

Transplant

Learning and Action Network (LAN)

February 27, 2025

End Stage Renal Disease National Coordinating Center (ESRD NCC)



Meeting Logistics



The 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 Practices From Today's LAN

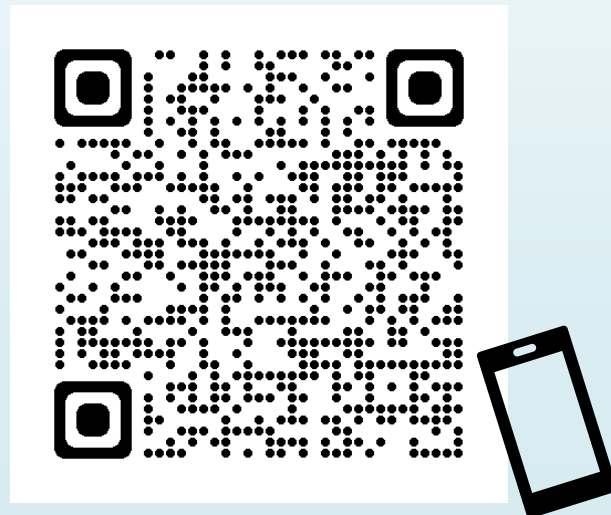
- Share your approaches and experiences via Chat.
- Identify how today's information could be used at your facility.
- Apply at least one idea from today's LAN at your facility.
- Commit to sharing your learnings and ideas with other colleagues.

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.

Answer using *Chat*.

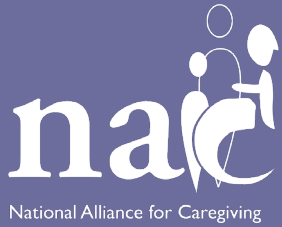
Make sure it is set *To: Everyone*

Have you previously applied best practices from the change packages to improve outcomes?



The screenshot shows the ESRD NCC National Coordinating Center website. At the top left is the logo, and at the top right are contact details: nccinfo@hsag.com, 844.472.4250, and social media icons for Facebook, LinkedIn, Twitter, and YouTube. Below the header is a navigation bar with tabs for Patients, Professionals, COVID-19, ESRD Network Map, and Fistula First Catheter Last. A breadcrumb trail reads: You are here: Home > Professionals > Change Packages. The main content area is titled "Change Packages" and features a list of categories, each with a dropdown arrow: Depression, Dialysis Care in Nursing Homes, Fistula First Catheter Last (FFCL), Health Equity, Home Dialysis, Hospitalizations, Patient Experience of Care, and Transplant. On the right side, there is a sidebar menu with a "Professionals" header and sub-items: Change Packages (highlighted), Health Equity, Expert Teams, and Learning and Action Network Call Series.





Bridging the Gaps: Improving Caregiver Support in Transplant

February 27, 2025

Presented by:
Yadira Montoya, Master of Science in
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(MPH)



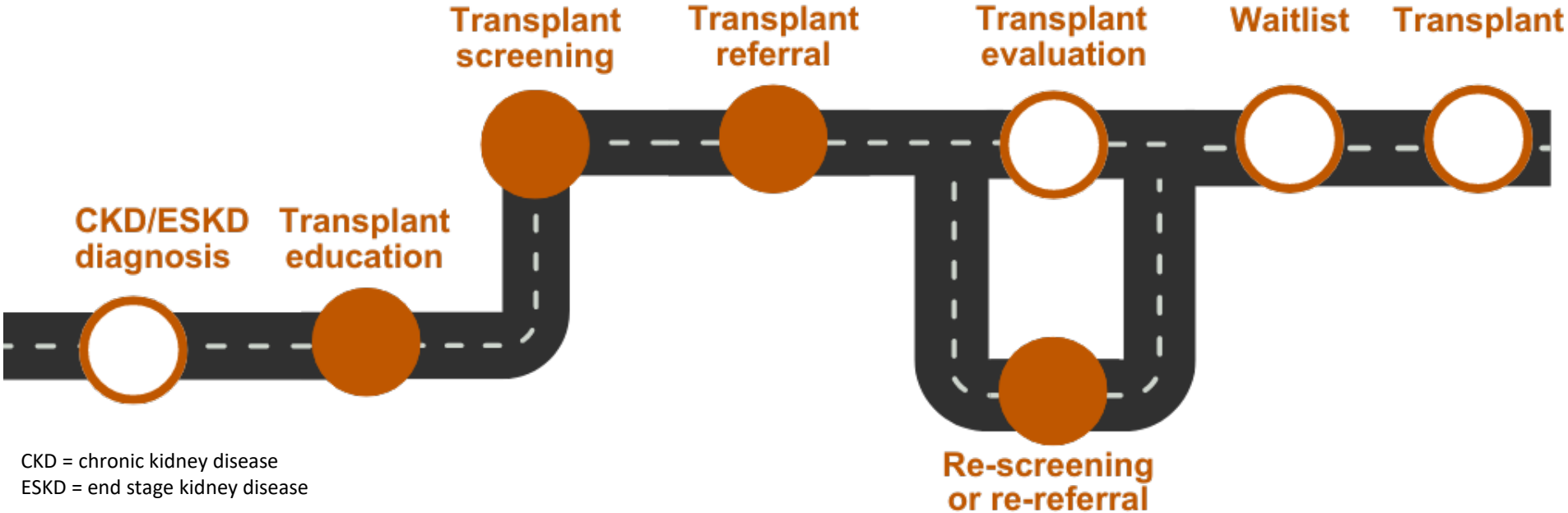
*Picture owned by National Alliance for Caregiving (NAC)

National Alliance for Caregiving (2024). *Gaps and Opportunities: Family Caregiver Programs in U.S. Transplant Centers* (p.9). https://www.caregiving.org/wp-content/uploads/2024/11/NAC_TransplantGapsReport_FINAL_11.05.2024.pdf

Objectives

- Describe the experiences and challenges family caregivers face throughout the transplant journey.
- Highlight key findings from NAC's 2024 report, "Gaps and Opportunities: Family Caregiver Programs in United States (U.S.) Transplant Centers."
- Discuss recommendations to improve caregiver support services in transplant care to enhance patient outcomes.

Road to Transplant



Dialysis social worker (DSW) is primary clinician



NAC's Transplant Caregiving Collaborative focuses on enhancing the recognition, inclusion, and support of family caregivers within the transplant system.

JAN 2022



Launched its Transplant Caregiving Collaborative

NOV 2023



Released *Transplant Caregiving in the U.S.: A Call for System Change*

MAY 2024



Commissioned a national survey of transplant centers

AUG 2024



Hosted Champions in Transplant Care Forum

NOV 2024



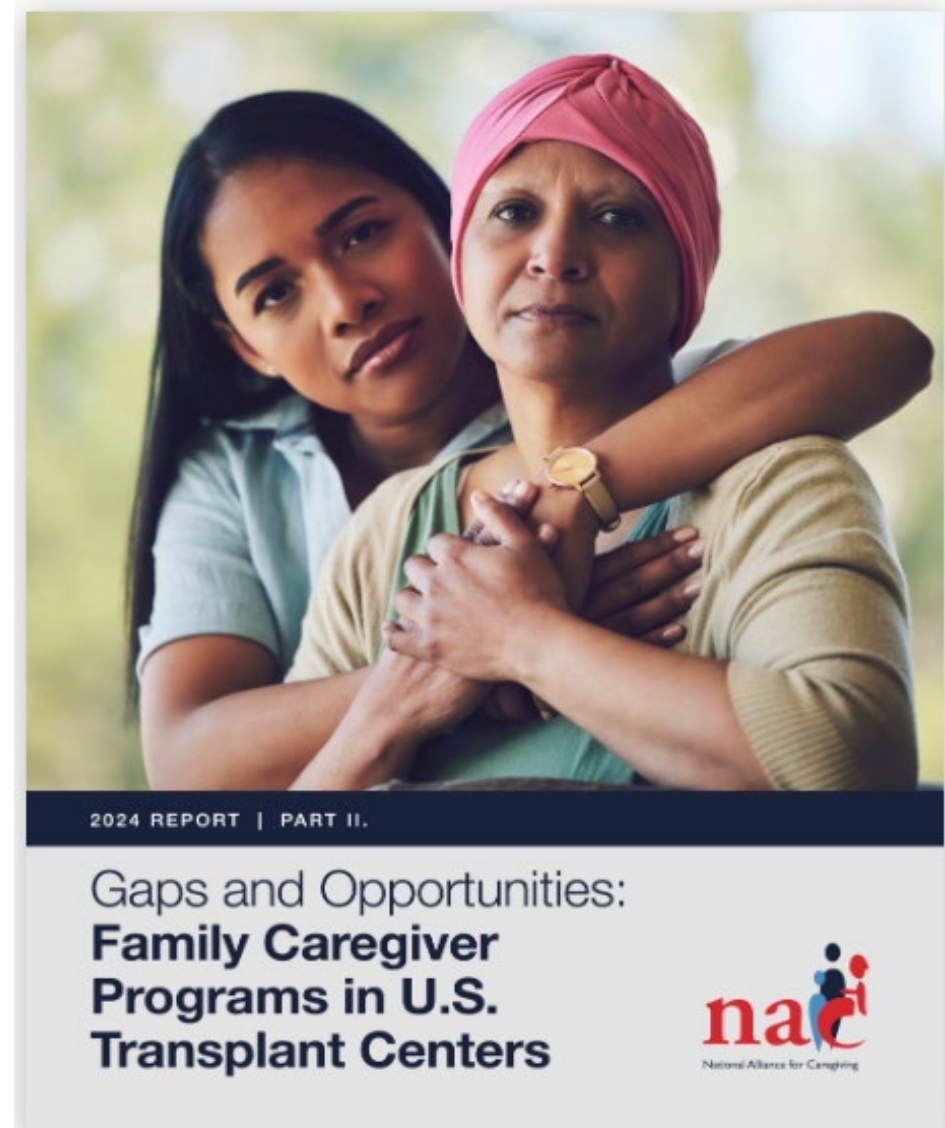
Released *Gaps and Opportunities: Family Caregiver Programs in U.S. Transplant Centers*



Melina Pineyro (2024). Mother-in-Law at the beach [Personal Photography]

Research Aims

1. Evaluate the current landscape of family caregiver support across transplant centers (TC) in the U.S.
2. Assess both existing practices and the availability of caregiver needs assessments, support programs, education, and training in TC.



Methodology & Center Characteristics

- April 30 - May 18, 2024
- 143 individuals were sampled representing 114 unique TC
- Respondents included: support staff and directors of caregiver support programs

Survey Respondent Roles



National Alliance for Caregiving (2024). *Gaps and Opportunities: Family Caregiver Programs in U.S. Transplant Centers* (p. 12). https://www.caregiving.org/wp-content/uploads/2024/11/NAC_TransplantGapsReport_FINAL_11.05.2024.pdf

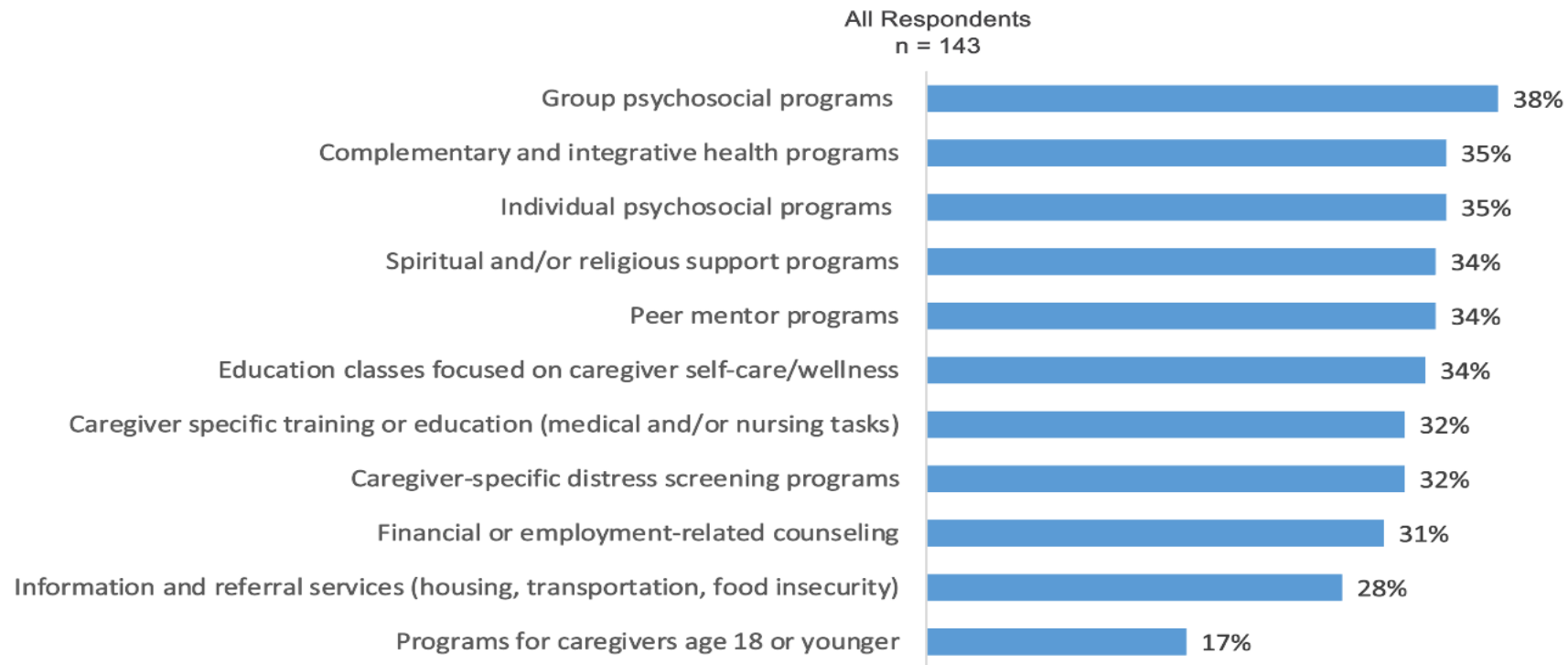
Transplant Center Types

	Kidney	Liver	Heart	Pancreas	Lung	Allogenic Bone Marrow Transplant	Autologous Bone Marrow Transplant	Intestine
Count	103	59	58	48	21	6	5	5
# of Transplant Centers	90%	52%	51%	42%	18%	5%	4%	4%
Academic medical center (i.e., university-based hospital)	50%	61%	48%	54%	71%	83%	100%	100%
Independently owned (i.e., single hospital or small regional network or an independent clinic/physician practice)	20%	17%	24%	19%	19%	33%	20%	0%
Hospital, clinic, or physician practice owned by a health system that <i>DOES include a health plan</i>	20%	20%	24%	17%	14%	17%	20%	0%
Publicly owned (e.g., state, county, city)	13%	12%	12%	19%	5%	0%	0%	20%
Hospital, clinic, or physician practice owned by a health system that <i>DOES NOT include a health plan</i>	5%	2%	3%	2%	0%	0%	0%	0%



Availability of Caregivers Support Programs

Most TC offer between 2-4 types of family caregiver support programs; however, 30% had none.



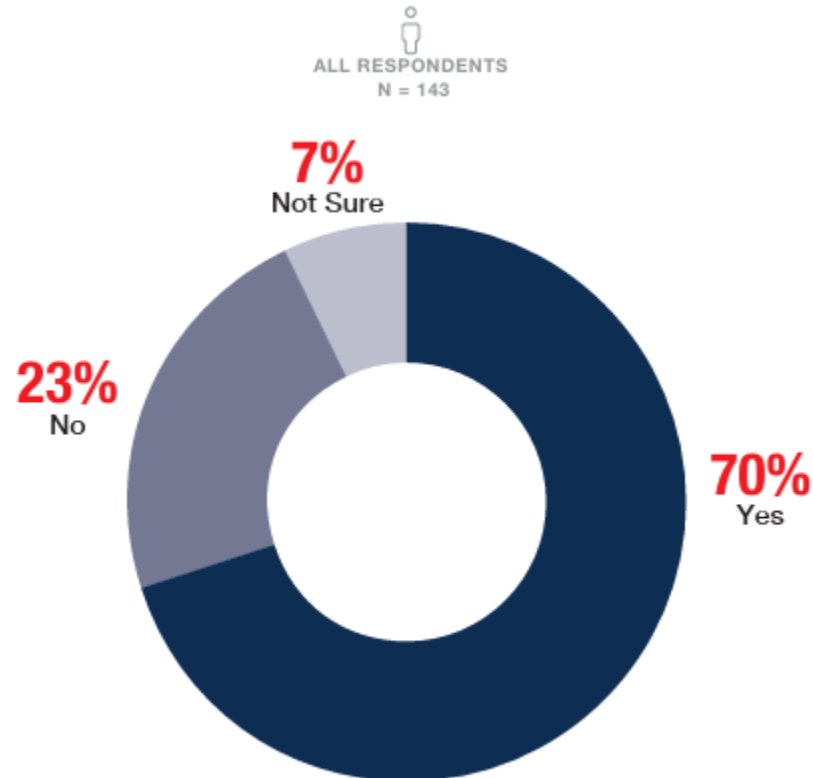
Barriers To...

Caregiver Support

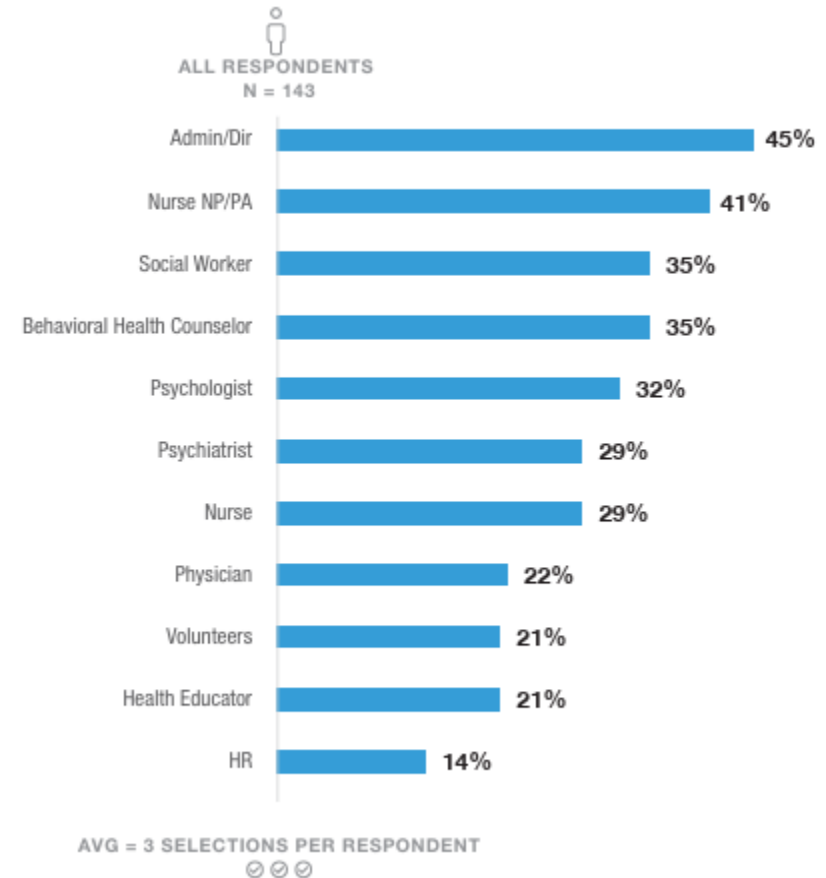
Support and Service Delivery for Caregivers

70% of survey respondents reported their TC had a designated coordinator for caregivers.

Dedicated Caregiver Support Staff



Staff responsible for Providing Support for Caregivers







Caregiver Identification and Evaluation

Only 58% of the respondents reported that their TC either lacked written procedures for assessing caregiver support needs or were unaware of such documentation processes.



Caregiver Needs Assessment

Respondents reported that their centers **may screen** for caregiver needs in the following circumstances:

-  During hospitalization for the transplant procedure **(41%)**
-  Post-transplant hospitalization discharge **(38%)**
-  In the event of a medical issue, complication, or adverse event **(38%)**
-  When the caregiver or transplant recipient requests assistance **(31%)**

While **58% of TC** offer some form of caregiver-specific education and training, there is **variability in the type and timing of the training offered.**

Education and Training

What?

- Education on necessary medical procedures required in transplantation **(45%)**
- Managing the transplant recipient's symptoms **(45%)**
- Managing and administering medications **(38%)**
- Understanding the transplant recipient's health condition **(38%)**
- Ability to identify and respond to the transplant recipient's adverse events or emergencies **(37%)**
- Understanding the scope/responsibilities of the caregiving role **(32%)**

When?

- When the recipient is placed on the waitlist **(42%)**
- While the recipient is on the waitlist **(49%)**
- When the patient is hospitalized, there is a post-transplant **(33%)**
- Post-discharge **(8%)**

Caregiver Support Across Demographic Groups

Program Availability by Race/Ethnicity Served at Transplant Centers

Programs Available	ALL CENTERS (N = 114)	Centers Serving Exclusively Low Income (N=9)	Centers Inol any Black / AA population (N=95)	Black / AA - Exclusively Low Income (N = 43)	Centers Inol any Hispanio / Latino (N=44)	Hispanio/Latino Exclusively Low Income (N = 29)	Centers inol White Only, no minority (N=16)
Group psychosocial programs for caregivers (e.g., support groups)	38%	33%	41%	42%	45%	38%	44%
Complementary/ integrative health programs for caregivers (e.g., yoga, massage, etc.)	35%	11%	33%	23%	39%	34%	44%
Individual psychosocial programs	35%	22%	32%	37%	41%	31%	31%
Spiritual and/or religious support programs	34%	22%	32%	30%	27%	24%	31%
Peer mentor programs	34%	22%	38%	28%	34%	34%	19%
Education on caregiver self-care/wellness	34%	11%	33%	33%	36%	31%	38%
Caregiver specific training or education on medical and/or nursing tasks	32%	33%	34%	30%	36%	34%	38%
Caregiver-specific distress screening (distinct from patient distress screening)	32%	44%	33%	26%	41%	48%	25%
Financial or employment-related counseling programs for caregivers	31%	22%	32%	23%	23%	14%	38%
Information and referral services (housing, transportation, food insecurity)	28%	33%	25%	21%	23%	21%	38%
Programs for caregivers age 18 or younger	17%	11%	25%	23%	30%	31%	6%

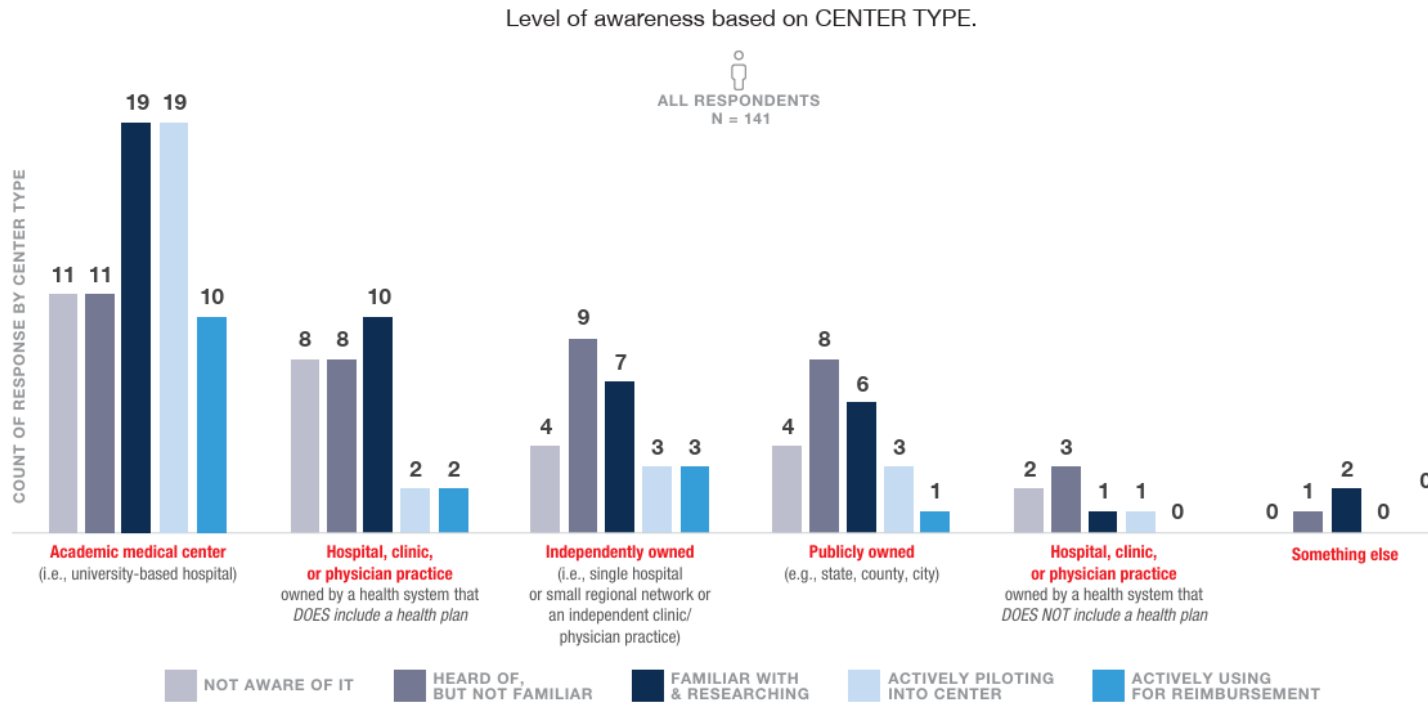
LOWER THAN AVERAGE
 ABOUT AVERAGE
 HIGHER THAN AVERAGE



Utilization of Medicare Billing Codes for Caregiver Training Services

While **80%** of transplant centers are aware of the new Medicare billing codes for reimbursement related to caregiver training

Level of Caregiver Training Services (CTS) Billing Code Awareness by Transplant Center Type



What part of the report's findings do you believe holds the greatest potential for advancing caregiver support in dialysis care?

Recommendations

Standardize Caregiver Identification and Social Support Evaluation Process During the Transplant Waitlist/ Referral Period

Implement a standardized screening process during the transplant waitlist/referral period to reduce bias and health inequities and to identify caregivers who need additional support at the onset of transplant care.



Establish a coordinator on the transplant team dedicated to the family caregiver

Integrate dedicated caregiver coordinators within transplant teams to identify, address, and support caregivers and their needs along the transplant journey.



Conduct Routine Family Caregiver Screenings and Delivery of Support Services to Respond to Unmet Needs at Critical Points Along the Transplant Continuum

Transplant centers should implement comprehensive, standardized caregiver support programs that are targeted, consistent, evidence-based, and provided continuously throughout the entire transplant journey, from pre-transplant evaluation through long-term post-transplant care, to ensure equitable and effective support for all caregivers.



Promote payment reform to increase coverage of transplant caregiver education, training, and supports

Promote the wide adoption of new Medicare caregiver training services (CTS) billing codes across all types of transplant centers to enhance access to essential training and support services for family caregivers.



How could similar strategies be adapted to better support patients and caregivers in dialysis care?

Q&A

Want to learn more?

*Gaps and Opportunities: Family
Caregiver Programs in U.S.
Transplant Centers*

*Transplant Caregiving in the
U.S.: A Call for System Change*

Scan to Read &
Download 2024
report



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report



Connect with Us!



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THANK YOU!

 www.caregiving.org

 [@NA4Caregiving](https://twitter.com/NA4Caregiving)

 [National Alliance for Caregiving](https://www.linkedin.com/company/national-alliance-for-caregiving)



*Picture owned by NAC

National Alliance for Caregiving (2024). *Gaps and Opportunities: Family Caregiver Programs in U.S. Transplant Centers* (p.5). https://www.caregiving.org/wp-content/uploads/2024/11/NAC_TransplantGapsReport_FINAL_11.05.2024.pdf

Moving from Learning to Action

Share best practices from this presentation with your colleagues.

Use the ESRD NCC Change Packages to improve patient outcomes and overall patient experience of care.

Please complete the post-event survey.



The diagram illustrates the transition from learning to action. On the left, a smartphone displays a QR code. A large black curved arrow points from the QR code to a screenshot of the ESRD NCC website. The website screenshot shows the 'Change Packages' page, which includes a navigation menu with options like 'Patients', 'Professionals', 'COVID-19', 'ESRD Network Map', and 'Fistula First Catheter Last'. The main content area lists various change packages such as 'Depression', 'Dialysis Care in Nursing Homes', 'Fistula First Catheter Last (FFCL)', 'Health Equity', 'Home Dialysis', 'Hospitalizations', 'Patient Experience of Care', and 'Transplant'. A sidebar on the right shows a dropdown menu for 'Professionals' with sub-options like 'Change Packages', 'Health Equity', 'Expert Teams', and 'Learning and Action Network Call Series'.

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Thank You.

Please take a moment to complete the post-call survey.

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