Working Toward a More Equitable Patient Referral and Waitlist System for Kidney Transplantation

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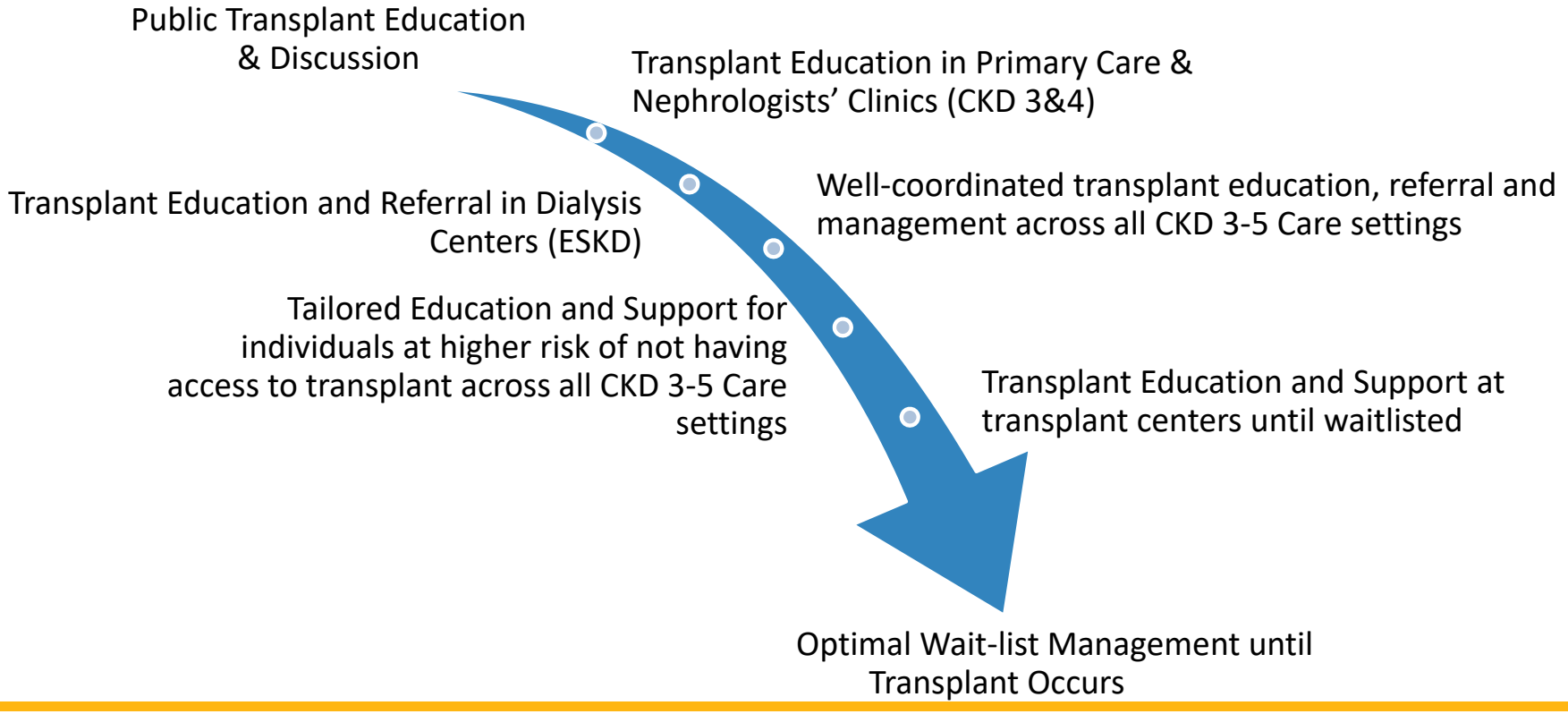
Failure to Advance Access to Kidney Transplantation over Two Decades in the United States

Conclusions Despite wide recognition, policy reforms, and extensive research, rates of WLT following ESKD onset did not seem to improve in more than two decades and were consistently reduced among vulnerable populations. Improving access to transplantation may require more substantial interventions.

Schold et al., JASN, 2021

We need a paradigm shift!

Equitable Patient Referral and Waitlist System



American Society of Nephrology & National Kidney Foundation

Stage 3a & GFR: 45-59 ***Stage 3b GFR: 30-44***	Evaluation and treatment of disease complications: **ESTIMATE** CKD progression rate **DIAGNOSE** and treat CVD risk factors and comorbid conditions with Medical Management including Lifestyle Changes and Drug Therapy **KIDNEY** imaging study, eg, US or CT **CONSIDER** Nephrology **CONSULTATION** and **EDUCATION** about Renal Replacement Therapies
Stage 4 ***GFR: 15-29***	Preparation for kidney replacement therapy (dialysis, preemptive transplant; transplantation): **NEPHROLOGY** consultation with transition of management and care **EDUCATE** and **INITIATE** decisions regarding kidney replacement therapy, vascular access, and preemptive kidney transplant **FIND** Living Donors **DIAGNOSE** and treat CVD risk factors and comorbid conditions **ADJUST** drug dosing for CKD stage
Stage 5 GFR: <15	**CARE MANAGEMENT** by a nephrologist **EDUCATE** and **INITIATE** chosen Kidney replacement therapy if uremia is present **FIND** Living Donors

Standardization of transplant metrics along pipeline: 2015 and 2021 Technical Expert Panels*

Facility level transplant waitlist measures

Measure for patients active on the waitlist

Considerations for development of transplant education and transplant referral measures at the facility and practitioner level

*University of Michigan Kidney Epidemiology and Cost Center

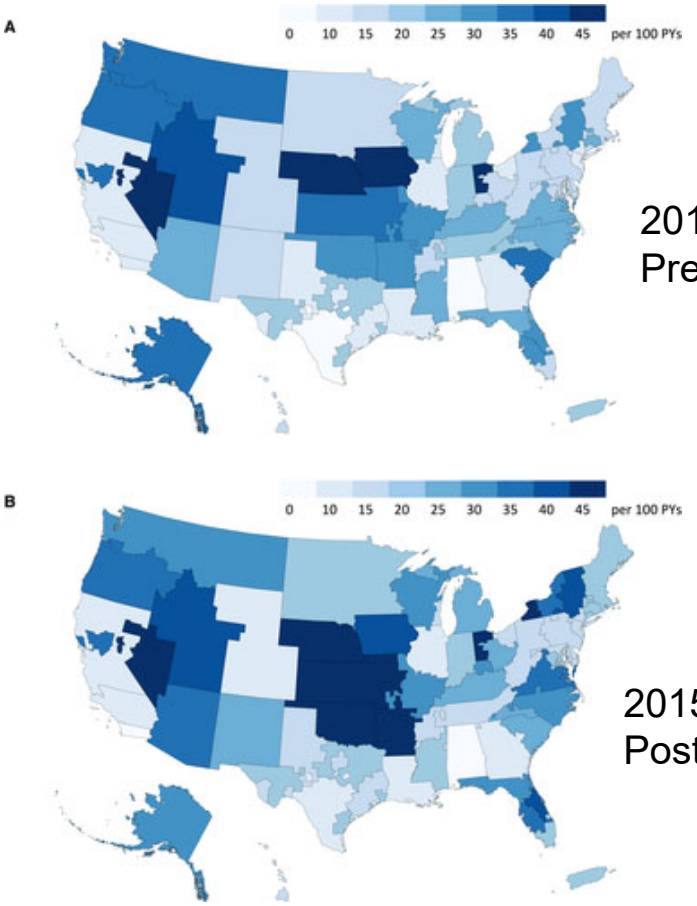
Centers for Medicare & Medicaid Services, 2021

Inequities and Barriers to Kidney Transplant

Geographic Disparities to Transplant Access

- Geographic disparities in transplant access have been observed for decades and have been worsening[1, 2]

- The OPTN's Kidney Allocation System (KAS) was implemented in 2014 to increase kidney transplant accessibility by improving matching metrics and access to blood type B candidates.
  - This should have affected geographic disparities, but no improvements were observed[1, 3]



1. King et al., JASN, 2020; 2. Davis et al., Transplantation, 2014; 3. Zhou et al., AJT, 2018

KAS Policy Changes to Increase Equity[1]

- Further policy changes made including removal of donor service area (DSA) and region from KAS to determine which candidates are eligible when a kidney becomes available.
  - **Effective March 15, 2021:** Kidneys are now offered to patients within 250 nautical miles of the donor's hospital. If no patient within 250 miles accepts, the kidney is then offered to candidates further away.
- Increasing multiple listing, therefore increasing possibility of receiving a transplant[2]

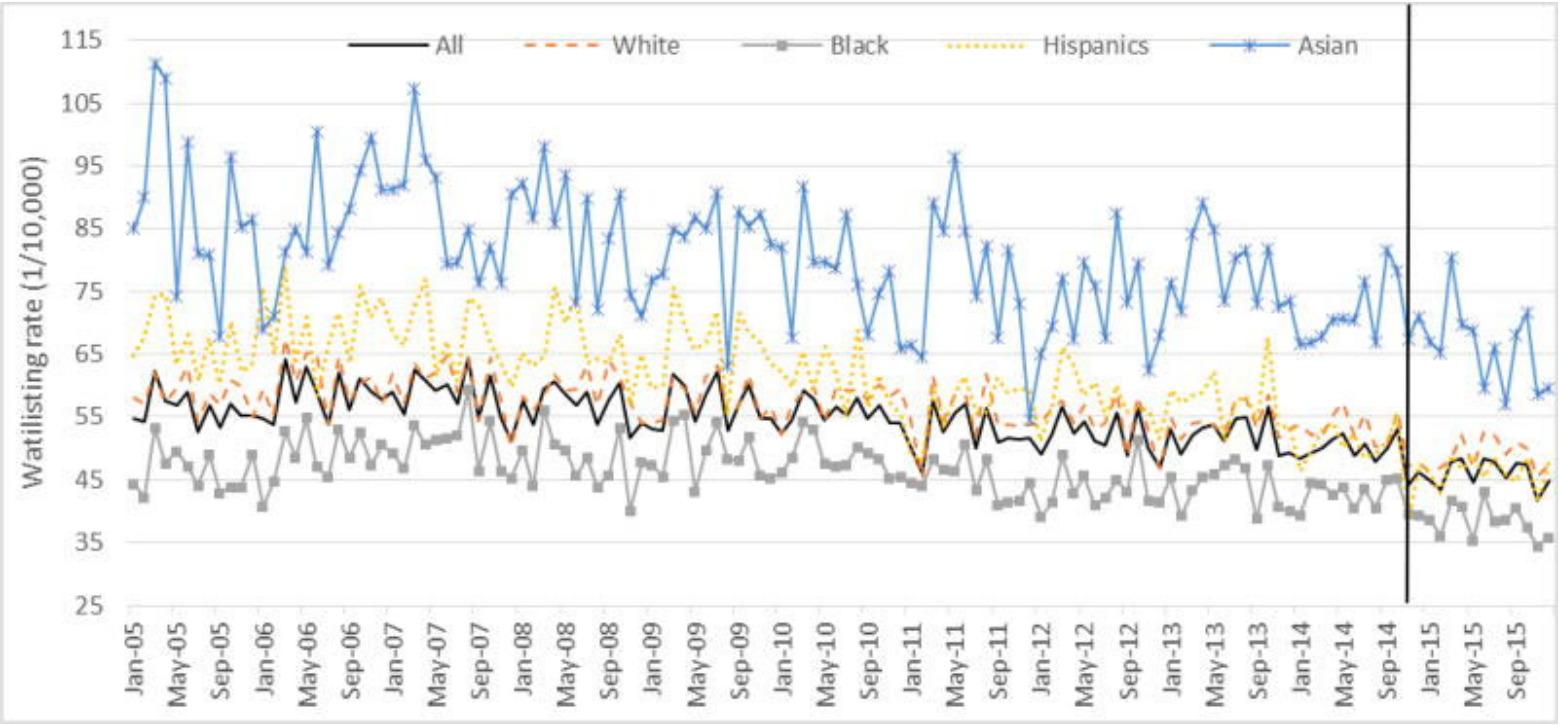
1. OPTN, 20212; . Decoteau et al. 2021

Racial/Ethnic Disparities in Transplant Access

- Compared to non-Hispanic Whites, Black and Latinx populations are more likely to have end-stage kidney disease (ESKD), but less likely to receive a kidney transplant[1]
- Racial minorities, particularly Black patients, are less likely to take steps to get on the waitlist[2, 3]
- Medical mistrust, discrimination, and structural racism contribute to their reduced likelihood of completing waitlisting evaluation.[2]

1. JAMA 2018; 2. Hamoda et al. Am J Transplant 2020; 3. Peng et al. Clin Transplant, 2018

Monthly rate of new waitlisting events per 10,000 patients in the U.S 2005-2015



Black vertical line represents launch of Kidney Allocation System

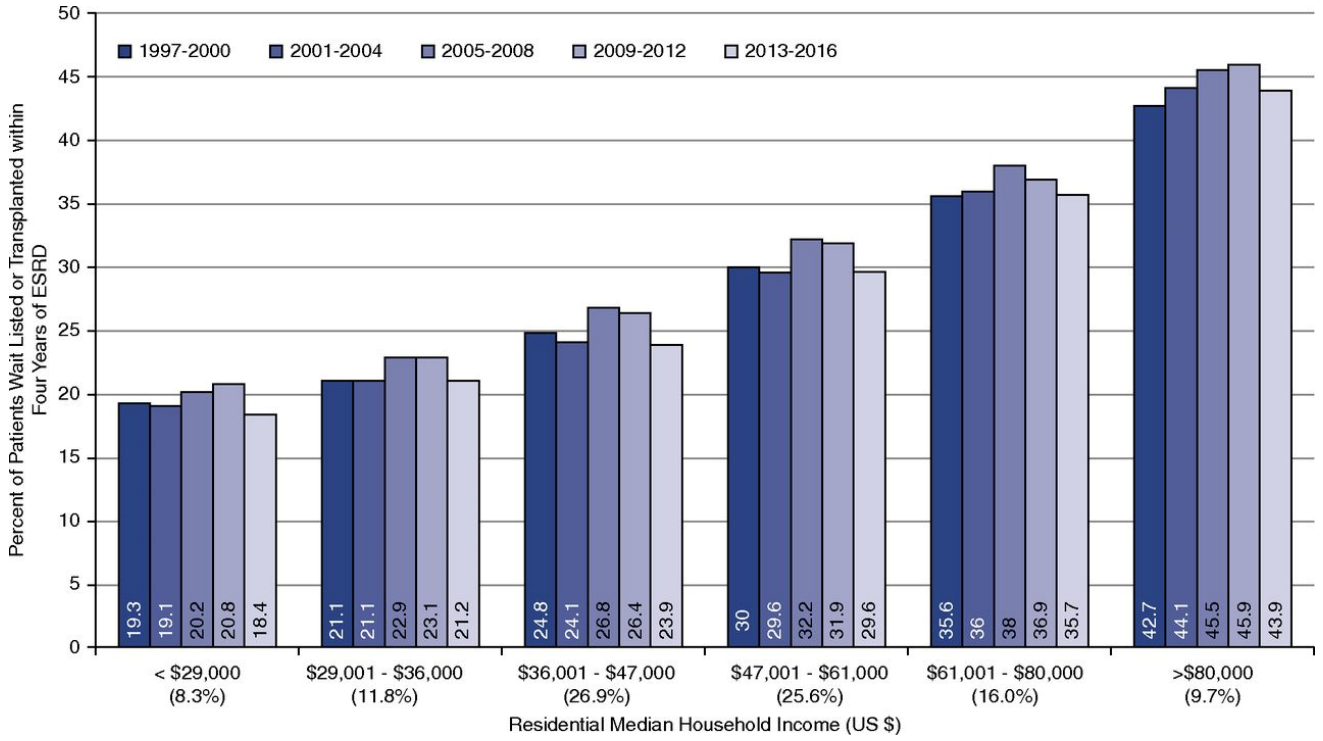
Zhang et al., Am J Transplant, 2021

Income Disparities in Transplant Access

- Low-income racial and ethnic minorities are significantly less likely to be waitlisted.[1]
- Low-income patients are less likely to be medically eligible for wait-listing, express interest in receiving a transplant, complete steps necessary to receive a transplant, and stay active on the waitlist.[2]
- Low-income patients, patients without private insurance, and patients without pre-ESKD nephrology care are less likely to take steps towards kidney transplant[3]

1. Peng et al., Clin Transplant, 2018; 2. Alexander et al., JAMA, 1998; 3. Patzer et al., JAMA, 2015

Wait-listing rates by median household income level



1. Schold et al., JASN, 2021

The UCLA Experience – Kidney Transplant Derailers Index

Development and Validation of a Socioeconomic Kidney Transplant Derailers Index

John D. Peipert, PhD,[1,2] Jennifer L. Beaumont, MS,[3] Mark L. Robbins, PhD,[4] Andrea L. Paiva, PhD,[4] Crystal Anderson, MPH,[5] Yujie Cui, MS,[3] and Amy D. Waterman, PhD[3,5]

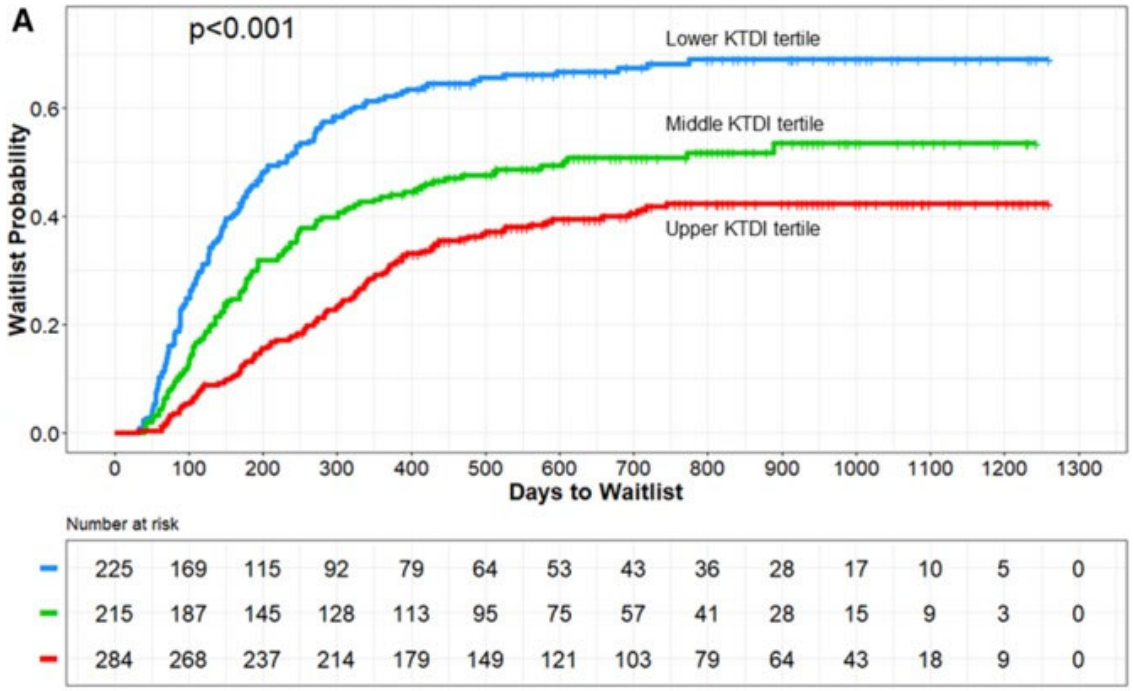
KTDI determines levels of potential socioeconomic kidney transplant derailers

- Higher levels indicated greater levels of barriers.

- Derailers: levels of health insurance, employment, financial insecurity, educational attainment, perception of neighborhood safety, access to a vehicle, having a washer and dryer, and quality of social support

Peipert et al., Transplant Direct, 2019

Time to Successful Waitlisting by KTDI Tertiles



Patients with higher KTDI scores (red line) have a reduced probability of getting waitlisted. Higher risk patients also take longer to get on the waitlist.

Peipert et al., Transplant Direct, 2019

Language Barriers to Transplant Access

- Racial and ethnic minority patients whose primary language is not English are less likely than Whites to complete evaluation, which may be attributed to language barriers they face in healthcare settings[1]

- Patients in linguistically isolated households are also more likely to remain inactive on the waitlist.[1] Linguistic isolation can also explain 7-9% of transplant delays specifically for Asian, Latinx, and Pacific Islander patients[2]

1. Talamantes et al., CJASN, 2017; 2. Hall et al., 2011, JASN;

Observational Study › Clin J Am Soc Nephrol. 2017 Mar 7;12(3):483-492.
doi: 10.2215/CJN.07150716. Epub 2017 Feb 9.

Linguistic Isolation and Access to the Active Kidney Transplant Waiting List in the United States

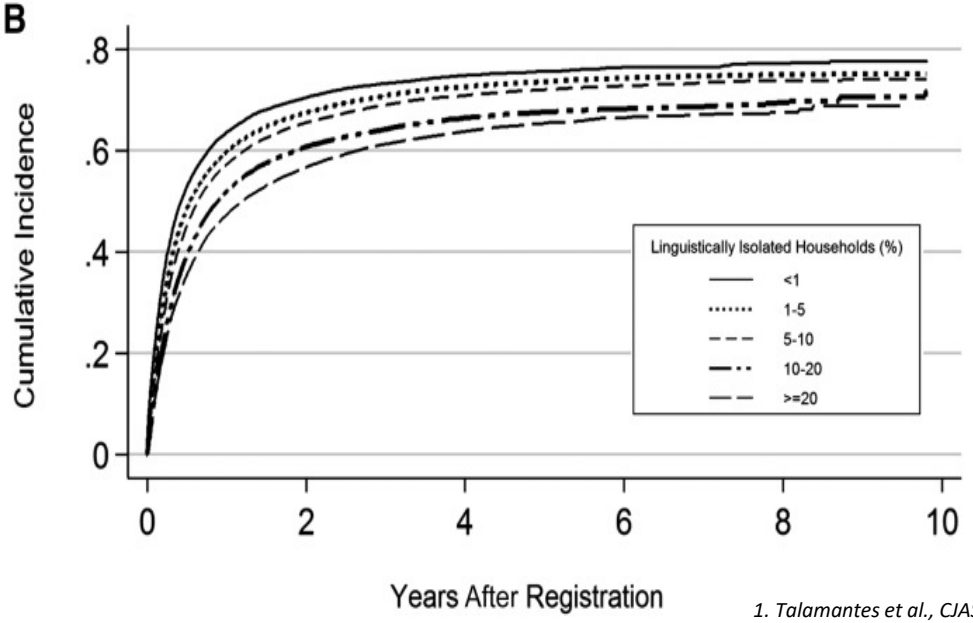
Efrain Talamantes [1], Keith C Norris [2 3], Carol M Mangione [3], Gerardo Moreno [4], Amy D Waterman [2 5], John D Peipert [2 5], Suphamai Bunnapradist [2 5], Edmund Huang [6 5 7]

Affiliations + expand

PMID: 28183854 PMCID: PMC5338711 DOI: 10.2215/CJN.07150716

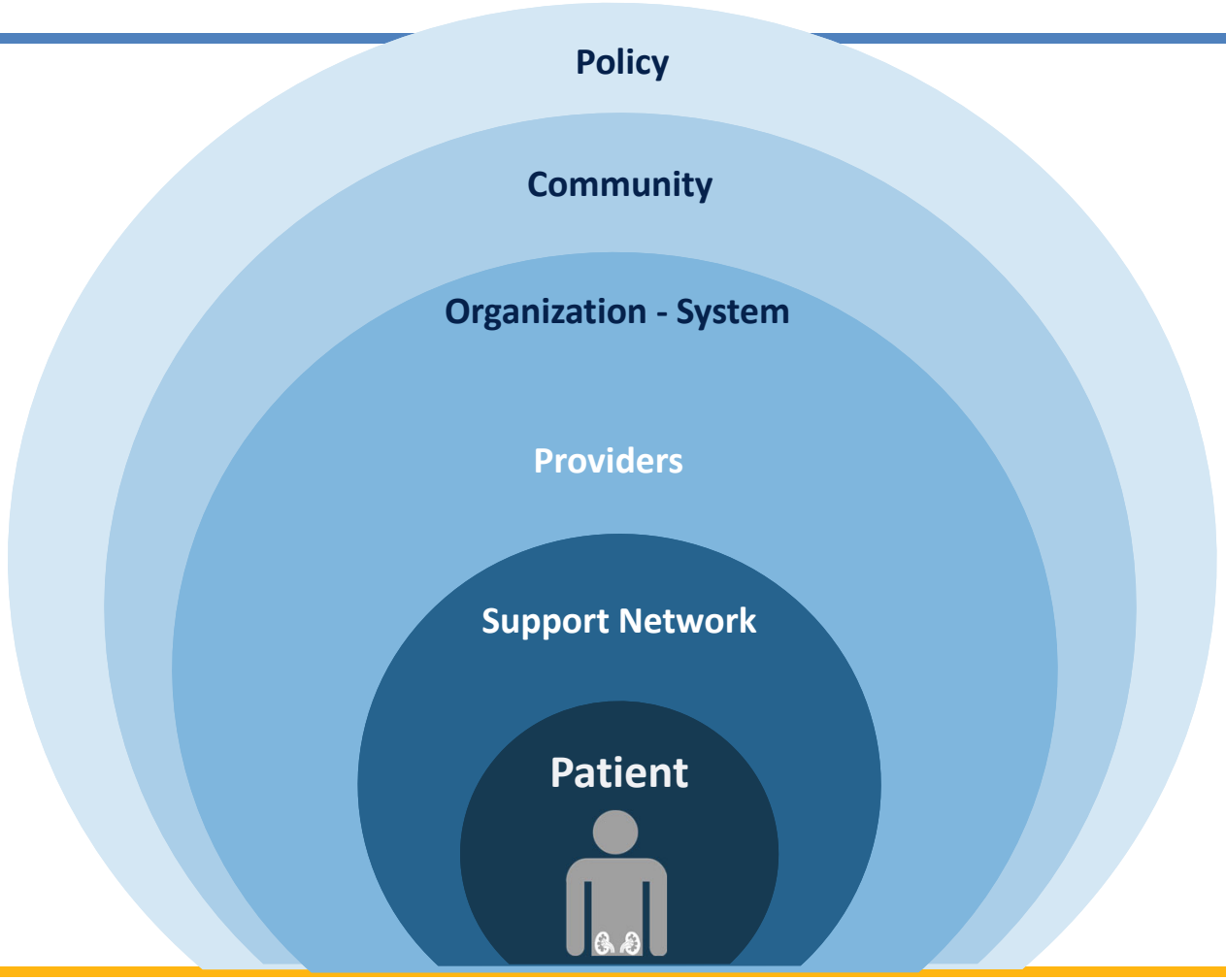
Patients in more linguistically isolated households are more likely to remain inactive on waiting list over time.

Cumulative incidence of transition to active waiting-list status



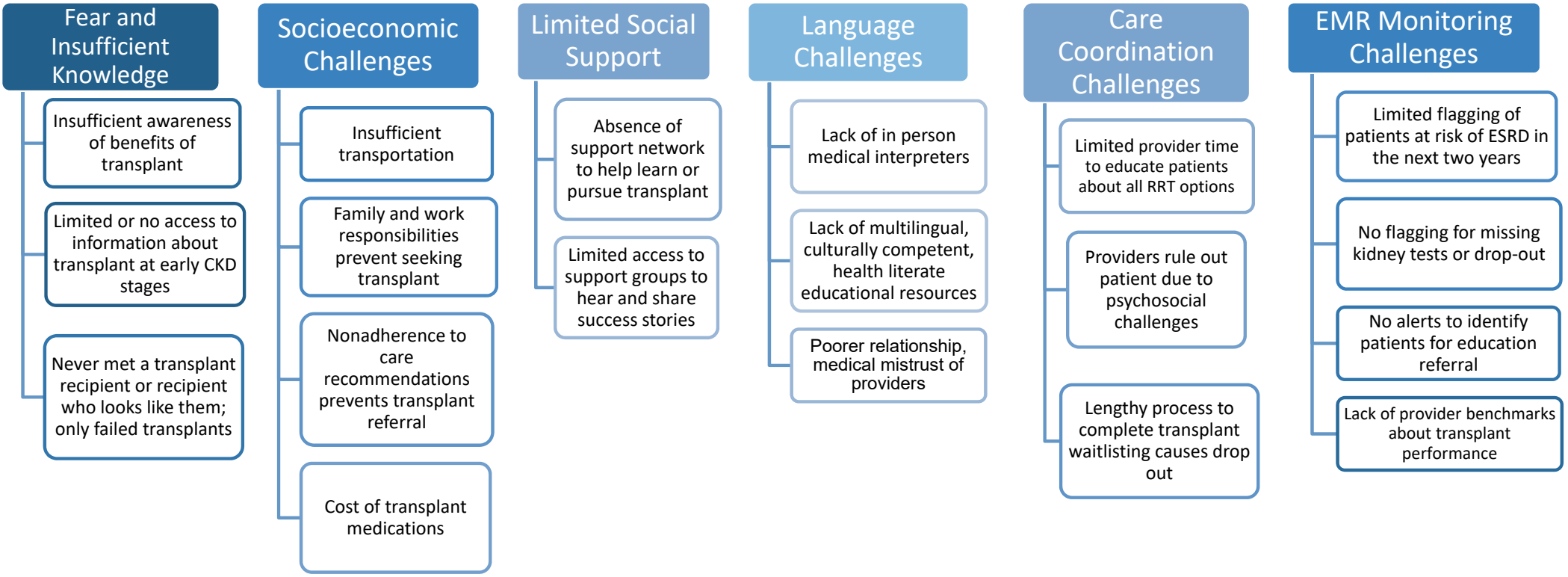
1. Talamantes et al., CJASN, 2017

What Best Practices or Recommendations could reduce inequities in access?

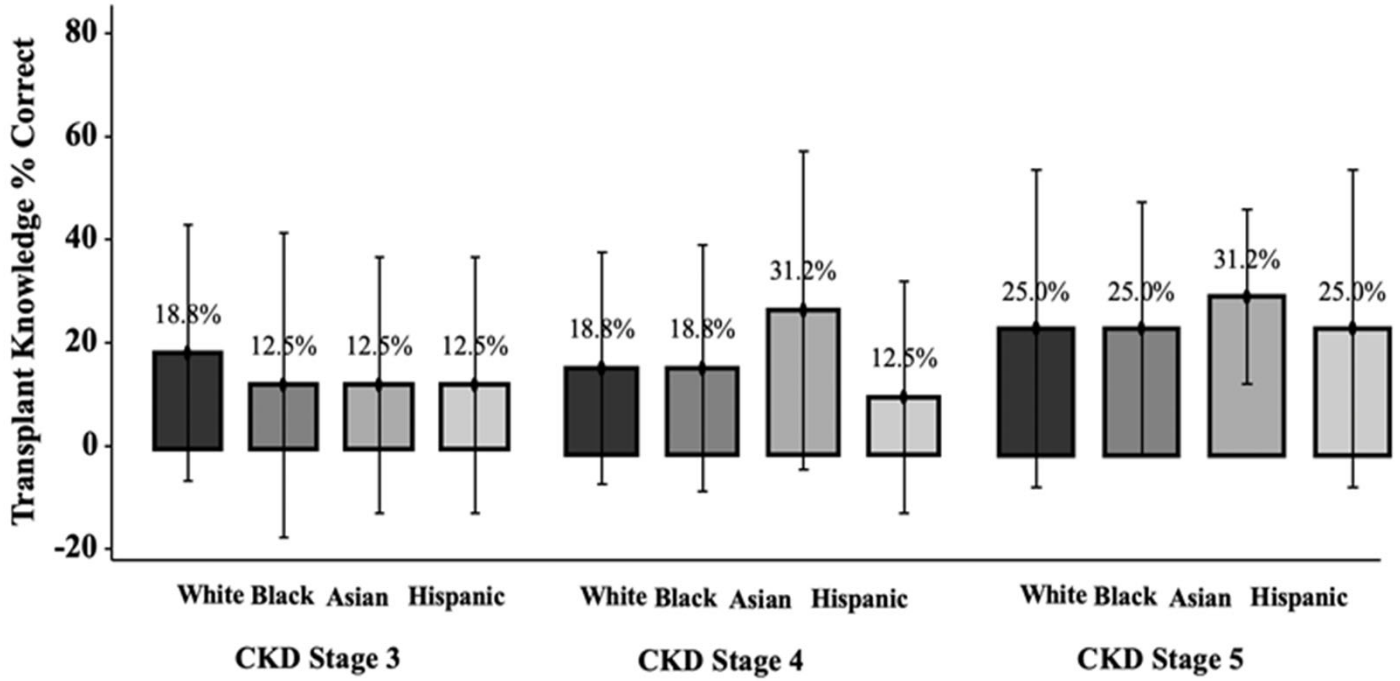


Build Recommendations to overcome Barriers at Every Level

Paskett et al., Hlt Aff., 2016; Taplin et al., JNCI Monographs, 2012; Patzer et al., JASN, 2017; Scholmerch et al.; Trickett et al., Am J Comm Psych., 2009

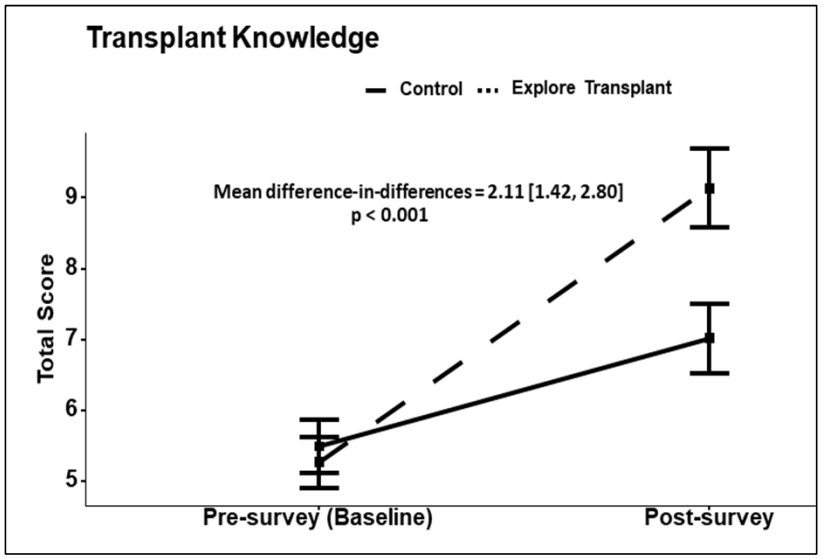

Fear and Insufficient Knowledge
Insufficient awareness of benefits of transplant
Limited or no access to information about transplant at early CKD stages
Never met a transplant recipient or recipient who looks like them; only failed transplants
Socioeconomic Challenges
Insufficient transportation
Family and work responsibilities prevent seeking transplant
Nonadherence to care recommendations prevents transplant referral
Cost of transplant medications
Limited Social Support
Absence of support network to help learn or pursue transplant
Limited access to support groups to hear and share success stories
Language Challenges
Lack of in person medical interpreters
Lack of multilingual, culturally competent, health literate educational resources
Poorer relationship, medical mistrust of providers
Care Coordination Challenges
Limited provider time to educate patients about all RRT options
Providers rule out patient due to psychosocial challenges
Lengthy process to complete transplant waitlisting causes drop out
EMR Monitoring Challenges
Limited flagging of patients at risk of ESRD in the next two years
No flagging for missing kidney tests or drop-out
No alerts to identify patients for education referral
Lack of provider benchmarks about transplant performance

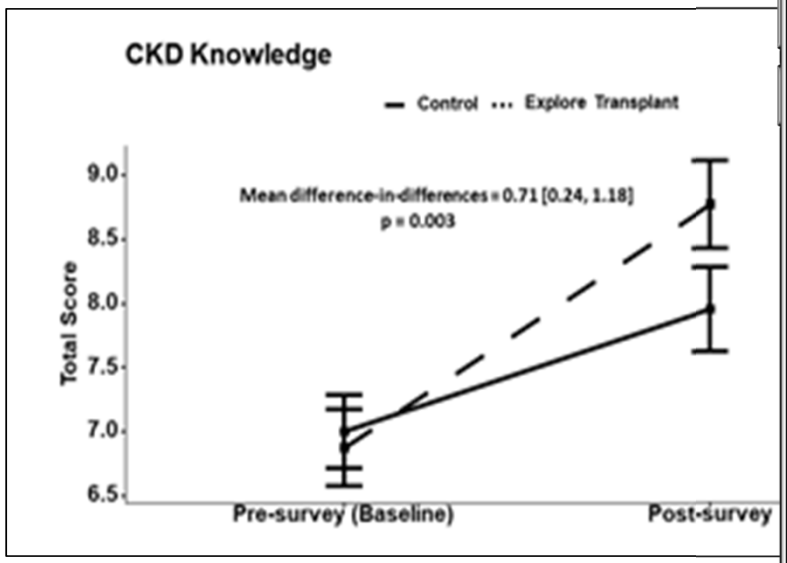
971 Kaiser Patients: Transplant Knowledge by CKD Stage and Ethnicity



1. Pines et al., ATC, 2021

Early Transplant Education Increases CKD 3-5 Patients' Knowledge and Informed Decision-Making





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doi: 10.1097/TP.0000000000002781

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NIHMSID: NIHMS1529232
PMID: 31335777

Education Strategies in Dialysis Centers Associated with Increased Transplant Wait-listing Rates

Amy D. Waterman, PhD,[1,2] John D. Peipert, PhD,[1,2,3,4] Huiling Xiao, MS,[4,5] Christina J. Goalby, MSW,[1] Satoru Kawakita, MS,[2] Yujie Cui, MS,[2] and Krista L. Lentine, MD, PhD[5,6]

Distribution of print education and using multiple intensive education practices within dialysis centers were associated with increased wait-listing rates.

American Journal of Transplantation
AST AMERICAN SOCIETY OF TRANSPLANTATION ASTS

ORIGINAL ARTICLE | Full Access

Your Path to Transplant: A randomized controlled trial of a tailored expert system intervention to increase knowledge, attitudes, and pursuit of kidney transplant

Amy D. Waterman ✉, John D. Peipert, Yujie Cui, Jennifer L. Beaumont, Andrea Paiva, Amanda F. Lipsey, Crystal S. Anderson, Mark L. Robbins

First published: 15 August 2020 | https://doi.org/10.1111/ajt.16262

UC-eLinks

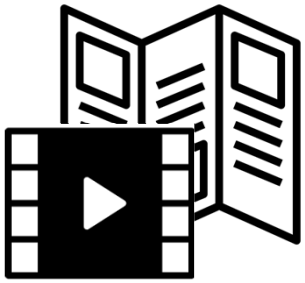
Waterman et al, AJT, 2020

Differences in LDKT Preparedness at Start of UCLA Transplant Evaluation (N=802)

Knowledge or Steps Taken	Black	Hispanic	White
Transplant Knowledge (% correct)**	44%	43%	51%
Read information/watch videos**	26%	15%	40%
Generally talk to people you trust about whether to get a living donor transplant*	39%	35%	50%

Waterman et al, AJT, 2020

Individually Tailored Education



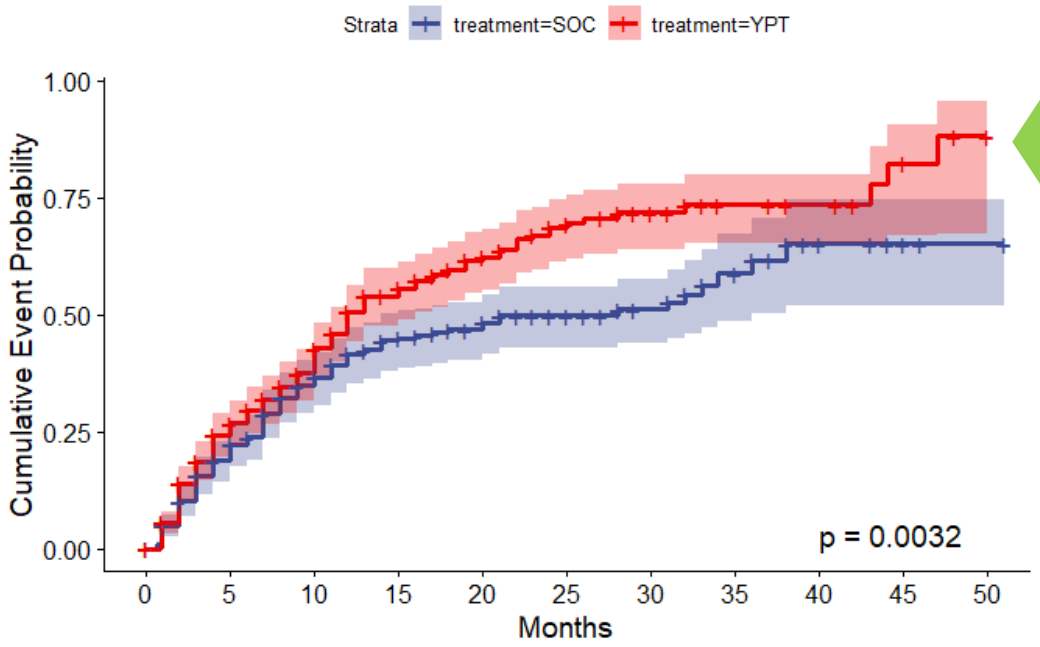
Print and Video Resources

Phone Coaching

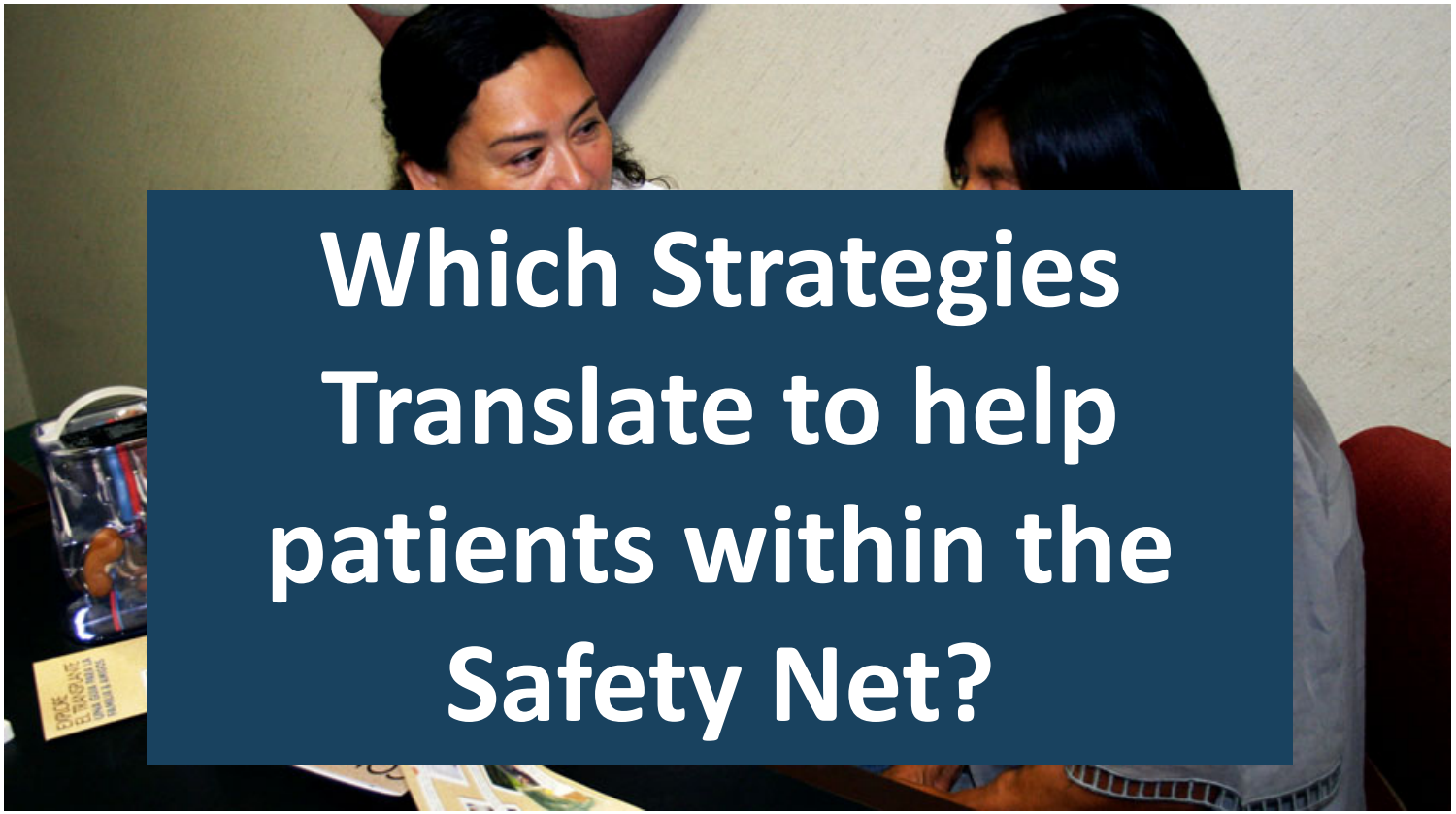
Support for SES Challenges

Image sources: www.flaticon.com: Study, Hand, Talking By Phone Auricular Symbol With Speech Bubble free icon by Freepik; Video Player by Smashicons; Brochure by Surang

18 Month Transplant listing rates



At 18 months post-baseline, YPT resulted in significantly higher listing for transplant



Which Strategies Translate to help patients within the Safety Net?

Some Ideas…

Activate low cost, supplementary education not requiring provider time

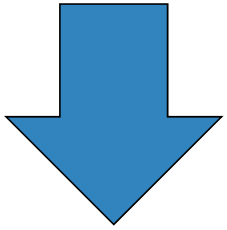
Reduce financial disincentives to transplant

Utilize Storytelling to Engage Learners Earlier, including families

Broader financial support for patients pursuing transplant

- Expansion of Medicaid services is associated with an increase in wait-listing rates among various ethnic groups[1]
- Provide education and resources for patients to seek access to transportation services, and other costs of transplant evaluation[2]

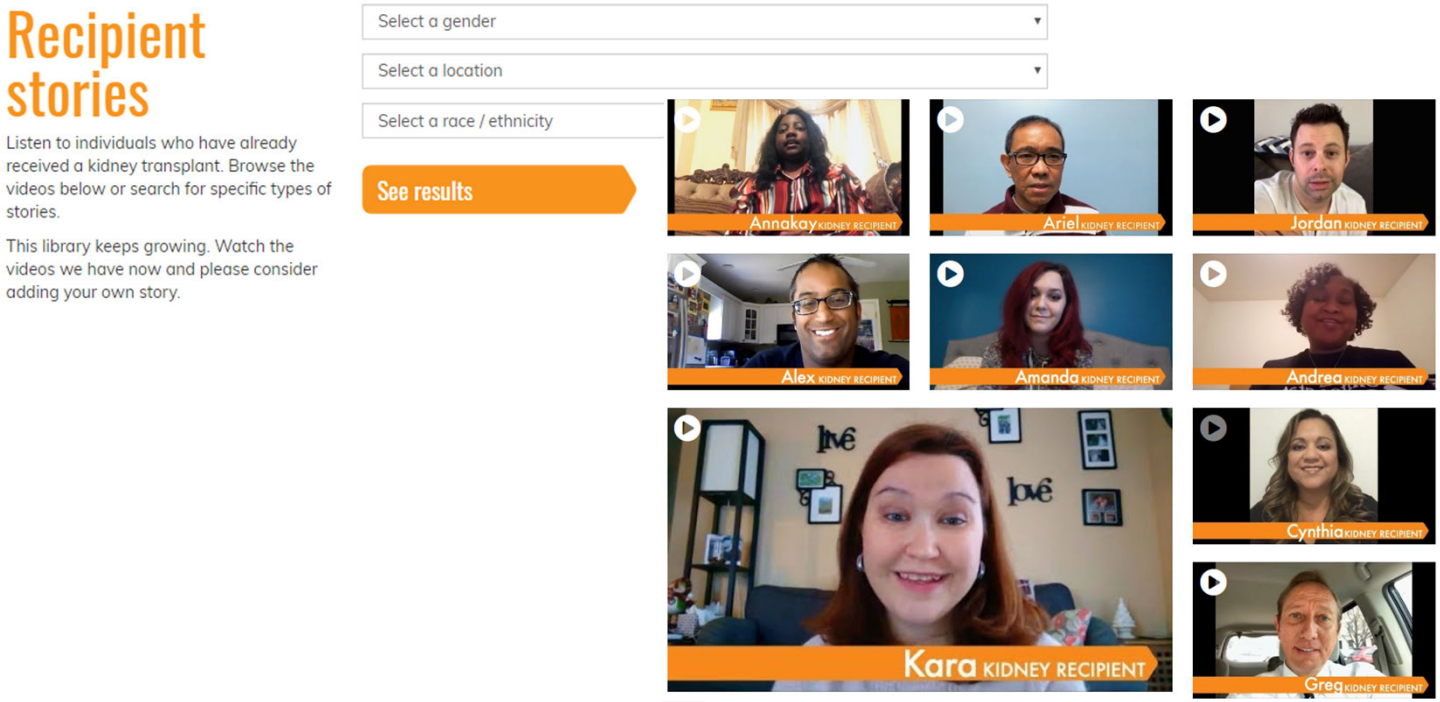
National Living Donor Assistance Center



All Transplants?

1. Harhay et al., CJASN, 2018; 2. Wang et al., Semen Nephrol, 2016

Disseminate Stories - Meet other transplant recipients that look like you



Story clips can be disseminated through tailored media campaigns to reach those facing CKD challenges.

Strategic and equitable transplant decisions

- Which types of deceased donor kidneys could I get the fastest?
  - Destigmatize high-risk and HIV kidneys for relevant patients
- What should I do if I want my kidney to last the longest time so I don't have to have multiple transplants?
- Should I turn down an offered kidney and wait for a better one?
  - Algorithms for individually tailored information by age and other clinical factors. MyTransplantCoach.org

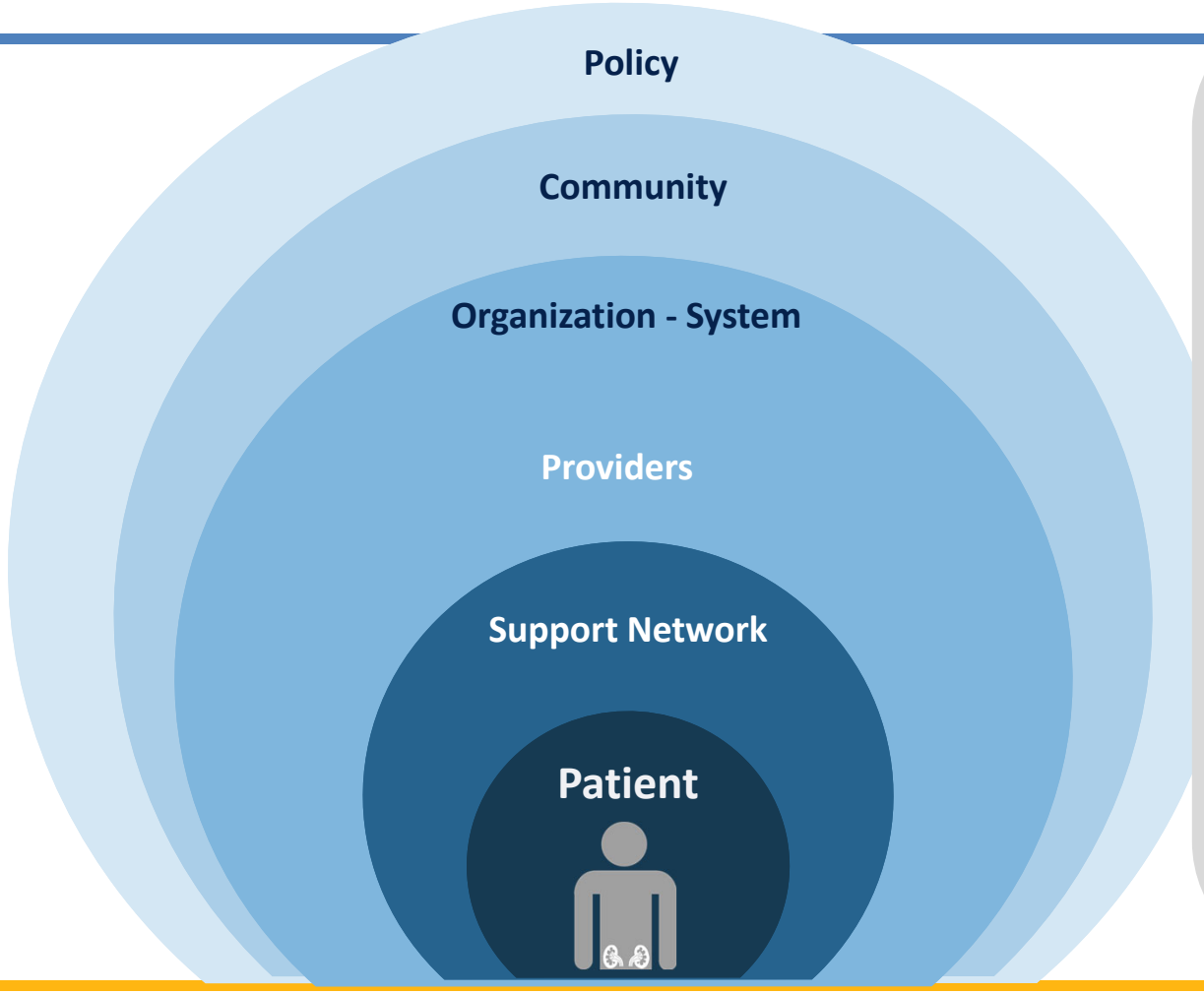
Waitlist and drop-out management

- Identify Implicit biases that may affect care
  - Patients facing complex psychosocial situations
  - Inequal attention in clinics of all patients to assess interest in transplant[1]

- Standardization of a protocol to follow-up with patients while waitlisted[2].
  - Use national metrics and a more efficient wait-listing process to mitigate time-constraint barriers[3].

Distinguish patients who are facing many challenges and dropping out but who are still interested in transplant and build programs to help them be successful.

1. McSorley et al. 2017; 2. Sokas et al. 2021; 3. Wachterman et al. 2015



Standardize Transplant Metrics

Link milestones and metrics to CKD Care reimbursement/penalties

Amplify a public, positive conversation about transplant through media and partnerships with diverse groups

Monitor progression to transplant using dashboards, EMR integration, and wait-list management for 5-10 years

Train all CKD providers best practices to educate and refer for transplant

Disseminate health literate education and storytelling in multiple languages broadly

Advocate for all eligible patients getting a transplant.

Thank you!

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