Successful Pathways to Transplant for Undocumented Immigrants:

*The PRUCOL Process*

Laura Ford, LCSW and Stanley Kerznerman, LCSW

Society for Transplant Social Workers Conference

San Diego, CA

October 10th, 2023
Marginalized Populations

- Marginalization suggests social disadvantage and exclusion
  - Dominant social groups vs. non-dominant social groups
  - Deserving vs. undeserving

- Many demographics in many different historical contexts:
  - BIPOC, immigrants (especially undocumented), unhoused, substance users, women, LGBTQIA+

- Identity is complex and intersectional
  - Unequal power dynamics

- Social acceptance and resources depend on geographical and cultural contexts
Impacts on Physical and Mental Health

- Social determinants of health
  - SES, nutrition, environmental quality, literacy, etc.
- Social stigma, discrimination, and violence
- Challenges accessing care
- Implicit and/or explicit provider biases
- Distrust of healthcare system
Undocumented Immigrants

- Individuals who do not possess a valid visa or other immigration documentation
  - Visa overstay
  - Unauthorized border crossing
  - Violation of the terms of admission to the US

- Especially disadvantaged and vulnerable population
  - Highly politicized issue in the US
  - Increased risk of victimization, labor exploitation, human trafficking, sexual abuse, illness, and injury (Misra et al., 2021)
Barriers to Care

- Political, legal, and socioeconomic factors
  - Fear disclosing immigration status and being reported to CBP/ICE
  - Changes to public charge rule in 2019 and “chilling effect” (Bernstein et al., 2019)
  - Limited English proficiency

- Limited access to healthcare
  - 44 states prohibit access to Medicaid and CHIP
  - ED as primary source of medical treatment (Ayon et al., 2020)
  - Difficulty getting referrals for transplant evals
UNOS Listing

- No UNOS listing restrictions based on immigration status
  - Listing decisions based on hospital/transplant program policy

- National Organ Transplant Act (NOTA) of 1984
  - Allocation based on “established medical criteria”

- UNOS 5% rule, now repealed
Disparities in Access to Transplant

- Undocumented immigrants ~3% of total US population
  - Only 0.4% of all LT cases (Lee & Terrault, 2019)

- 3% deceased donation rate, proportional to population (Glazier et al., 2014)

- 65% (n=108) of all LTs for undocumented immigrants occurred in NY and CA from 2012 - 2018 (Lee & Terrault, 2019)

- POC referred to transplant centers less often and at later stages of liver disease compared to White patients (Rosenblatt et al., 2021)
What is PRUCOL?

- Permanently Residing Under the Color of the Law (PRUCOL)
  - Established by Congress in 1972
  - Used to determine eligibility for public benefits
  - Not a formal immigration status
  - US government aware of person in US and not actively trying to deport

- NY, CA, CT, HI, IL, and MA allow access to Medicaid and solid organ transplant

- Access to benefits in NY without PRUCOL
  - CHIP for children <19yo
  - Emergency Medicaid
  - Outpatient care at NYC public hospitals and FQHC clinics
  - Temporary public assistance
The PRUCOL Process

● Complicated referral process
  ○ Importance of early psychosocial evaluation and prompt referral to legal health
  ○ Mean time from start of LT eval to PRUCOL confirmation 268 days (range: 0 to 957)
Risks and Limitations

- Increased risk of deportation and criminal prosecution for patients
  - Expect limited access to post-transplant care in country of origin if deported
  - Potential risks to undocumented family members

- Uncertainty about future political landscape and legislation

- No insurance coverage to cover outpatient care while PRUCOL pending

- No guarantee of PRUCOL eligibility
Case Example: NY vs. State without PRUCOL

- Pt is a 35yo Spanish-speaking woman from Mexico with ALD cirrhosis c/b ascites. Her parents brought her to the US at age 16 without documents. She has 2 minor children and an adult brother who are US citizens.

- In NY:
  - LT eval in outpatient transplant clinic
  - Referral to LegalHealth
  - Referral to substance use tx at NYC public hospitals
  - LVP via charity care/fellows clinic or NYC public hospitals
  - Referral to REAP/ACCESS NY for public assistance
  - Apply for Medicaid once PRUCOL confirmed
  - LT listing

- In states without PRUCOL:
  - Unable to secure referral for outpatient LT eval, would likely not be a candidate due to lack of insurance coverage
  - Presents to local ED with acute decompensation
  - ???
LT Outcomes at MSH

- 82 undocumented immigrants evaluated for LT but not transplanted (2010 - 2020)
  - From 33 different countries
  - 60 outpatient evals vs. 22 inpatient transfers
  - 32 PRUCOL-eligible at time of eval
  - 5 expired on waiting list
  - 8 expired prior to listing

- Increasing evals but stable transplants
  - Suspect further increases through COVID-era

![Graph showing the number of undocumented patients evaluated for LT vs. transplanted (2010 - 2020)]
LT Outcomes at MSH

- 16 LTs for undocumented patients at MSH from 2010 - 2020
  - ~10% of all cases in US
- Higher MELD at time of eval and LT
- May need additional support and resources pre- and post-LT
- Post-LT outcomes comparable to US citizens and permanent residents
- Complications *not* due to psychosocial issues
  - Mortality and graft loss caused by early surgical complications

<table>
<thead>
<tr>
<th>n</th>
<th>16</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (Years) at LT</td>
<td>46 (mean) (25-63 range)</td>
</tr>
<tr>
<td>Male, %</td>
<td>68.8</td>
</tr>
<tr>
<td>Race/ethnicity, %</td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>0</td>
</tr>
<tr>
<td>Black</td>
<td>12.5</td>
</tr>
<tr>
<td>Hispanic</td>
<td>56.3</td>
</tr>
<tr>
<td>Asian</td>
<td>31.25</td>
</tr>
<tr>
<td>Employed, %</td>
<td>37.5</td>
</tr>
<tr>
<td>Indication for LT, %</td>
<td></td>
</tr>
<tr>
<td>ALD</td>
<td>25</td>
</tr>
<tr>
<td>NASH</td>
<td>25</td>
</tr>
<tr>
<td>HCV</td>
<td>6.3</td>
</tr>
<tr>
<td>HBV</td>
<td>18.8</td>
</tr>
<tr>
<td>Wilson’s Disease</td>
<td>12.5</td>
</tr>
<tr>
<td>PSC</td>
<td>6.3</td>
</tr>
<tr>
<td>Cryptogenic Cirrhosis</td>
<td>6.3</td>
</tr>
<tr>
<td>Known Malignancy, %</td>
<td>31.3</td>
</tr>
<tr>
<td>MELD-Na at Presentation</td>
<td>24.4</td>
</tr>
<tr>
<td>MELD-Na at LT</td>
<td>37</td>
</tr>
<tr>
<td>LT Admission Length of Stay (Days)</td>
<td>31</td>
</tr>
<tr>
<td>1-Year Graft Survival, %</td>
<td>87.5</td>
</tr>
<tr>
<td>1-Year Patient Survival, %</td>
<td>87.5</td>
</tr>
</tbody>
</table>
End Stage Renal Disease

- CKD and ESRD disproportionately affect minority and low-SES populations (Berger et al., 2020)
- Outpatient HD covered by Emergency Medicaid in 12 states
- In other states, pt must present to ED for emergent dialysis under EMTALA
  - Need emergency indication (hyperK, volume overload, uremia, etc.)
- Delays in care lead to increased morbidity/mortality
  - Increased rates of inpatient admissions, access-related complications, anxiety about death compared to outpatient HD (Berger et al., 2020)
- Increased burden on hospital systems (Rizzolo et al., 2020)
  - ~35–45 patients/day presented for emergent HD at high volume ED in TX (2013-14), 33% of all ED visits
  - Costs ~$6000/month more than outpatient HD per patient
Kidney Transplant

- KT has significant QOL and survival benefits compared to dialysis (Rizzolo et al., 2020)
  - ~20% 1-year and ~50% 5-year mortality on HD
  - ~80% 5-year survival post-KT

- Similar post-KT outcomes between undocumented immigrants and US citizens/residents (Eguchi et al., 2023)

- Mortality risk of emergent HD is 14x higher compared to outpatient HD (Khullar et al., 2019)

- Higher levels of moral distress and professional burnout for ED clinicians witnessing “needless suffering and jeopardizing patient trust” (Khullar et al., 2019)
Heart and Lung Transplant

- May be eligible for “bridge to transplant” with VAD
  - Covered by Emergency Medicaid in NY
  - Can potentially increase life expectancy by 5-7 years without HT
  - Risks include infection and other complications
  - Difficult to coordinate outpatient care and weekly labs without insurance

- ECMO may also provide a bridge to transplant
  - Usually need ICU-level care
  - Must continue until transplant, poor QOL
  - $$$

- Usually not eligible for listing until PRUCOL/insurance coverage is confirmed
Some states provide insurance coverage for children regardless of immigration status
  - Risk of losing coverage in transition to adulthood

Deferred Action for Childhood Arrivals (DACA)
  - ~600k individuals since 2012
  - Ruled unconstitutional by 5th Circuit in 2022, no new applications
  - Biden admin expanded access to ACA plans and Medicaid for current DACA recipients in 2023
Living Donation

- Undocumented recipients more likely to have a living donor compared to US citizens, 40% vs 32% (Cervantes et al., 2018)

- Living donors tend to be undocumented, younger, and Hispanic (Shen et al., 2018)

- Undocumented donors do not qualify for many financial assistance programs
  - e.g. NLDAC

- Increased risk of coercion and organ trafficking (Delmonico, 2009)
  - "Declaration of Istanbul" in 2008

- Challenges accessing post-donation care
Case Studies

Ms. M is a 49yo F, h/o NASH cirrhosis, from Mexico
- Crossed border without docs in 2006
- Presented to MSH October 2019
- Legal referral, applied for medical deferred action as outpatient
- PRUCOL confirmed December 2019
- Coverage started February 2020
- Transplanted November 2020
- Deportation orders in September 2021
- NYLAG representing in court, still waiting for date
- Now doing well post-transplant

Ms. B is a 38yo F, h/o EtOH hepatitis, from Mexico
- Crossed border without docs many years ago
- Presented to MSH May 2020, poor mental status delayed work-up and referrals
- Applied for deferred action July 2020
- Insurance coverage started August 1st 2020
- Decompensated and became too sick for OLT
- Died August 7th 2020
Public Response

Why Undocumented Immigrants Struggle to Receive Organ Transplants
A few states have expanded health insurance benefits to include organ transplants for undocumented immigrants. Some lawmakers hope New York will be next. (Goldstein)

faceless nameless
Earth, May 16

“Why on God's green earth would we provide organ transplants to illegal immigrants? Do you have any idea how many Americans die each year waiting for an organ transplant? I do: 6,000. Meanwhile we are going to spend extraordinary amounts of taxpayer money to not only give illegals an organ, but pay for the surgery, and then presumably the extraordinarily expensive continuing care? Meanwhile we have no idea about these peoples' medical history, which is often a deciding factor in whether someone gets an organ transplant. Where does this insanity stop? Honestly!?”

KM
Pittsburgh, May 16

“If you're in the country illegally then the country owes you nothing except a deportation order. If these people don't like the healthcare they receive here they should go back to their own countries. There are many Americans and legal immigrants who are struggling to afford and access healthcare, and until they are all taken care of not a single cent should go towards healthcare for those who have no right to be here.”
Ethical Considerations

- Significant inequities in access to care/resources
  - How to ensure fairness in access to eval, listing, and transplant?

- Explicit and implicit bias in subjective assessments
  - Who is actually high risk?

- National demand for organs already far exceeds supply
  - Future impact of bioartificial organs/xenotransplant
  - Principle of Solidarity
Ethical Considerations

- Imagine a situation where all undocumented patients decided to stop donating to the deceased organ pool at time of death
  - Why should they be donors if they can't be recipients?
  - What would happen?

- A transplant candidate arrives from another country and self-pays for all costs associated with eval, transplant surgery, and post-transplant care
  - Is “transplant tourism” more or less morally acceptable than an undocumented person who actually lives in the US and participates in our society getting a transplant from the organ pool?

- A patient who is a US citizen presents for eval with h/o ALD cirrhosis c/b HCC with very high risk of recurrence
  - How can you quantify which patient would “benefit more” from transplant?
  - Is any given population inherently more deserving?
  - How much does etiology matter?
Costs of Care

- State-funded HD for >2.75 years is more expensive than KT (Ansell et al., 2014)
- ECMO costs $5,000 - $10,000/day, requires highly labor intensive ICU-level care (Mishra et al., 2010)
- Undocumented immigrants contribute more to Medicare and Medicaid via taxes than those programs spend on undocumented patients (Zallman et al., 2013)
- $2 billion annual spending on Emergency Medicaid (Khullar et al., 2019)
  - CA receives half of all reimbursement
- Shifting focus to preventative care and early diagnosis reduces costs over time (Gostin et al., 2019)
Opportunities for Improvement

● Advocate for increased access to care at local, state, and national levels

● Increased awareness among community providers and streamlined referral processes

● Expanded Medicaid eligibility criteria

● Increased funding for public hospitals, outpatient HD, and nonprofits (e.g. Legal Health, Illinois Transplant Fund)

● Increased access to legal resources

● Best practices and ongoing work to build trust
  ○ “Cultural competence”
  ○ Maintaining confidentiality
  ○ Shared decision-making
  ○ Use a professional interpreter
  ○ Avoid dehumanizing language (e.g. “illegals” or “aliens”)
References

Debrief and Questions
Thank you!