

# Breaking Barriers – Strategies to Advance Health Equity at Dialysis Facilities

*Learning and Action Network (LAN)*

March 7, 2023

Facilitator: Chiao Wen Lan, ESRD National Coordinating Center



# Meeting Logistics

- Call is being recorded
- All participants are muted upon joining the call
  - We want to hear from you
  - Type questions and comments in the “Chat” section, located in the bottom-right hand corner of your screen.
- Meeting materials will be posted to the ESRD NCC website

# Ways to spread best practice from today's LAN

- Listen and share your approaches/experiences via Chat
- Identify how shared information could be used at your facility
- Apply at least one idea from today's LAN at your facility

Learning and Action Networks (LANs) bring people together around a shared idea, opportunity, or challenge to offer and request information and experiences to improve the identified topic of discussion.

# Who Is On The Call?

Patients and  
Caregivers

Dialysis Facility  
and Transplant  
Professionals

ESRD Network  
Staff

Centers for  
Medicare &  
Medicaid Services  
(CMS) Leadership

# Key Objectives for Today

- Explain approaches to identify patients with social needs
- Describe methods to address patients' social needs
- Discuss how to implement strategies to advance health equity in your facilities

**March is Social Work Month!**

**SOCIAL WORK**

**BREAKS BARRIERS**



# Nephrology Social Workers' Role in Health Equity

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Dialysis Social Worker  
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# Topics Covered



Screening Patients for Health-Related Psychosocial Needs with a Health Equity Lens



Educating Staff to Support Patients



Connecting Community Resources to Enhance Outcomes



Facilitating Patient and Care Team Communication & Education



# Screening Patients for Needs with a Health Equity Lens



# Educating Staff to Support Patients

- **Be a Part of New Employee Training: Social Worker Provides Education on**
  - Clinical Issues Patients May Have
  - Social Determinants of Health
- **Webinars**
  - Implicit Biase Training
  - Structural Racism
- **Mentoring Staff**
  - Experienced Staff Mentor New Staff
- **Staff Meetings**
  - Role-Playing
  - Discussion with Handouts



# Connecting Community Resources to Enhance Outcomes – Food Insecurity Example

- SNAP/EBT Benefits (Wisconsin Foodshare)
  - Farmer's market
- Local Food Pantry
- Second Harvest Foodbank (Feeding America)
- Aging and Disability Resource Center
- Meals on Wheels
- Mom's Meals (Home Delivered Microwavable Meals)
- Monthly Community Sharing Supper
- School Nutrition Program
- Community Supported Agriculture
- Faith Communities
- Senior Meal Sites



# Facilitating Patient and Care Team Communication & Education



- Limited Health Literacy
  - Video Education
  - Handout with pictures to explain
  - Discussion with patients regarding education
- Limited English Proficiency
  - In-person Interpreter
  - Telephone Interpreter Service
  - Video interpreting for sign language
  - Not using family

**Everyone on the care team has an important role in advancing health equity.**

**The social worker can be a leader in promoting and improving health equity in the dialysis setting.**



# Breaking Barriers – Strategies to Advance Health Equity in the Kidney Community

Lara Tushla, LCSW, NSW-C, FNKF  
Rush University Transplant Program

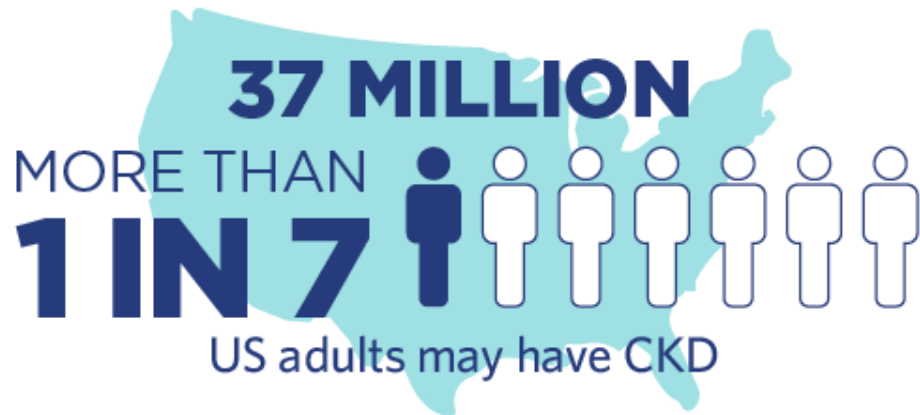


# SOCIAL WORK

# BREAKS BARRIERS

**Happy Social Work Month**

# Our Context



- Kidney transplant is the best treatment for advanced chronic kidney disease (CKD) for most people
- According to the 2020 United States Renal Data System (USRDS) – 786,000 people with ESKD in the US
  - 71% on dialysis
  - 29% have had a transplant
- According to United Network for Organ Sharing (UNOS) 2-27-23
  - 90,572 people listed for kidney or combined kidney and pancreas
    - 31,748 White, Non-Hispanic
    - 27,328 Black, Non-Hispanic
    - 19,650 Hispanic/Latino
  - 26,309 people received a kidney or combined kidney and pancreas transplant in 2022
    - 21,757 White, Non-Hispanic
    - 9,639 Black, Non-Hispanic
    - 8,019 Hispanic/Latino



# Beyond the diagnoses and labs

- “Health” ability to optimize, it doesn’t exist in a vacuum
- People who have relatively poorer Social Determinates of Health (SDOH) are disproportionately impacted by CKD and ESRD
  - Well-documented disparities in the CKD arena related to:



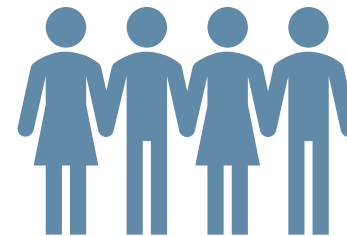
Socioeconomic  
Status



Social  
Environment



Educational  
Level



Race, Gender



Access to  
Healthcare

**Social Determinants of Health (SDOH) are the “conditions in which people are born, grow, live, work and age.”**

Figure 1  
Social Determinants of Health

Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
Employment	Housing	Literacy	Hunger	Social integration	Health coverage
Income	Transportation	Language	Access to healthy options	Support systems	Provider availability
Expenses	Safety	Early childhood education		Community engagement	Provider linguistic and cultural competency
Debt	Parks	Vocational training		Discrimination	Quality of care
Medical bills	Playgrounds	Higher education		Stress	
Support	Walkability				
	Zip code / geography				

**Health Outcomes**  
Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations



Source: Kaiser Family Foundation, <https://www.kff.org/racial-equity-and-health-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/>



# Social Determinants of Health of Kidney Disease

- Food insecurity
- Housing instability
- Unreliable transportation
- Safety fears
- Inadequate access to utilities
- Limited access to educational opportunities
- Poor income and employment opportunities
  - Insurance
- Environmental Exposures
- Support Systems (Lara's addition)

# Focus on Two Social Determinants of Health Areas

- Support System
- Education

# Support System – What role can caregivers play?

Provide emotional support through a challenging situation.

Assist in navigating health care systems, especially while the person with CKD is not feeling well

Second set of ears with teaching, note taker, and question asker.

Managing medications

Transportation assistance

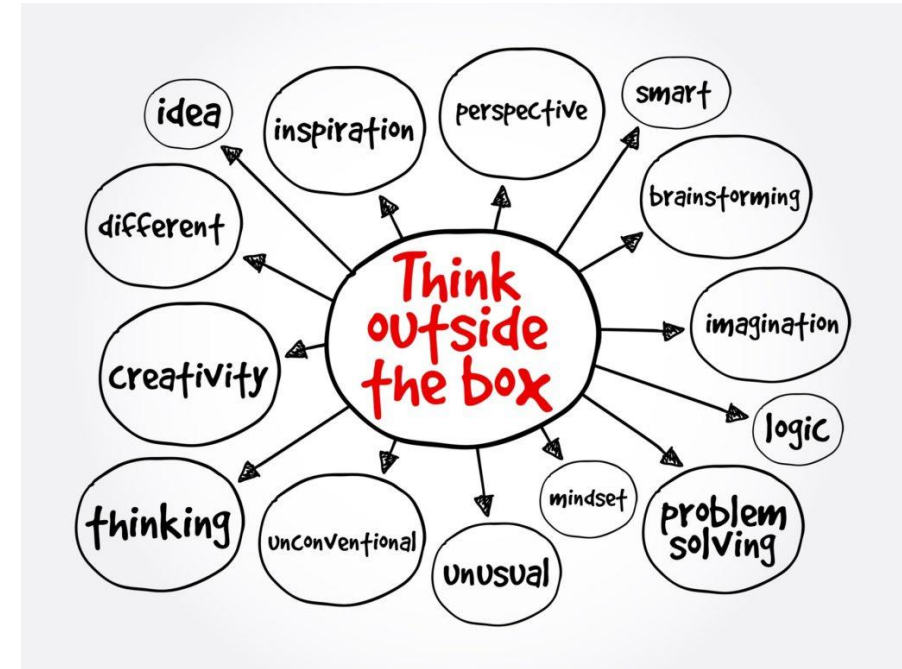
Assist with household responsibilities

# Support System (cont'd)

- Impact of treatment options for people with limited support systems
  - May not be encouraged to try home dialysis
  - May not be a transplant candidate
    - 10-20% of candidates at a given center are not considered for transplant if they do not have an “adequate support system”
  - May not be perceived to be unable to undertake complex care on their own
- Research showing the “... role of social support and its link to treatment adherence, quality of life, and graft survival in transplant patients.” (Maldonado, 2019)
- “Social support may be an unreliable predictor of post-transplant adherence and outcomes.” (Ladin 2018, 2019)

# Support System – How Can Providers Help?

- Biologically related people aren't always supportive
- Brainstorm non-traditional sources for support: friends, coworkers, church family, neighbors, community fraternal organizations
- Adopt a team model. Doesn't need to be one person doing everything.
- Supplement with paid caregivers, home health aids through Department on Aging, Rehabilitation, or private pay.
- Access skilled nursing, home health as able
- Enroll in transportation services out there
- Veterans' benefits



# Education



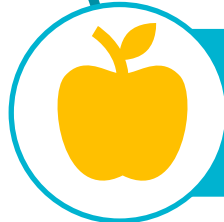


# Education about CKD

It is nearly impossible to care for yourself if you don't understand what's happening to your body, treatment options, and your role in optimizing the options!



Medications: dose, what it's for, and when to take it



Nutrition and fluid limitations



Procedures: preparation, post-procedure care



Diagnoses and treatment options: how is the condition affecting you, how do you best manage it and whom do you need to have on your medical team to address most effectively?

# Education about CKD – What can providers do?



**Have a resource list to share with patients and family about common topics**

Most common languages in your area

Various methods: internet, audio, video, written, in person

Varying levels of detail

6-7<sup>th</sup> grade reading level recommended for medical information



**Have different providers offer education on the same topic**

MD, RN, RD, MSW, CHT, peer educators

# Education about CKD – What can providers do?



**Spread out the education**



**Revisit topics regularly**



**Explain in different ways**



**Help patients come up with a list of questions and support them as they get their answers**



**Use qualified interpreters!**

# Bibliography (1)

- Quiñones, J., & Hammad, Z. (2020). Social determinants of health and chronic kidney disease. *Cureus*, 12(9).
- National Kidney Foundation (n.d.). *Social determinants of kidney disease*. Retrieved March 6, 2023, from <https://www.kidney.org/atoz/content/kidneydiscauses>
- Park, C., Jones, M. M., Kaplan, S., Koller, F. L., Wilder, J. M., Boulware, L., & McElroy, L. M. (2022). A scoping review of inequities in access to organ transplant in the United States. *International Journal for Equity in Health*, 21(1), 1-20.
- Chan, N. W., & McElroy, L. M. (2022). Using Social Determinants of Health Data to Address Racial Disparities in Kidney Transplantation. *ASN Kidney News*, 14(7): 21.
- Wesselman, H., Ford, C. G., Leyva, Y., Li, X., Chang, C. C. H., Dew, M. A., ... & Myaskovsky, L. (2021). Social determinants of health and race disparities in kidney transplant. *Clinical Journal of the American Society of Nephrology*, 16(2), 262-274.
- Song, Y., Chen, S., Roseman, J., Scigliano, E., Redd, W. H., & Stadler, G. (2021). It takes a team to make it through: the role of social support for survival and self-care after allogeneic hematopoietic stem cell transplant. *Frontiers in Psychology*, 12, 624906.
- Maldonado, J. R. (2019). Why it is important to consider social support when assessing organ transplant candidates?. *The American Journal of Bioethics*, 19(11)., 1-8.

# Bibliography (2)

- Ladin, K., Emerson, J., Berry, K., Butt, Z., Gordon, E. J., Daniels, N., ... & Hanto, D. W. (2019). Excluding patients from transplant due to social support: results from a national survey of transplant providers. *American Journal of Transplantation*, 19(1), 193-203.
- Ladin, K., Daniels, A., Osani, M., & Bannuru, R. R. (2018). Is social support associated with post-transplant medication adherence and outcomes? A systematic review and meta-analysis. *Transplantation Reviews*, 32(1), 16-28.

# My observations



**Each transplant center has its own listing criteria, absolute contra-indications, and relative contra-indications which are broadly written.**

These change over time:

- Best practice guidelines adapt to what is known in the larger transplant community and new data
- Governmental guidelines may change
- As experience with various factors increases, certain recipient characteristics may change
- As staff members change, experience and expertise change



**Transplant centers are required to provide copies of their listing criteria available to those who request it including patients, dialysis units and nephrology groups**

These are broadly written

Just because someone is not a candidate at one transplant center... does not mean they are disqualified everywhere.

# Transplant Advocates can...



**Gather the Listing Criteria** for all the transplant centers that your patients may work with, to help guide patients to centers they most likely will have success with.

Make additional notes based on experiences you/your patients have had. Or in conversation with the transplant centers

- BMI or other weight-related guidelines
- Age or medical complexity
- Need for listing vs having living donors
- Vaccination status
- Gaps in insurance
- Support system

# Transplant Advocates can... (cont'd)

## If the transplant centers have Outreach Coordinators

- Invite them to talk with your dialysis/nephrology team about their listing criteria, referral process, and ways to collaborate.
- The coordinator might be able to be a point person as your patients work through the referral process.
- Perhaps their staff could provide in-services or continuing education for your staff to better understand what they are looking for in transplant candidacy.
- Consider inviting them to talk with your patients in your clinics.

## Consider “Multi-Listing”

- It is not as useful as it used to be with the new nautical mile distribution model, but people could be exposed to more potential donors if they list at multiple centers.
- Patients need to be good communicators to optimize this, talk more about that next slide



# Transplant Advocates can... (cont'd)



**Consider simultaneously initiating evaluation in the same area**

Some patients will start the evaluation process at several areas simultaneously to see which will place them on the waiting list or move forward with living donors first.



**Working with multiple centers requires patients/support persons to be actively involved in keeping each of the centers up to date so they don't unnecessarily duplicate testing.**

Stay organized to keep track of appointments and tests across several systems.

# Set Reasonable Expectations

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Transplant evaluation will seem like a never-ending list of tests to complete, consultations, and hoops to jump through. And just when you think you've done them all... it will be time to update them.

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The ultimate goal of the transplant evaluation is to make sure that we are going to improve someone's life with a transplant, not cause "new problems."

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The standards for clearance from a transplant perspective may be different than for people living their lives, e.g., cardiology clearance for transplant surgery is often different than for dialysis access surgery.

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While we cannot see everything through EMRs, we can see quite a bit. It is best if someone is upfront with the transplant team than for us to find the information in records, e.g., substance use, and mental health admissions.

# Get Ready For Starting the Transplant Evaluation

**Organize yourself.** Bring copies of these lists to give to the transplant team.

1. Medical, surgical, and mental health histories, with dates of diagnosis or procedures as best as possible. Don't assume we can see everything on the computer
2. Medications (name, dose, frequency, and reason for taking). Take your bottles so the team can check your refill history as well
3. List of providers (doctors, hospitals, pharmacies, outpatient procedure locations)

**Keep a calendar with all future appointments, don't double book**

**Make a list of YOUR questions**

# Patients' First Contact With Transplant Team



**Be prepared it might last several hours**

Bring snacks, water, a phone charger, or something to help the time pass (there could be gaps between providers)



**Bring someone with you if at all possible.**

There will be a lot of information shared and questions asked in that first session, which can be overwhelming.

Another set of eyes and ears will help you pick up additional information.

Shows the transplant team that you are not going through the transplant process on your own.



**Ask how the team would like you to communicate. Call, fax, email, or via the patient portal?**



**Make sure you know your next steps before you leave the appointment.**

Will they schedule appointments or give you orders to do close to home?

# Questions?



# Thank you!

FL-ESRD NCC-NC2HEQ-03062023-01



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