Cultural Competence in Living Donation
Cultural Barriers, Health Literacy, African Americans

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Cultural Competence
A set of values, principles, behaviors, attitudes, policies and structures that enable organizations and individuals to work effectively in cross-cultural situations.

National Standards for Culturally and Linguistically Appropriate Services in Health Care
FINAL REPORT
March 2001
Washington, D.C.
Challenges we’re facing

Health Literacy and Living Donation Transplant

1. Patients with inadequate health literacy 78% less likely to be referred for kidney transplant evaluation.¹

2. Health literacy may be a barrier to kidney patients not completing steps to transplant.²

3. Ethnic minorities have worse health literacy compared to whites.³


Health literacy barriers to living donation

UNABLE TO UNDERSTAND MATERIALS

EXACERBATE KNOWLEDGE GAPS ABOUT RISKS

CRITICAL TO OBTAINING INFORMED CONSENT

UNANTICIPATED COMPlications

Challenges we’re facing

African Americans and Living Donor Kidney Transplant

1. African Americans are about half as likely as whites to get a preemptive living donor kidney transplant. 1

2. Living donor kidney transplants highest in white patients. 2

3. African Americans less willing to donate kidneys for living donor transplant. 3

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“Racial parity in living donor kidney transplantation was not seen at any of the 275 transplant centers in the United States. Racial disparity in attainment of LDKT exists at every transplant center in the country.”

African Americans had 35%-76% lower odds of receiving LDKT


African American barriers to living donation

- MISTRUST OF HOSPITALS
- PHYSICIANS DON'T TALK ABOUT IT
- CONCERNS ABOUT THE SURGICAL DONATION
- DENIAL
African American barriers to living donation

CONCERNS ABOUT THE DONOR

DON'T KNOW HOW TO APPROACH DONORS

LACK OF KNOWLEDGE ABOUT LDKT

UNSURE ABOUT RISKS, COSTS

Hispanic barriers to living donation

LACK OF KNOWLEDGE

DESIRE TO AVOID HARMING THE DONOR

FEAR OF DONATION

EXPECT THAT THE RELATIVE WOULD OFFER


Hispanic barriers to living donation

50% felt comfortable in asking a loved one to be a live kidney donor

Physician distrust

Transplant Professionals’ Perceptions

- Pre-existing medical conditions
- Financial concerns
- Reluctance to ask potential donors
- Distrust of medical community
- Fear of surgery
- Unaware of living donor transplant

Dialysis Professionals’ Perceptions

Only 23% of dialysis facility staff perceive that > 50% of their patients are eligible for KTx.

Dialysis staff members responsible for KTx felt equipped to discuss KTx with their patients.

37% of facilities reported that >75% of their patients are ineligible for transplantation.

Challenges we’re facing1

1. Racial/ethnic minorities were significantly less likely to receive LDLTs when compared to white patients.

2. African American patients received fewer per-patient donation inquiries than white patients.

References:

**Live liver donor considerations**

- Independent living donor advocate plays critical role
- Donors more likely to feel pressure to donate
- “‘Heart’ rather than ‘head’-based decision”
- >1 meeting needed
- Even greater need to attend to health Literacy and cultural/ethnic barriers

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**What to do?**

- **Health literacy**
  - Tailored educational materials.
- **Technology**
  - Interactive decision aids about donation.\(^1\)
- **Assess**
  - Comprehension of donation process.\(^1\)
- **Reading level**
  - 6\(^{th}\)–8\(^{th}\) grade materials needed (including consents).\(^1\)

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What to do?

Universal discussions
Patient-physician discussion of living donor transplant.

Family involvement
Include social network members in discussion about living donation.

Patient centered care
Shared decision making about living donation.

Early discussions
Need to start conversations about living donation early.

Education
Modify unrealistic expectations.

Home visits
Education in patient home about living donation.\(^1,2\)

Counseling
Improve recipient coping skills.

Early discussions
Focus on quality-of-life and health benefits possible with transplant.\(^3\)

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\(^3\) Watmough A. Improving preemptive transplant education to increase living donation rates: teaching patients earlier in their disease adjustment process. Progress in Transplantation. 2006;6(1):59-64.
What to do?

**Dialysis unit interventions**
A transplant champion in every dialysis unit.

**Role plays**
Practice approaching donors.¹

**Address barriers**
Trust, burial concerns, socioeconomic factors.²

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What to do?

**System level change**
Systems and providers need to change.¹

**Culturally competent care**
Need educational sessions in Spanish, employ bilingual and bicultural staff.²

**Spanish language media**
TV and radio advertisement.³

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What to do?^1

“Patients must believe that it is appropriate to ask a family member to be a living donor.”

Focus on positive outcomes and low risk.

Patients need help accepting the offer of donation.

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What to do?^2

Increase donation inquiries

- Outreach to patient and social networks.

Living liver donor champion

- To help patients find a living donor.

House calls?

More research needed

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What to do?

Interdisciplinary Interventions
Nurses (97%), social workers (72%) & surgeons (55%) doing transplant education.¹


What to do?

Talking about Living Kidney Donation (TALK) Materials

Book:

Living Kidney Donation and Transplantation

Play Video
“[It would be helpful]” just to have someone just inform you and talk to you about different options or, you know, just try and encourage you. You know, my first few years on dialysis was a disaster. I didn’t have nobody to talk to me, I didn’t have nobody, you know, I had my family but they don’t know.”

“I believe the one gets it [KTx] is who has the most money to pay for it.”

“If you’re educated, you can make it through.”
They show us a tape every year [about KTx] when we sit in the little lobby, and they pop that little tape in, and they say you need to watch this, and we don’t watch it because we sit in the lobby and talk. And then we go in the back [to the dialysis unit], and then they say, sign this piece of paper saying you saw the video. So we sign it. [They ask] “Did you understand all that you saw”? Yes we did. And you know, we don’t, we sitting out there talking about what we cooked, what the kids did, all the things but what’s actually going on on that video screen. We never saw it. But we lie when we get in the back and say yes, I did watch it. And they know that we didn’t watch it either.

When we started with the nephrologist, when we were first diagnosed with renal failure, and we went into the office and saw the nephrologist, we should have been given options then…when I came in to see her, she never introduced herself, she walked in the room and she said…we’re going to put you in the hospital today, we’re going to do a biopsy, we’re going to do, she said like twenty things. I said well…who are you? She said I’m Dr. so and so, I said interesting, I’m not doing any of that. You gonna need to rewind, go back out the door, come back in, tell me who you are, and then after you tell me who you are, let’s discuss my options. Because you not giving me a choice, so if you don’t give me a choice, well that doesn’t work for me, I don’t know about anybody else, I shut down. If I don’t have no hope, what’s the purpose in us doing this? If you told me I have the ability to have a transplant, and showed me my option for transplant then, oh we could have probably had a wonderful relationship, but to this day she don’t like me because it was ugly. When you walk in the door and you’re not giving your people the option [of KTx], and I’m, well anyway… when you are given no hope, transplant is hope. We’re not given that hope.
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Any questions?