
Compared to living related kidney donors Vendors had:

- More symptoms
- Higher creatinine
- More proteinuria
- More HCV
- More HBV

Table 5: Laboratory findings in vendors and controls

5	Kidney vendors	Control donors	V/ I
Parameter	(n = 104)	(n = 184)	p-Value
Hemoglobin gm / dL	$14.09 \pm 1.8$	$14.21 \pm 1.36$	0.268
PCV	$41.96 \pm 6.0$	$41.4 \pm 3.5$	0.351
Leukocyte count / cmm	$8684 \pm 1867$	$8327 \pm 2137$	0.52
Platelets $\times$ 10 $^{9}/L$	$223.2 \pm 62.7$	$227.1 \pm 177.2$	0.0001
Creatinine mg/dL	$1.17 \pm 0.21$	$1.02 \pm 0.27$	0.0001
Random blood glucose mg/dL	$93.02 \pm 20.6$	$99.0 \pm 14.2$	0.0005
GFR by Cockcroft-Gault mL/min	$70.94 \pm 14.2$	$95.4 \pm 20.44$	0.0001
< 60	27 (23.9%)	5 (2.7%)	0.0001
60 – 90	68 (65.4%)	69 (37.5%)	0.0001
91 – 120	9 (8.7%)	110 (59.8%)	0.0001
Urine protein/creatinine ratio	$0.15 \pm 0.11$	$0.10 \pm 0.10$	0.0001
0–0.1	37 (36.3%)	136 (73.9%)	0.0001
0.1–0.2	49 (47.1%)	33 (18.0%)	0.0001
0.2–0.3	10 (9.6%)	11 (5.9%)	0.25
>0.3	8 (7.7%)	4 (2.1%)	0.02
ALT IU/L	$26.6 \pm 21.3$	$28.17 \pm 17.0$	0.01
AST IU/L	$38.2 \pm 18.4$	$27.0 \pm 12.34$	0.0001
Deranged liver functions	14 (13.4%)	5 (8.7%)	0.02
Anti-HCV positive	25 (24%)	2 (1.0%)	0.0001
HbSAg reactive	4 (3.8%)	1 (0.5%)	0.04
Anti-HCV + HbSAg positive	2 (1.9%)	0 (0.%)	0.059

Travel for transplantation usually involves organ trafficking..it should not be lumped with medical tourism



#### Transplant tourism is NOT the best therapy for our patients

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Transplant Infectious Disease . ISSN 1398-2273

Short communication

Table 6. Infectious complications after transplantation<sup>a</sup>

Complication	Tourist $(n \ [\%]; n = 33)$	Matched Cohort $(n [\%]; n = 66)$
Total	17 (52.0) <sup>b</sup>	32 (48.5) <sup>b</sup>
Viral	12 (36.0)	9 (13.6)
CMV	10 (30.0)	8 (12.1)
HBV	1 (3.0)	0
HSV	1 (3.0)	0
EBV	0	0
VZV	0	1 (1.5)
Bacterial	7 (21.0)	21 (31.2)
pneumonia	1 (3.0)	5 (7.6)
UTI	4 (12.0)	14 (21.2)
wound	2 (6.0)°	2 (3.0)

<sup>a</sup>EBV, Epstein-Barr virus; HBV, hepatitis B virus; HSV, herpes simplex virus; VZV, varicella zoster virus.

<sup>b</sup>Total number of patients with at least one infection (includes patients with multiple infections).

<sup>c</sup>Perinephric abscess and peripancreatic abscess.

#### Invasive filamentous fungal infections associated with renal transplant tourism

#### Outcomes of Commercial Renal Transplantation: A Canadian Experience

G.V. Ramesh Prasad, <sup>1,2</sup> Ashutosh Shukla, <sup>1</sup> Michael Huang, <sup>2</sup> R. John D'A Honey, <sup>2,3</sup> and Jeffrey S. Zaltzman<sup>1,2,4</sup>

52% had opportunistic infections, with 2 deaths from fungal related infections

#### Transplant Tourism: Outcomes of United States Residents Who Undergo Kidney Transplantation Overseas

Muna T. Canales, 1,3 Bertram L. Kasiske, 1,2 and Mark E. Rosenberg 1

4/10 had "life-threatening" infections, with 1 infectious death

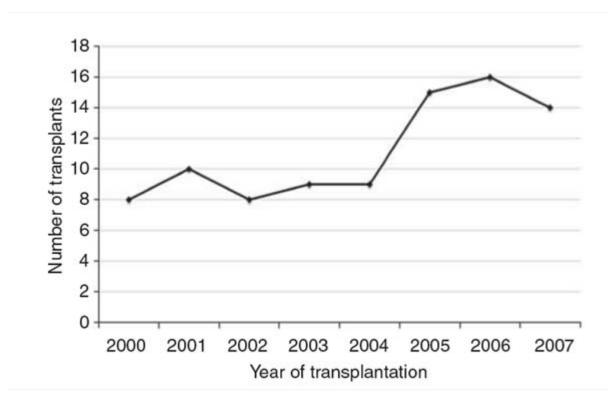
#### **Graft outcomes**

Table 4. Graft and patient outcomes of tourists and all patients who underwent transplantat

Parameter	Tourist $(n = 33)$	UCLA (n = 2507)	P
Acute rejection at 1 yr (%) <sup>c</sup> Serum creatinine level after transplantation (mean ± SD)	30	15.4	0.019 0.183
1 mo	$1.57 \pm 1.10$	N/A	
6 mo	$1.43 \pm 0.63$	N/A	
1 yr	$1.27 \pm 0.38$	1.45 ± 0.57	
Graft survival at 1 yr (%)	89.3	94.0	0.754
Patient survival at 1 yr (%)	100.0	96.4	0.466

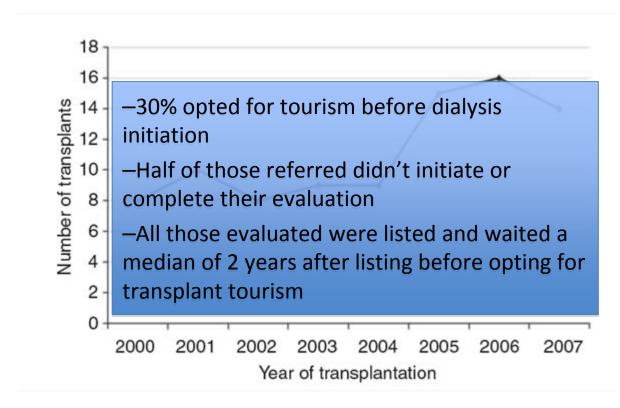
#### Some of our patients perceive TT as a legitimate option

Vancouver (2000-2008), n=93



#### Some of our patients perceive TT as a legitimate option

Vancouver (2000-2008), n=93



 This is a problem the renal community has to address

## Challenge

What is our goal?

 What are the responsibilities of the renal community?

Can we really change our patients' behaviours?

 How do we move this discussion forward to meet these goals?

## What is the goal?

To eliminate transplant tourism

### What is the goal?

To eliminate transplant tourism

 To eliminate the demand for transplant tourism

# Responsibilities of the renal community

Identify patients at risk

- Be proactive in reducing the impetus to opt for transplant tourism
  - Bring this up with patients
  - Reinforce the down sides (and our objection)
  - Highlight legitimate alternatives
  - Help facilitate alternatives

#### Who is at risk?

Table 1 | Characteristics of transplant tourists and comparison with adult first kidney only transplant recipients in BC during the study period

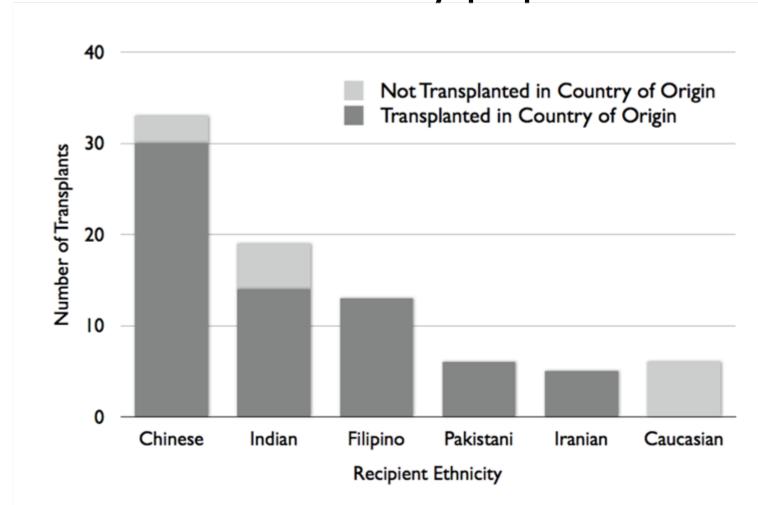
	Tourists (n=93)	Transplanted in BC (n=1217)	<i>P</i> -value
Mean age (years)	53 ± 11.3	49 ± 6.8	< 0.01
Female gender (%)	43	38	0.09
Donor type (%)			< 0.01
Deceased	27	41	
Living	40	59	
Unknown	33	0	
Mean dialysis exposure (months)	27 ± 20	$65 \pm 34$	<0.01
Preemptive transplantation (%)	29	21	
ESRD because of diabetes (%)	26	13.3	< 0.01
Ethnicity			< 0.01
Caucasian	9.7	67.3	
East Asian <sup>a</sup>	43.0	13.6	
South Asian <sup>b</sup>	26.9	9.0	
Filipino	14.0	4.8	
Black	0	0.8	
Other	6.5	0.4	

Abbreviations: BC, British Columbia; ESRD, end-stage renal disease.

<sup>&</sup>lt;sup>a</sup>East Asian (Chinese, Japanese, Korean, and Taiwanese).

<sup>&</sup>lt;sup>b</sup>South Asian (Indian, Pakistani, Sri Lankan, and Bangladeshi).

## Most transplant tourists are from ethnic minority populations



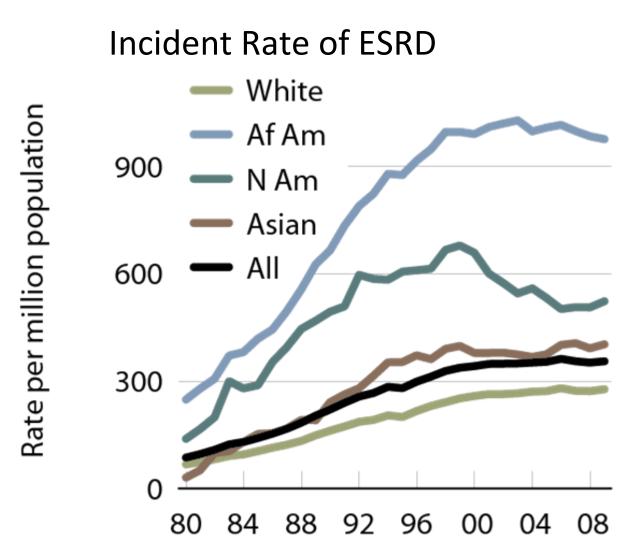
# Immigrant populations are at higher risk for transplant tourism

TABLE 2. Region of birth of recipients and countries where transplants were performed, January 1998 to February 2005

Region of birth (n=20)	h	Region of transplantation (n=22)		
Middle East	5	South Asia	12	
South Asia	5	East Asia	5	
Africa	4	Middle East	4	
East Asia	3	Southeast Asia	1	
Southeast Asia	2			
North America	1			

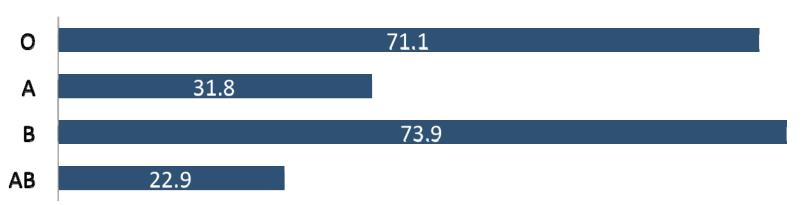
Why are ethnic minorities at higher risk?

#### The demand for transplant is greater



### Wait-times are longer

#### Median Wait (months) for 1st DDK transplant in BC\*



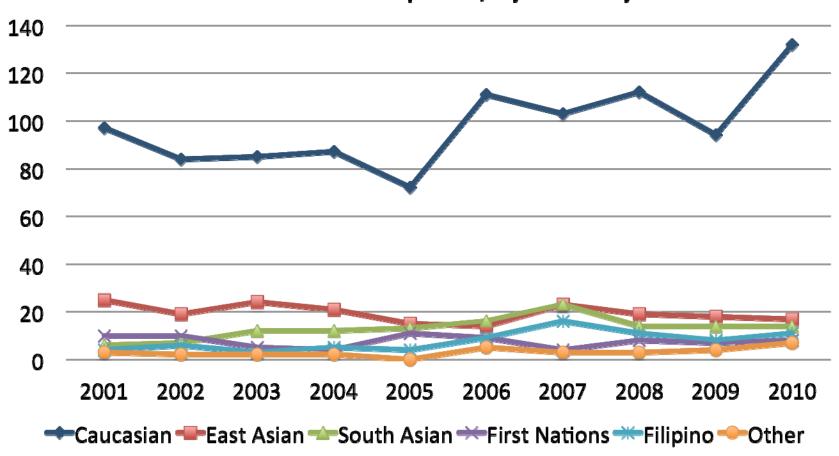
Cohort of incident dialysis patients in Canada n (%)

	East Asian	Indo Asian	White	<i>P</i> -value
Blood group type				
0	312 (41)	157 (35)	5948 (45)	< 0.0001
Α	212 (28)	113 (25)	5405 (41)	< 0.0001
В	178 (23)	150 (33)	1436 (11)	< 0.0001
AB	58 (8)	35 (8)	536 (4)	< 0.0001

<sup>\*</sup>Data Source: BCT - WT reflects median duration of dialysis prior to transplantation among transplanted patients in 2011 Tonelli et al. KI 2007

### No increase in transplantation

#### Number of transplants, by ethnicity



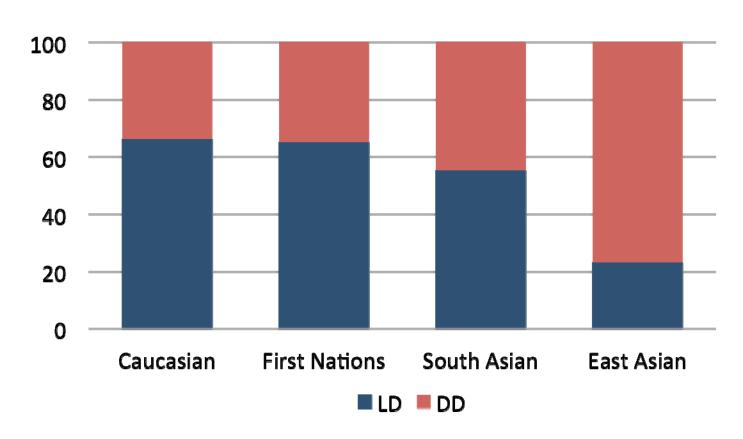
Data source: BCT

## Asian ESRD patients have reduced access to deceased donor transplantation

		Any transplan	it
	N (%)	Age-adjusted HR (95% CI)	Adjusted <sup>a</sup> HR (95% CI)
East Asian	380 (31)	0.88 (0.79, 0.97)	0.71 (0.63, 0.79)
Indo Asian	203 (28)	0.69 (0.60, 0.80)	0.69 (0.60, 0.80)
White	4841 (25)	1.0	1.0

#### LD transplants are less common in Asians

#### % LDTX and DDTX, by recipient ethnicity



<sup>\*</sup>Based on SPH transplants 2000-2008

# Ethnic disparities most marked for access to Living donor transplantation

Table 2	Transp	lantation	by	race
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	Any transplant			Dec	Deceased donor transplant only		Living donor transplant only		ant only
	N (%)	Age-adjusted HR (95% CI)	Adjusted <sup>a</sup> HR (95% CI)	N (%)	Age-adjusted HR (95% CI)	Adjusted <sup>a</sup> HR (95% CI)	N (%)	Age-adjusted HR (95% CI)	Adjusted <sup>a</sup> HR (95% CI)
East Asian	380 (31)	0.88 (0.79, 0.97)	0.71 (0.63, 0.79)	335 (27)	1.03 (0.92, 1.15)	0.90 (0.80, 1.01)	45 (3.6)	0.42 (0.31, 0.56)	0.27 (0.20, 0.37)
Indo Asian	203 (28)	0.69 (0.60, 0.80)	0.69 (0.60, 0.80)	163 (22)	0.74 (0.63, 0.87)	0.82 (0.70, 0.97)	40 (5.4)	0.55 (0.40, 0.75)	0.42 (0.31, 0.58)
White	4841 (25)	1.0	1.0	3576 (18)	1.0	1.0	1265 (6.5)	1.0	1.0

East Asians are 73% less likely to undergo LDKT

South Asians are 58% less likely to undergo LDKT

# We need to better characterize patients at risk for transplant tourism

- Identify patients with a high willingness to consider transplant tourism
  - Detailed sociodemographic characteristics
  - Understand their knowledge/perception on the risks of transplant tourism
  - Understand their barriers to local transplantation
  - Understand barriers to pursue living donor transplantation locally

#### There are multiple opportunities to intervene

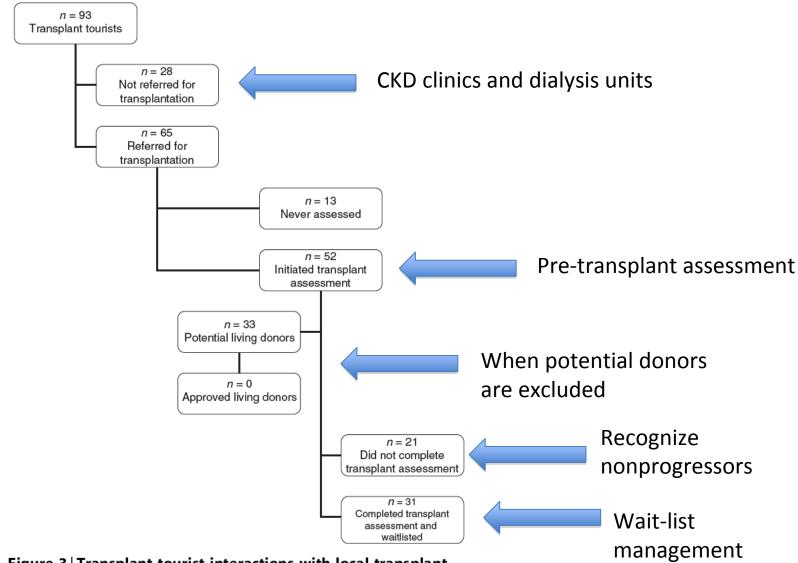


Figure 3 | Transplant tourist interactions with local transplant program and potential living donors.

#### What is the intervention?

 Focused on increasing the pursuit of living donor kidney transplantation

- This is where the greatest ethnic disparities exist
- It is most amenable to patient-level intervention
- It is the best therapy available

## Interventions to increase the pursuit of LDKT have been effective in other marginalized populations

American Journal of Transplantation 2007; 7: 394–401 Blackwell Munksgaard

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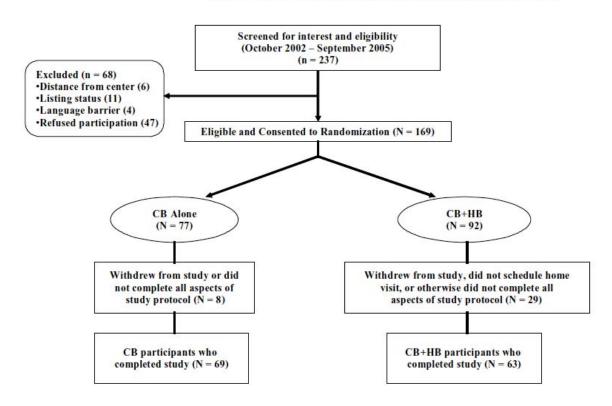
doi: 10.1111/j.1600-6143.2006.01623.x

## Increasing Live Donor Kidney Transplantation: A Randomized Controlled Trial of a Home-Based Educational Intervention

J. R. Rodrigue<sup>a,\*</sup>, D. L. Cornell<sup>b</sup>, J. K. Lin<sup>c</sup>, B. Kaplan<sup>d</sup> and R. J. Howard<sup>e</sup>

## Single Center prospective randomized trial at the University of Florida

#### Home-Based Educational Intervention to Increase LDKT



#### Clinic Based

- -brief discussion with MD
- -60 minute group education session
- -Written materials

#### Home Based

- -'guest list' generated at the CB visit
- -Written materials on the HB intervention
- -60-90 minute interactive session by 1-2 nurse educators within 6 weeks

#### **Table 1:** Primary content of the HB education session

Benefits of transplantation before dialysis (or as soon as possible after dialysis)

Relationship between dialysis time and transplant outcomes

Average waiting times for transplantation

Transplant evaluation process

Types of transplant and donors (deceased donor, including standard criteria, expanded criteria, and donation after cardiac death; living donor)

Transplant outcomes

Current deceased donation rates

Differences in donation rates (living and deceased) by race

Living donor evaluation process

Living donor eligibility criteria

Living donor surgery (open, laparoscopic)

Typical donor recovery

Risks of living donation

Benefits of living donation

Common donor concerns

Common recipient concerns

Possible indirect costs

Helpful resources for transplant patients

Helpful resources for living donors

Transplant center contact information

## More donor inquiries, donor evaluations, and LDKT with HB education

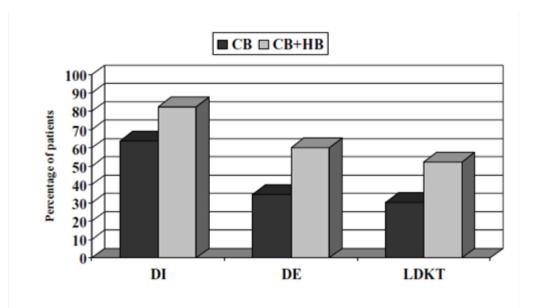


Figure 2: Percentage of patients with living donor inquiries (DI), living donor evaluations (DE) and live donor kidney transplant (LDKT).

African Americans: %LDKT 13.8% in CB vs 45.2% in CB+HB

# The interventions need to target culture-specific barriers

- Potential barriers to LDKT in South and East Asian populations
  - Concern about donor safety (lack of knowledge on safety of kidney donation)
  - Lack of knowledge on benefits of LDKT
  - Discomfort discussing their illness within their community
  - Less willing to approach certain potential donors (eg. children)
  - Fear/presumption that no one will come forward
  - Mistrust of the health care system
  - Viewing transplant tourism as a safe and viable alternative to LDKT

Protocol of a Randomized Controlled Trial of Culturally Sensitive Interventions to Improve African Americans' and Non-African Americans' Early, Shared, and Informed Consideration of Live Kidney Transplantation: The talking about Live Kidney Donation (TALK) study

L Ebony Boulware<sup>1,2,3\*</sup>, Felicia Hill-Briggs<sup>1,3,4</sup>, Edward S Kraus<sup>5</sup>, J Keith Melancon<sup>6</sup>, Raquel McGuire<sup>7</sup>, Bobbie Bonhage<sup>7</sup>, Mikiko Senga<sup>3</sup>, Patti Ephraim<sup>2,3</sup>, Kira E Evans<sup>3</sup>, Brenda Falcone<sup>7</sup>, Misty U Troll<sup>1,3</sup>, Nicole Depasquale<sup>4</sup> and Neil R Powe<sup>8</sup>

#### Abstract

**Background:** Live kidney transplantation (LKT) is underutilized, particularly among ethnic/racial minorities. The effectiveness of culturally sensitive educational and behavioral interventions to encourage patients' early, shared (with family and health care providers) and informed consideration of LKT and ameliorate disparities in consideration of LKT is unknown.

Methods/Design: We report the protocol of the Talking About Live Kidney Donation (TALK) Study, a two-phase study utilizing qualitative and quantitative research methods to design and test culturally sensitive interventions to improve patients' shared and informed consideration of LKT. Study Phase 1 involved the evidence-based development of culturally sensitive written and audiovisual educational materials as well as a social worker intervention to encourage patients' engagement in shared and informed consideration of LKT. In Study Phase 2, we are currently conducting a randomized controlled trial in which participants with progressing chronic kidney disease receive: 1) usual care by their nephrologists, 2) usual care plus the educational materials, or 3) usual care plus the educational materials and the social worker intervention. The primary outcome of the randomized controlled trial will include patients' self-reported rates of consideration of LKT (including family discussions of LKT, patient-physician discussions of LKT, and identification of an LKT donor). We will also assess differences in rates of consideration of LKT among African Americans and non-African Americans.

**Discussion:** The TALK Study rigorously developed and is currently testing the effectiveness of culturally sensitive interventions to improve patients' and families' consideration of LKT. Results from TALK will provide needed evidence on ways to enhance consideration of this optimal treatment for patients with end stage renal disease.

Trial Registration: ClinicalTrials.gov number, NCT00932334

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Helpful resources for living donors

Transplant center contact information

Risks of transplant tourism

### Moving forward

- Transplant tourism is not an abstract practice that impacts a small group of people
- It highlights our inability to meet the needs of our patients
- Eliminating disparities in access to transplantation is critical to eliminate the demand for transplant tourism
- Deterring transplant tourism is critical to increasing the pursuit of LDKT

## Thank you





