Improving Access to Kidney Transplantation

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Objectives

• To describe variability in early transplant access across dialysis facilities and transplant centers

• To describe the mission, goals, and accomplishments of a regional collaboration aimed at reducing disparities in access to kidney transplant

• To offer opportunities for improving the quality of care of patients with kidney disease throughout the course of their disease
Establishing the Problem: Substantial Variability in Transplant Rates among U.S. Dialysis Facilities


STR = \frac{\text{Actual # of first transplants}}{\text{Expected # of first transplants}}

101 facilities with no transplants

Standardized Transplant Ratio (STR) among Dialysis Facilities by State: 2013-2016

\[
\text{STR} = \frac{\text{Actual # of first transplants}}{\text{Expected # of first transplants}}
\]

<table>
<thead>
<tr>
<th>State</th>
<th>STR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indiana</td>
<td>0.93</td>
</tr>
<tr>
<td>Kentucky</td>
<td>0.88</td>
</tr>
<tr>
<td>Ohio</td>
<td>1.03</td>
</tr>
</tbody>
</table>

2018 Dialysis Facility Report Data
Disparities in Access to Kidney Transplantation are Multilevel and Multifactorial

Data collection will be ongoing quarterly

DSA/OPO Characteristics

Transplant Center Characteristics

Organ Supply

Organ Demand

Patient Factors

Neighborhood characteristics

Health System Factors

Provider Factors

Access to Transplantation

ESRD patients shared across healthcare settings

DSA=Donor Service Area
OPO = Organ Procurement Organization
Establishing the Problem in ESRD Network 6

• The Southeastern United States has the
  – Highest burden of CKD and ESRD
  – Lowest kidney transplant rates
Standardized Transplant Ratio (STR) among Dialysis Facilities by Network: 2013-2016

\[ STR = \frac{\text{Actual # of first transplants}}{\text{Expected # of first transplants}} \]
Establishing the Problem in ESRD Network 6

• The Southeastern United States has the:
  • Highest burden of CKD and ESRD
  • Lowest kidney transplant rates

• Creation of the **Southeastern Kidney Transplant Coalition** to identify and reduce barriers in the kidney transplant process
Southeastern Kidney Transplant Coalition

- Formed in September 2010 at request of Southeastern Kidney Council
- A collaboration between partners in the kidney disease community who share the common goal of improving transplant rates in the Southeast
  - Highest burden of CKD and ESRD
  - Lowest rate of kidney transplantation
- Eliminating health disparities in access to kidney transplantation in the Southeast
Mission and Goals of the Southeastern Kidney Transplant Coalition

• **Mission**
  – To increase the kidney transplant rate by identifying and reducing barriers in the kidney transplant process

• **Goals**
  – To increase dedication and awareness among kidney disease patients, providers, and the public
  – To build an alliance of Network 6 transplant centers
  – To increase the availability of organs
  – To identify, test, and distribute best practices through the Network
Increase Dedication and Awareness

- 2017 National Kidney Foundation Patient Centered Outcomes Research Stakeholders’ Conference
  - Coalition Members in attendance, including patient partners
  - First national effort to identify patient-led kidney disease national research priorities

- AAKP RENALIFE Magazine, Volume 51, No. 1 – January 2018
  - Article titled: “Southeastern Kidney Transplant Coalition”
  - Describes the Coalition’s mission and current work
Build an Alliance of Transplant Centers

- Georgia transplant centers collaborated to collect patient-level referral data, 2005-2018

- Successfully collected patient-level referral/evaluation data across GA, NC, and SC transplant centers, 2012-2018
  - Data collection will be ongoing quarterly
Increase Availability of Organs

- **NIDDK R01**: “Reducing Disparities in Living Donation among African Americans”, using Project Living ACTS & T-REX
  - Dr. Kimberly Jacob Arriola & Dr. Rachel Patzer (Co-PIs)
  - Coalition Site Collaborators:
    - Dr. Derek DuBay (MUSC)
    - Dr. Erica Hartmann (Piedmont)
    - Dr. Carlos Zayas (Augusta), & Dr. Laura Mulloy (Augusta)
  - Recruitment and data collection to began in 2019

- **R01 Project: Allocation System Changes for Equity in Kidney Transplant (ASCENT)**
  - Improving equity in organ allocation and patient/provider awareness of the new kidney allocation system implemented in 2014
  - “Awareness of the New Kidney Allocation System among United States Dialysis Providers with Low Waitlisting”, *American Journal of Nephrology* – March 2018
• T-REX: Enhancing Care Coordination Between Dialysis Facilities and Transplant Centers
  – Successfully implemented in several transplant centers and dialysis facilities in ESRD Network 6
  – Positive feedback received, with new software update pending

• Example: Patient Education CHECKLIST
  – Educational tool for dialysis providers to guide discussion about kidney transplant with patients
  – New layout with updated resources

• RaDIANT Community (GA only) Study
• Ongoing RaDIANT Regional (GA, NC, SC) Study
Steps to Kidney Transplantation: 
**ESRD patients shared across healthcare settings not tracked in national surveillance data**

- Pre-ESRD NephCare
- ESRD
- Education
- Referral
- Evaluation Start
- Eval Complete
- Waitlist
- Transplant

- 48.2% Agreement with claims\(^1\)
- 56.2% provider/patient agreement\(^2\)

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1. Kim JASN 2012; 23(6)
2. Salter JASN 2014; 25(12)
Established a Pre-Transplant Data Registry - Data Collection Methods, 2005-2011

Transplant centers submit patient-level Excel file via a Secured Filed Transfer Protocol

IPRO Digital Health Coordinating Center

Patient-Level Pre-Transplant Data Registry – Collected Fields

<table>
<thead>
<tr>
<th>Patient Name</th>
<th>Referred Transplant Center</th>
<th>Referral Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient DOB</td>
<td>Preemptive Referral</td>
<td>Eval Start Date</td>
</tr>
<tr>
<td>Patient SSN</td>
<td>Dialysis Start Date</td>
<td>Eval Completion Date</td>
</tr>
<tr>
<td>Patient Race</td>
<td>Dialysis Facility Name</td>
<td>Waitlisting Date</td>
</tr>
<tr>
<td>Patient Sex</td>
<td>Dialysis Facility Address</td>
<td>Referring Physician</td>
</tr>
<tr>
<td>Patient Address</td>
<td>Dialysis Facility CCN</td>
<td>Referring Staff</td>
</tr>
<tr>
<td>Patient Insurance</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*BOLD indicates required field
RaDIANT Community Study: Examining Referral Rates across Georgia Dialysis Facilities
308 Georgia Dialysis Facilities, 2005-2011

- In Georgia overall, limited proportion of dialysis patients referred for kidney transplant evaluation during this time period.

- Substantial variability in referral among dialysis facilities (Range: 0% to 75%)
Characteristics associated with lower referral for transplant not necessarily the same as lower waitlisting

Older patients less likely to be referred but NOT less likely to be waitlisted

Females less likely to be referred

Black patients more likely to be referred but less likely to be waitlisted

<table>
<thead>
<tr>
<th>Covariate</th>
<th>Referral Within 1 Year of ESRD (n = 15279)</th>
<th>Waitlisting or Transplant Receipt Within 1 Year of Referral, Among Patients Referred Within 1 Year of ESRD (n = 4280)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Odds Ratio (95% CI)</td>
<td>Odds Ratio (95% CI)</td>
</tr>
<tr>
<td><strong>Patient-Level Characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, y</td>
<td></td>
<td></td>
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<tr>
<td>18-29</td>
<td>1 [Reference]</td>
<td>1 [Reference]</td>
</tr>
<tr>
<td>30-39</td>
<td>0.77 (0.62-0.94)</td>
<td>0.82 (0.58-1.15)</td>
</tr>
<tr>
<td>40-49</td>
<td>0.48 (0.40-0.58)</td>
<td>0.77 (0.56-1.10)</td>
</tr>
<tr>
<td>50-59</td>
<td>0.35 (0.28-0.42)</td>
<td>0.73 (0.53-1.00)</td>
</tr>
<tr>
<td>60-69</td>
<td>0.19 (0.15-0.23)</td>
<td>0.83 (0.57-1.20)</td>
</tr>
<tr>
<td>Female vs male</td>
<td>0.89 (0.83-0.96)</td>
<td>0.93 (0.78-1.09)</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic white</td>
<td>1 [Reference]</td>
<td>1 [Reference]</td>
</tr>
<tr>
<td>Hispanic white</td>
<td>0.94 (0.66-1.34)</td>
<td>1.12 (0.70-1.78)</td>
</tr>
<tr>
<td>Non-Hispanic black</td>
<td>1.22 (1.10-1.35)</td>
<td>0.77 (0.64-0.93)</td>
</tr>
<tr>
<td>Other</td>
<td>1.95 (1.47-2.58)</td>
<td>1.35 (0.86-2.13)</td>
</tr>
</tbody>
</table>

Patients with pre-ESRD nephrology care more likely to be referred & waitlisted

Patients with private insurance more likely to be referred & waitlisted

Patients living in high poverty neighborhoods less likely to be referred & waitlisted
Standardized Transplantation Referral Ratio to Assess Clinical Performance of Transplant Referral among Dialysis Facilities

Study Population
- 8,308 dialysis patients
- from 249 Georgia dialysis facilities
- referred to 3 Georgia kidney transplant centers
- 2008-2012

STReR

- Standardized Transplant Referral Ratio
- Risk-adjusted for
- In this pop.:
  - Range: 0-4.87
  - Mean: 1.16
  - SD: 0.76

Actual referrals

Expected referrals

The STReR is a new dialysis-facility-level quality metric for referrals to transplant.

Coordinates with the 2018-2019 CMS Statement of Work

C.4.2 Improve Transplant Coordination – Intent is to promote early referral to transplant, and assist patients and providers to improve referral patterns

By 2023, increase the percentage of ESRD patients on the transplant waitlist to 30% from the 2016 national average of 18.5%

C.4.2.B. Increase Rates of Patients on a Transplant Waitlist

- Monthly facility metrics of each of the 6 steps leading to receiving a transplant (right)
- Promote communication between dialysis facilities, transplant centers, hospitals, nephrologists and other healthcare providers to improve the rate of patients on the transplant waitlist
- Engaging hospitals, transplant centers, and nephrologists along with other healthcare providers to educate patients at the earliest diagnosis of ESRD about transplant and begin the process of successfully being on a transplant waitlist
- Demonstrate a 2 percentage point improvement in the natural trend of the Network of patients on the transplant waitlist in 30% of facilities in the Network service area
Targeted Interventions to Populations and Regions with Low Transplant Rates

• The RaDIANT Community Study
  – Georgia facilities with either low transplant referral or racial disparities in referral randomized (n=134)
  – Multicomponent quality improvement and educational interventions
  – Outcome: referral for transplant and racial disparity reduction

Patzer et al. BMC Nephrology 2014
Highlighted Intervention: Facility feedback reports detailing transplant referral practices

ESRD NETWORK 6 TRANSPLANT REFERRAL BASELINE FEEDBACK REPORT

110000 Peachy Keen Dialysis

WHY ARE CMS AND NETWORK 6 INTERESTED IN REDUCING RACIAL DISPARITIES IN TRANSPLANT REFERRALS IN GEORGIA?

Kidney transplant is the optimal treatment for most people with ESRD

- Longer survival
- Better quality of life
- Lower hospitalization rates

And Georgia has the lowest transplant rate in Network 6 and the US

HOW DID MY FACILITY GET SELECTED FOR THIS PROJECT?

- The Transplant Project is based in Georgia since it has the lowest transplant rate.
- Facilities were selected based on low overall crude referral rates and/or racial disparities in referrals.

WHAT ARE WE REQUIRED TO DO?

- Increase transplant referrals for all of Georgia patients
- Monitor and eliminate any racial disparity in patient referrals
- See Project Timeline for more details on required activities
- Call the Network if you need help: 919.855.0882

*Method: The 3 Georgia transplant centers provided a list of all patients referred for transplant in 2012 and CMS provided a list of all patients dialyzing in Georgia in 2012. Rate=Referrals/Patients. This does not account for patients referred prior to July 2012 and is only used as a screen for facility selection. However, we encourage you to assess patients for transplant referral each year if they have not yet been waitlisted or transplanted. Future calculations will be based on actual referrals as documented by you and the transplant center.
Change in Proportion of Patients Referred for Transplant by Study Group

Patzer RE, Paul S, Plantinga L, Gander J, McClellan WM, Arriola KJ, Pastan SO, JASN 2017
Expanded Pre-Transplant Data Registry, 2012-2018 – Data Collection Methods

Patient-Level Pre-Transplant Data Registry – Collected Fields

- Patient Name
- Patient DOB
- Patient SSN
- Patient Race
- Patient Sex
- Patient Address
- Patient Insurance
- Referred Transplant Center
- Preemptive Referral
- Dialysis Start Date
- Dialysis Facility Name
- Dialysis Facility Address
- Dialysis Facility CCN
- Referral Date
- Eval Start Date
- Eval Completion Date
- Waitlisting Date
- Referring Physician
- Referring Staff

*Bold indicates required field
Variation in Key Steps in the Kidney Transplant Process among ESRD Network 6 Dialysis Facilities, 2012-2016

- **Referral**: Referred within 1 year of ESRD start date
- **Evaluation Start**: Started evaluation at a transplant center within 6 months of referral date

Median % referred and starting evaluation: 15.05%
Median % referred: 31.30%

20 facilities with no referrals
22 facilities with referred patients that did not start an evaluation at a transplant center

End-Stage Renal Disease Network 6 Dialysis Facilities with >10 Patients (n=698)
Transplant centers (n=48) and dialysis facilities (n=1,833) included in ESRD Networks 1, 2, 6, and 9

- Characterize health center variation in access to early steps of the kidney transplantation process in larger region with support of ESRD Networks and transplant centers.
- Conduct epidemiologic analyses to understand the barriers/facilitators to early transplant access across different regions.
- Use early transplant steps as outcomes (or process measures) in interventions or quality improvement projects.
A PATH FORWARD
The Ideal Quality Metric for Transplant: Shared Accountability

Figure 1. Treatment pathways and quality oversight for ESRD health care delivery. Currently, dialysis centers, organ procurement organizations (OPOs), and transplant (Tx) centers are evaluated for quality in isolation (red circles). Our proposed model is to evaluate providers simultaneously on the basis of outcomes for a population of patients with ESRD throughout transitions of care (green box). The Centers for Medicare and Medicaid Services uses data to evaluate quality of each of these providers. ARF, acute renal failure; DD, deceased donor.

Schold et al, CJASN 2017
Summary & Future Directions

• There are interventions that work to increase transplant access for different regions, and for different transplant steps.
  – First, need for data collection on early transplant steps
  – Epidemiologic analyses to determine barriers and facilitators by region
  – Target interventions and quality improvement projects to the needs of the population

• Advocacy for quality metrics that are aligned between the multiple health sectors (dialysis facilities and transplant centers)
  – Need for more coordination between dialysis facilities & ESRD Networks to ensure
  – Ultimate goal should be to save lives, for all ESRD patients
Acknowledgements

Southeastern Kidney Transplant Coalition

Emory University
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Augusta University
ESRD Patients
DaVita Dialysis
Transplant Recipients
UNC Transplant
Fresenius Medical Care
Georgia Transplant Foundation
IPRO ESRD Network 6
Dialysis Clinic, Inc.
Vidant Medical Center

American Association of Kidney Patients
National Kidney Foundation
Health Systems Management
LifeShare of the Carolinas
Medical University of SC
Wake Forest Transplant
Lifelink of Georgia
Carolina Donor Services
Carolinas Healthcare Transplant

Southeastern Kidney Transplant Coalition

IPRO ESRD Network of the South Atlantic

- Shannon Wright, BSW, PMP, ITIL v3
- Alexandra Cruz
- Joseph Gulotta
- Jaz Michael-King
- Steve Smith
- Sue Caponi

Project Region Champions:
- Network 1: Ana Rossi, MD, MPH (ME)
- Network 2: Sumit Mohan, MD, MPH (NY)
- Network 6: Stephen Pastan, MD (GA)
- Network 9: Anne Huml, MD (OH)

Emory Transplant Health Services Research Team

- Vaughn Barry, PhD
- Reem Hamoda, MPH
- Julien Hogan, MD, PhD
- Laura McPherson, MPH
- Taylor Melanson, PhD
- Katie Ross, MPH
- Larissa Teunis, MPA
- Laura Plantinga, PhD, MS
- Sudeshna Paul, PhD, MS
- Elizabeth Walker, BS
- Rebecca Zhang, MS

Relevant Funding Sources:
National Institute on Minority Health and Health Disparities (U01MD010611)
BACKUP SLIDES
Multicomponent Intervention Activities

**Required Activities**

1. Facility In-Service Orientation to Transplant Project
2. Dialysis Facility Quality Improvement Plan
3. Formation of Patient and Family Advisory Group (monthly meetings)
4. **Peer Mentor Program**
5. **Educational Webinars for Dialysis Facility Leadership and Staff**
6. Standard Quality Improvement Activities and Monthly Monitoring of Transplant Referral and Evaluation Data
7. Patient and Family Education Programs
8. Facility-Wide Movie Night
9. 5 Diamond Patient Safety Module on Transplantation
10. **Receipt of Facility-specific feedback report**

**Optional Activities** (Facilities had to complete at least two of the following activities)

1. Kidney Transplantation Bulletin Board
2. Distribution of “A Patient’s Guide to Kidney Transplant”
3. Transplant Education Month
4. Transplant Symposium hosted by Georgia Transplant Foundation
5. Kidney Transplant Toolkit
Process Evaluation Results

Survey of staff from 65 of 67 facilities

- **50.8%** of intervention facilities adhered to all required RaDIANT intervention activities
- **63.1%** reported RaDIANT activities as helpful
- **90.8%** willing to continue at least one activity beyond study period

Facilities were asked to participate in 10 “required” activities and 2 out of 5 “optional activities”

**Activities with High Participation (>75%)**
- In-service staff orientations
- Standard QI and monitoring activities
- Staff educational webinars

**Activities Perceived as Helpful**
- In-service staff orientations
- Staff educational webinars
- Patient and family education programs

**Top Activities Willing to Continue**
- Peer mentoring program
- Patient and family education programs
- In-service staff orientations
Slides based on data collected in pre- and post- survey administered by ESRD Network 6 as part of the RaDIANT Regional Study
Standardized Transplant Ratio (STR) among Dialysis Facilities in Indiana: 2013-2016

<table>
<thead>
<tr>
<th></th>
<th>STR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Min</td>
<td>0</td>
</tr>
<tr>
<td>Q1</td>
<td>0.6</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>0.92 (0.6, 1.28)</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>1.01 (0.6)</td>
</tr>
<tr>
<td>Q3</td>
<td>1.28</td>
</tr>
<tr>
<td>Max</td>
<td>3.8</td>
</tr>
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</table>

* 58 facilities missing STR data from DFR
Standardized Transplant Ratio (STR) among Dialysis Facilities in Kentucky: 2013-2016

<table>
<thead>
<tr>
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<th>STR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Min</td>
<td>0</td>
</tr>
<tr>
<td>Q1</td>
<td>0.48</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>0.72 (0.48, 1.2)</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>0.89 (0.6)</td>
</tr>
<tr>
<td>Q3</td>
<td>1.2</td>
</tr>
<tr>
<td>Max</td>
<td>3.1</td>
</tr>
</tbody>
</table>

*31 facilities missing STR data from DFR
Standardized Transplant Ratio (STR) among Dialysis Facilities in Ohio: 2013-2016

- **Min**: 0
- **Q1**: 0.63
- **Median (IQR)**: 1.02 (0.63, 1.49)
- **Mean (SD)**: 1.09 (0.59)
- **Q3**: 1.49
- **Max**: 3.01

*114 facilities missing STR data from DFR*