Reducing Healthcare Disparities: What We Know and Where We Need to Go

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Objectives

- Describe factors influencing healthcare disparities in end stage renal disease and access to transplants
- Highlight examples of new programs and ongoing research that may help to reduce these disparities
- Share key lessons learned to inform future initiatives

Disclosures

- No conflicts of interest
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Motivation: This is My Home State
These Are The Images That Come to My Mind about MS....
National Burden of End Stage Renal Disease

Health Disparities vs. Health Equity

- **Health Disparities**: “preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations”\(^1\)

- **Health Equity**: “When every person has the opportunity to “attain his or her full health potential” and no one is “disadvantaged from achieving this potential because of social position or other socially determined circumstances”\(^2\)

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Disadvantaged Populations

<table>
<thead>
<tr>
<th>People of Color</th>
<th>Immigrants</th>
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<tbody>
<tr>
<td>Low-Income</td>
<td>LGBTQ</td>
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<tr>
<td>Women</td>
<td>Individuals with Special Needs</td>
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<tr>
<td>Children</td>
<td>Rural and Urban Residents</td>
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<td>Older Adults</td>
<td>Low Literacy and Numeracy</td>
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- Complex factors influence the presence of health and healthcare disparities
- Persistent disparities in end stage renal disease
Disparities in End Stage Renal Disease

- Defined as permanent loss of kidney function (GFR <15 mL/min/1.73m²)
- ESRD prevalence ~678,000
- Compared to Whites, ESRD prevalence:
  - 3.7 times ↑ in Blacks
  - 1.5 times ↑ in Asians
  - 1.4 times ↑ in Native Am.
  - Also ↑ in Hispanics

Reference: US Renal Data System Annual Reports
Case Study: A 65-year-old African American woman with multiple chronic conditions

- Mrs. D. is a 65-year-old African American woman with diabetes, hypertension, and ESRD.
- History of poor diabetes and blood pressure control
- Treated with several medications over past 5 years
- Admits she sometimes does not adhere to lifestyle changes, skips her pills, and misses appointments
- Recently began dialysis treatment for kidney failure

Case adapted from Cooper, JAMA 2009 and Pavlakis, JAMA 2011. Photo courtesy of Google.
Health Disparities are Complex

The Social Ecological Model of Population Health

Case Study in Healthcare Disparities: Live Donor Kidney Transplantation
Live Donor Kidney Transplantation

- LDKT offers longer life expectancy and quality of life than dialysis or deceased donor transplantation
- Patients may bypass transplant waiting list if they identify a living donor
- Racial/ethnic minority patients with ESRD less likely to receive LDKT than Whites
- Disparities in transplant rates have persisted since the 1980s (or earlier). **WHY?**

LDKT Rates in the US by Race

Data Source: USRDS Annual Data Reports
Perceptions of Barriers Influencing Transplant Access

- Communication barriers between dialysis facilities and transplant centers
- Misunderstanding of Allocation System Changes
- Overcoming Patient Modifiable Lifestyle Changes
- Misconception of Patient Self-Referral Process
- Availability of Spanish-language Resources
- Educating an Aging/Nursing Home Population

Courtesy: Island Peer Review Organization (IPRO) – Jeanine Pilgrim, BSHSM
Evidence-Based Model Highlighting Barriers That Contribute to Disparities in Kidney Transplantation

<table>
<thead>
<tr>
<th>Multilevel Influences</th>
<th>Donor Identification</th>
<th>Transplant Evaluation</th>
<th>Kidney Transplant</th>
<th>Post-Transplant</th>
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<tr>
<td>Recipient-Donor Level</td>
<td>Clinical Suitability</td>
<td>Family Structure</td>
<td>Graft Failure/Rejection</td>
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<td>Surgical Concerns</td>
<td>Occupational Structure</td>
<td>Future Health Risks</td>
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<td>Medical Mistrust</td>
<td>Economic Costs</td>
<td>Medication Side Effects</td>
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<td>Religious Concerns</td>
<td>Health Literacy</td>
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<td>Denial and Coping</td>
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<td>Knowledge and Beliefs</td>
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<td>Health Care Provider Level</td>
<td>Communication Skills</td>
<td>Perceptions of patient preferences for LDKT</td>
<td>Transplant referral, evaluation, and workup</td>
<td>Healthcare follow-up</td>
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<td>Perceptions of Suitability</td>
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<td>Preemptive Referral</td>
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<td>Training/Knowledge</td>
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<td>Cultural Competence</td>
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<td>Health System Level</td>
<td>Insurance Coverage</td>
<td>Availability and quality of financial counseling</td>
<td>Availability of ABO incompatible, HLA desensitization, and kidney paired donation programs</td>
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<td>Information Quality</td>
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<td>Educational Setting</td>
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<td>Decision Support</td>
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<td>Population-Community Level</td>
<td>Chronic Disease Burden</td>
<td>Availability of mandated sick leave from work and donor reimbursement</td>
<td>Medication Coverage</td>
<td>Future Insurance Eligibility</td>
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<td>Social Network/Support</td>
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<td>Geographic Constraints</td>
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<td>Healthcare Access</td>
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Which factors should we target to make the biggest difference in addressing LDKT disparities?

Results: Neighborhood Poverty, Health Insurance, and Access to Nephrology Care Played Greater Roles in Explaining Disparities in LDKT Than Differences in Medical Conditions

Note: Less than 5% of measured differences in LDKT rates were attributed to active substance use, comorbid conditions, household linguistic isolation, or body mass index across racial-ethnic groups.

Addressing Healthcare Disparities
Model: Disparities Intervention Targets

INTERVENTION TARGETS

- Neighborhood and community resources
- Organizational motivation, resources, staff attributes, climate, and teamwork
- Patient programs and services, insurance and affordability, and provider- and system-level supports
- Ongoing support from family and friends
- Patient education and clinical care; and biological, sociodemographic, and psychological factors

HEALTH CARE PROCESSES

KEY INTERACTIONS

- Patients and support networks
- Health care providers
- Community health workers
- Other organizational members and stakeholders

OUTCOMES

- Clinical outcomes
- Avoidable hospital admissions
- Patient experiences of care
- Equity of services
- Costs

Existing Efforts to Address LDKT Disparities

Targeting Patients and Potential Donors
• Home, community, and clinic-based educational and behavioral programs to improve LDKT knowledge

Targeting Health Care Systems
• Paired kidney donation, HLA desensitization, and ABO-incompatible programs to overcome immunological barriers

National and State Legislation
• Paid or unpaid time away from work for living donors
• Reimbursement for travel and other non-medical costs
• Tax benefits

However, disparities in transplant access persist. WHY?
15 Critical Knowledge and Translation Gaps

1. Incorporates broad stakeholder engagement in intervention development, testing, and dissemination
2. Tests whether multi-level interventions are more effective than those targeting single-level (e.g., only patient) factors
3. Tests effectiveness of universal plus tailored or targeted approaches
4. Describes and addresses challenges to program implementation, sustainability (e.g., cost-effectiveness), and translation of research into practice

5. Builds, strengthens, or evaluates the impact of existing linkages between healthcare systems and community resources (including telephonic outreach)

6. Addresses the entire care spectrum for a particular condition or set of conditions, including care transitions
7. Demonstrates how team-based care can be used to improve access and coordination of care for disparity populations
8. Determines how to optimize data sources and health information technology to inform, implement, and evaluate intervention strategies
9. Develops and evaluates interventions to improve communication skills, cultural competence, and social determinants to reduce the impact of implicit bias and stereotyping among health professionals
10. Addresses organizational focus on health equity

11. Determines how to better address cultural differences in family decision-making and social network dynamics in targeted intervention approaches

12. Aims to reduce disparities in patient outcomes across populations and not just improve patient outcomes in one population
13. Includes less well-studied minority and/or rural patients
14. Addresses medication access, patient empowerment, & treatment adherence
15. Measures durability of intervention effects over time and longer-term patient outcomes (e.g., >12 months)

4 Critical Gaps At All Model Levels

1. Incorporate broad stakeholder engagement in development, testing, and dissemination
2. Test whether multi-level interventions are more effective than those targeting single-level
3. Demonstrate effectiveness of universal plus tailored or targeted approaches
4. Describe and address challenges to program implementation, sustainability, and translation

Ongoing Studies at Johns Hopkins

- Patient and Community Strategies to Reduce Disparities in Kidney Transplantation (PI: Purnell, AHRQ/K01)
- Expanding Live Donor Transplantation through Advocacy Training and Social Media (PI: Cameron, NIDDK/RO1)
- Long Term Health Outcomes after Live Kidney Donation in African Americans (PI: Segev, NIDDK/R01)
- National Registry Data Analysis
  - Scientific Registry of Transplant Recipients (SRTR)
  - United States Renal Data System (USRDS)
Patient and Community-Engaged Strategies to Reduce Disparities in Kidney Transplantation

- **Goal**: To quantify the extent to which social determinants influence racial/ethnic differences in completion of the KT evaluation process.

- **Design**: Prospective cohort study of adults who are being evaluated for a kidney transplant at Johns Hopkins Hospital (R01AG042504)

- **Data Sources**: Patient surveys; geocoded neighborhood and community data to assess social determinants; focus groups with patients, community members, and other stakeholders

- **Key Features that Address Gaps in Transplant Equity Research**
  1. Incorporates broad stakeholder engagement in all study phases
  2. Assessment of social determinants of disparities (intervention targets)
Social Determinants of Disparities

Stakeholder-Engaged Research Approach

- Stakeholder advisory board comprised of community residents, organizations, health system leaders, health professionals, and patients
- Guides research through all phases from planning, to intervention development, implementation, evaluation, and dissemination
- Done using relationship-centered principles:
  - Respect for diverse perspectives
  - Partnership in decision-making
  - Clear communication
  - Trustworthiness
  - Concordance in values

*Courtesy: Johns Hopkins Center to Eliminate Cardiovascular Disparities*
Expanding Live Donor Kidney Transplantation through Advocacy Training and Social Media

- **Goal:** To assess the comparative effectiveness of the Live Donor Champion program and/or Facebook app in increasing rates of LDKT.

- **Design:** RCT with adult kidney transplant candidates (at Johns Hopkins, Northwestern, and UAB) who were added to the waitlist in the last year and have no potential live donors who are eligible.

- **Key Features that Address Gaps in Transplant Equity Research**
  1. Assessment of cultural competence of interventions
  2. Refinement of protocols based upon needs of centers and participants
  3. Comparison of multi-level and single-level intervention approaches
  4. Assessment of barriers to implementation; cost effectiveness studies
ENGAGE
Expanding Live Donor Kidney Transplantation through Advocacy & Social Media
Ongoing Studies at Other Institutions

- Putting Patients at the Center of Kidney Care Transitions (**PI: Boulware**)
- A Culturally Targeted Transplant Program to Increase Live Donation in Hispanics (**PI: Gordon**)
- Reducing Racial Disparities in Access to Kidney Transplantation: The Radiant Study (**PI: Patzer**)
- Tailored Computer Education to Increase Living Donation in African Americans (**PI: Waterman**)
ESRD Network 2 Reducing Disparities

- **Peer Mentoring Program**
  - Trained Patient Advisory Committee members on cultural sensitivity as a component of one of the modules
  - Initiated the program with AIM 2 project facility leads and participating patients, though live module trainings and/or self study toolkit

- **Educational Materials** - Worked with members of the disparate group to identify problems causing racial disparities and to overcome these barriers

- Promoting spread of **patient success stories** through facility site visits and use of Network compiled toolkit

- Site visits to work with facilities to review their referral patterns, strategy unique approaches with **cultural groups** and discuss successes/barriers

- Initiated challenge to participating facilities to develop education stations to share perspectives from the disparate group

**Courtesy:** Island Peer Review Organization (IPRO) – Jeanine Pilgrim, BSHSM
ESRD Network 2 Resource Toolkit

- Transplant Center Referral Guide
- Conditions of Coverage Excerpt
- External Organization Article Sampling
- Patient Education Materials
- Staff Education Resources
- Peer Mentoring Training Program
- Patient Story Sampling

_Courtesy_: Island Peer Review Organization (IPRO) – Jeanine Pilgrim, BSHSM
Network Educational Opportunities

– Patient Success Stories
  • Identify patients with success stories overcoming modifiable changes to become eligible for transplant waitlist i.e. weight loss, smoking cessation etc.

– Peer Mentor Program Rollout
  • Facilities identify ideal candidates to enroll in Network-offered peer mentorship training course

– Technician Training Program
  • Network-led training course designed to support facilities in improving communication between staff and patients

– Transplant Advisory Committee
  • Provide expertise and recommendations for best practices
Where Do We Go From Here?
Key Lessons to Inform Future Initiatives

1. Patients and families prefer holistic intervention approaches.

2. Leverage community strengths and partnerships between health systems and community organizations to enhance acceptability, implementation, and long-term effectiveness.

3. Engage organizational leaders, front-line providers, and staff through all study phases to enhance uptake and feasibility.

4. Seek diverse funding streams to support stakeholder engagement, sustainability, translation, and scalability.

5. Universal policies to improve population health should be coupled with targeted approaches to address disparities.

Conclusion

- Sustained efforts are needed to better address barriers influencing healthcare disparities.
- Emerging programs show promise in helping to address barriers and informing future efforts.
- Collaborations among researchers, patients, providers, policy makers, and other key stakeholders are critical to achieve equity.
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Reducing Healthcare Disparities: What We Know and Where We Need to Go

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