

Building Better Support for Family Caregivers in Transplant Care



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A Virtual Event



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**A national catalyst for change
— transforming how the
United States recognizes,
supports, and values family
caregivers.**

30 years advancing family
caregiving

29 years of the Caregiving in the US data project

40+ member
organizations

OUR PRIORITIES



Champion caregiver health & wellness

Put caregivers' own physical and mental health on the national agenda.



Drive economic inclusion

Address the financial toll of caregiving through policy and workplace change.



Foster caregiver-friendly communities

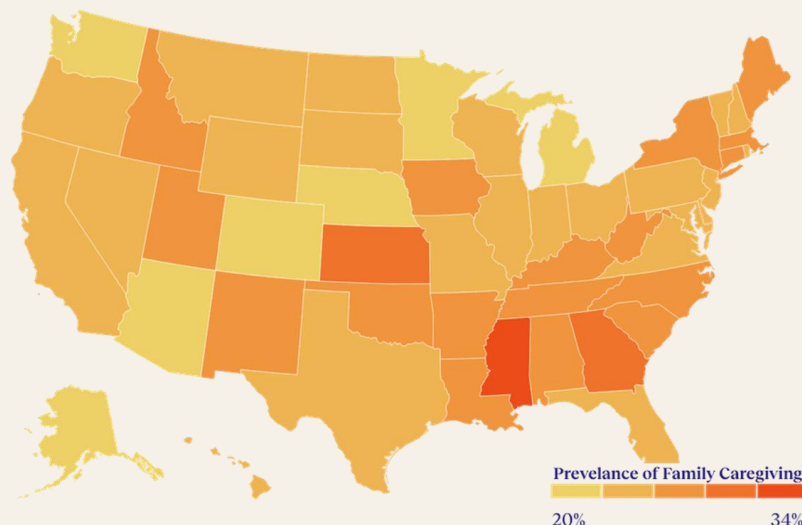
Build the local supports that let caregivers thrive where they live.

Family caregiving by the numbers.

63M+

Americans are family caregivers.

≈ 1 in 4 adults. Up 46% since 2015.



\$1.01T

value of care provided annually

27.3

hours of care per
week, on average

29%

are "sandwich" caregivers
— care for kids and adults

47%

report negative
financial impacts

Source: AARP / NAC, Caregiving in the U.S. 2025

Family caregivers are essential to healthcare delivery

55%

of family caregivers perform medical/nursing tasks.

≈ 32M+ people. Injections, wound care, tube feedings, vitals monitoring, medical equipment.

Family caregivers as health navigators



22%

receive training for these clinical tasks

96%

of those trained say it prepared them well

58%

of women perform medical tasks vs. 51% of men

62%

of Black caregivers do these tasks — most of any group

Source: AARP / NAC, Caregiving in the U.S. 2025

Poll Question

Who's in the room?

Caregivers are Present at Every Stage

Essential

- Caregivers influence transplant eligibility, recovery, and long-term outcomes.

Expected

- Caregivers manage medical, logistical, and emotional responsibilities.

Under-supported

- Support systems are inconsistent and rarely focused on caregiver needs.

HEALTH

After loved ones' long-awaited organ transplants, caregivers often find challenges are just beginning



By Annalisa Merelli Jan. 4, 2024

[Reprints](#)



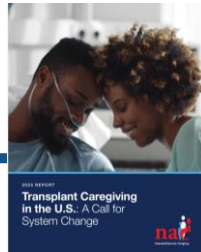
Ira Copperman with his wife, Glenda Daggert.
JESSICA RINALDI/GLOBE STAFF

To understand how transplant centers support caregivers, NAC surveyed transplant centers across the U.S.

The **Transplant Caregiving Collaborative** works to strengthen the recognition, inclusion, and support of family caregivers across the transplant system.

Initiated a project focused on the needs of family caregivers of transplant patients/candidates

JAN 2022



NOV 2023

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

Hosted first Champions in Care Forum

AUG 2024

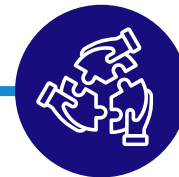


NOV 2024

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

Launched the Transplant Caregiving Collaborative

JAN 2025



AUG 2025

Released *Disparities and Missed Opportunities in Support Services Across U.S. Transplant Centers*

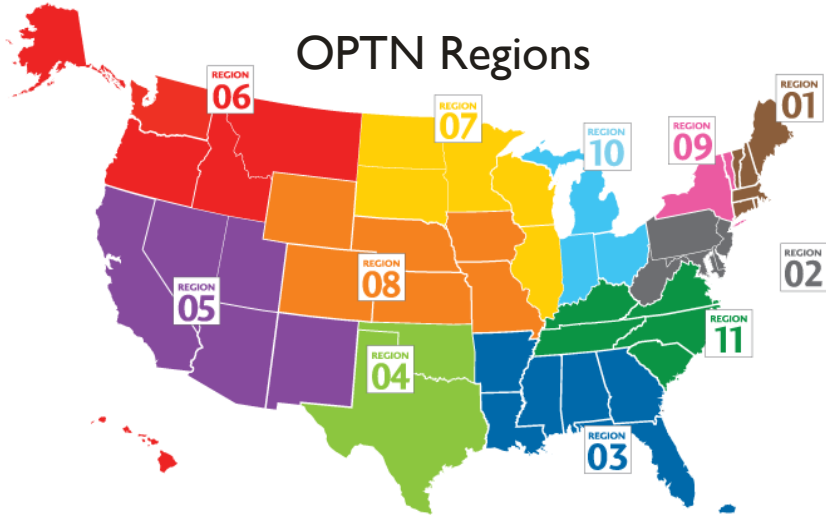
Peer Learning Network & Transplant Caregiving Hub

PRESENT



Caregiver Support Programs in U.S. Transplant Centers

All respondents were recruited from US transplant centers April 30 - May 18, 2024.



Unique Transplant Centers

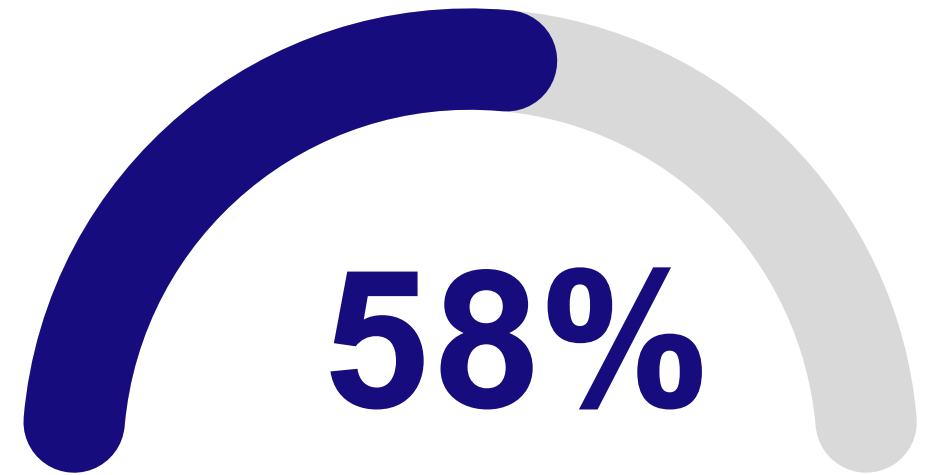
114

Caregiver Assessment

Assessing Family Caregiver Needs

Assessment is inconsistent, patient-focused, and eligibility-driven, so caregivers' own needs are rarely captured

- 58% have a written process
- 27% No written process
- 15% are not sure

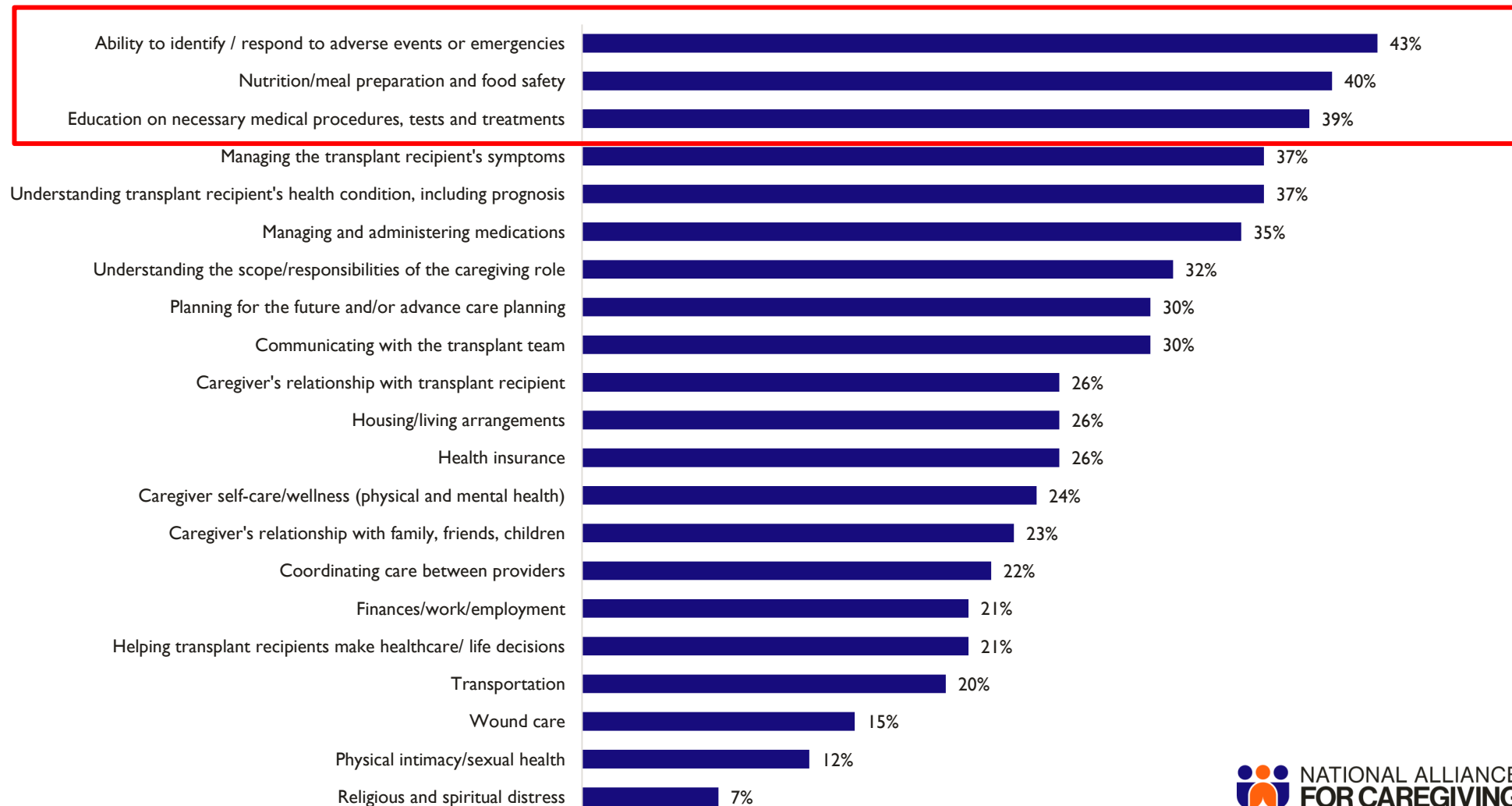


Transplant centers with a written process to assess the support needs of caregivers.

Even when centers assess, they don't address the caregiver's own need or challenges.

Asked only of centers answering "Yes" to having a written process to assess caregivers' needs for support
n = 82 of 143 centers

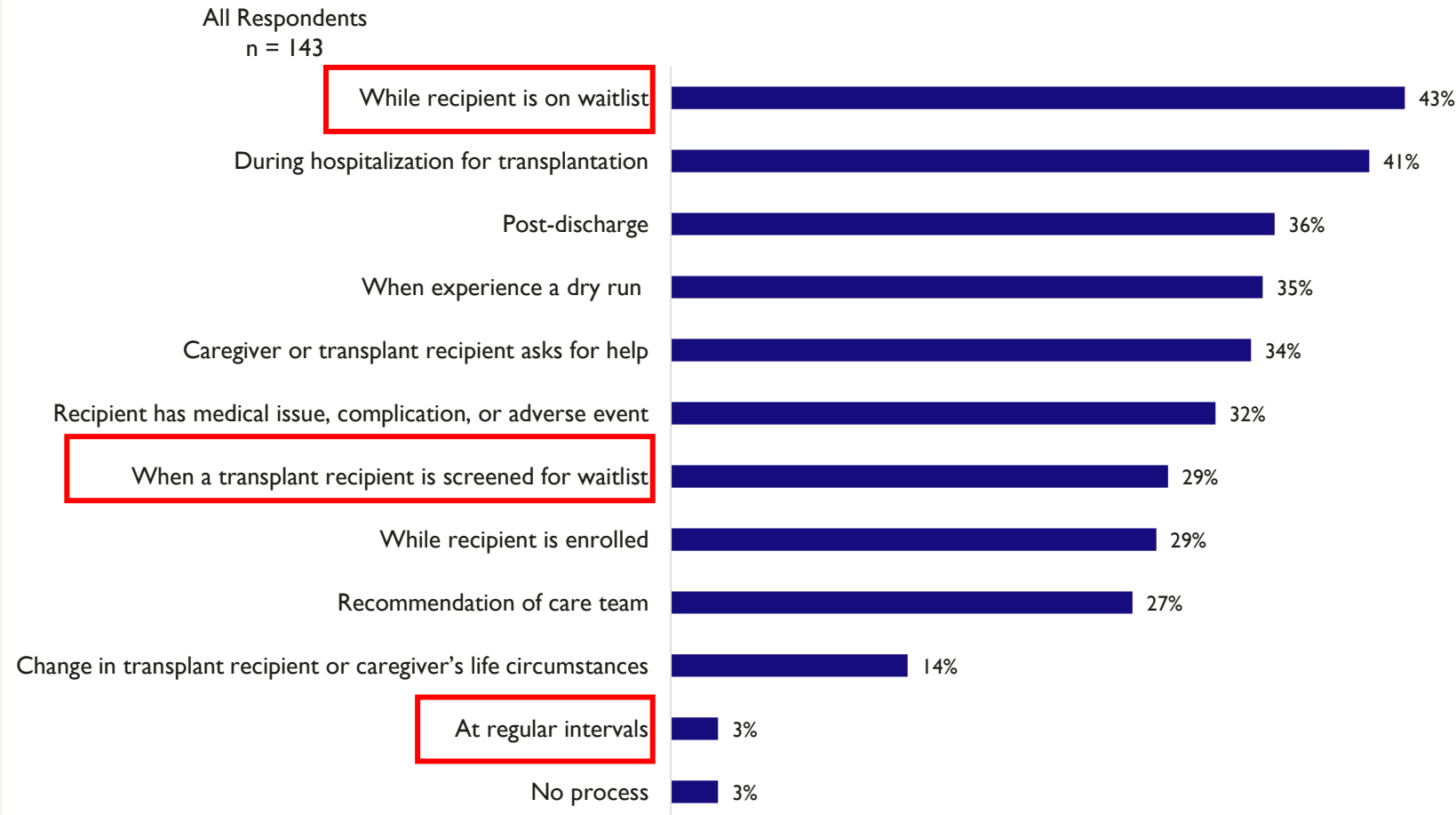
**What transplant
caregiver needs
are assessed?
(Select all that
apply)**



Caregivers are screened for eligibility, not supported over time

Eligibility screening, not needs assessment: only 3% of transplant centers review caregiver circumstances at regular intervals.

On average, how frequently are individual caregivers' circumstances reviewed to ensure the caregiver is meeting the minimum requirements of your center?



Support, Education, and Training

Support offerings vary across centers, with 70% most providing 2-4 types of caregiver support.

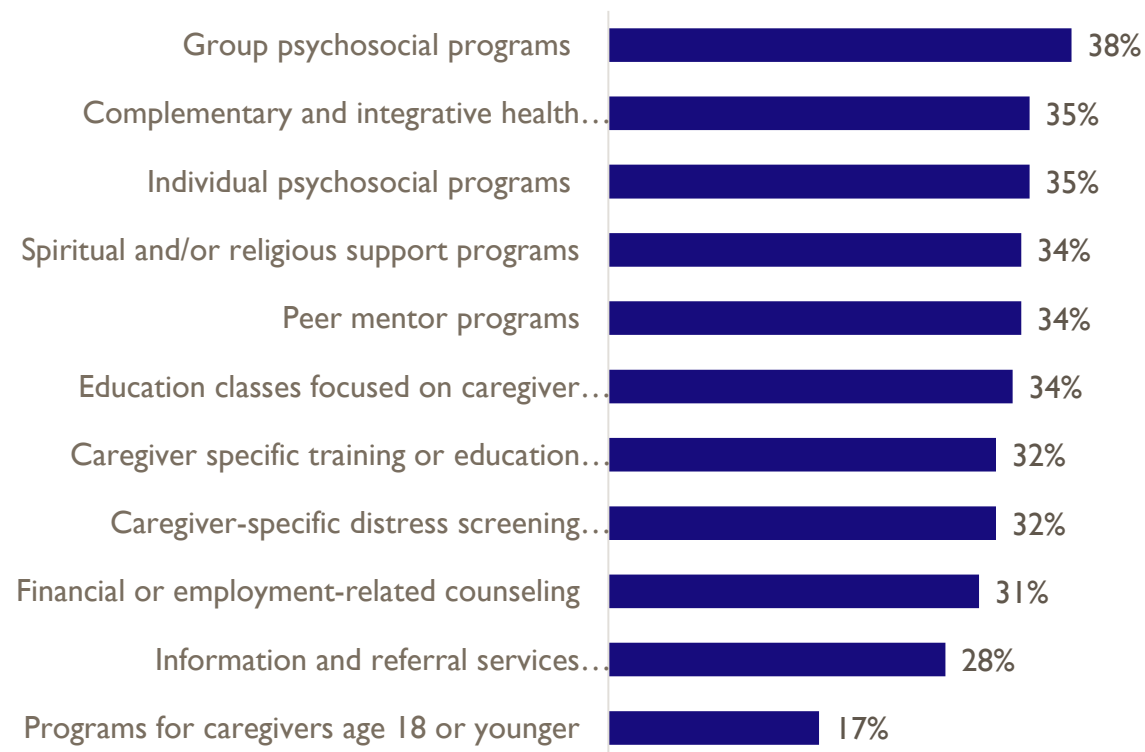
70%

Transplant centers have a caregiver support program.

Availability of Caregiver Support Programs

To the best of your knowledge, which of the following types of support programs does your transplant center currently offer to caregivers of transplant recipients?(Select all that apply)

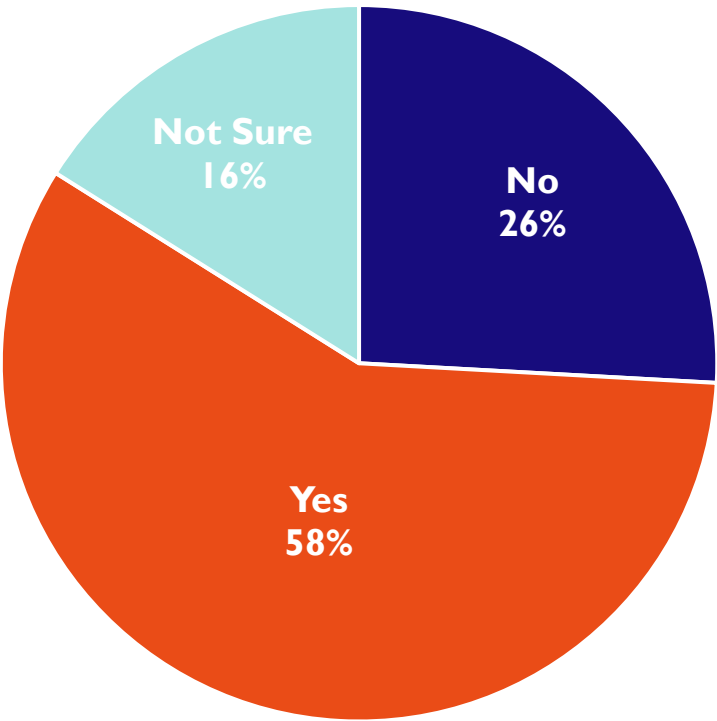
All Respondents
n = 143



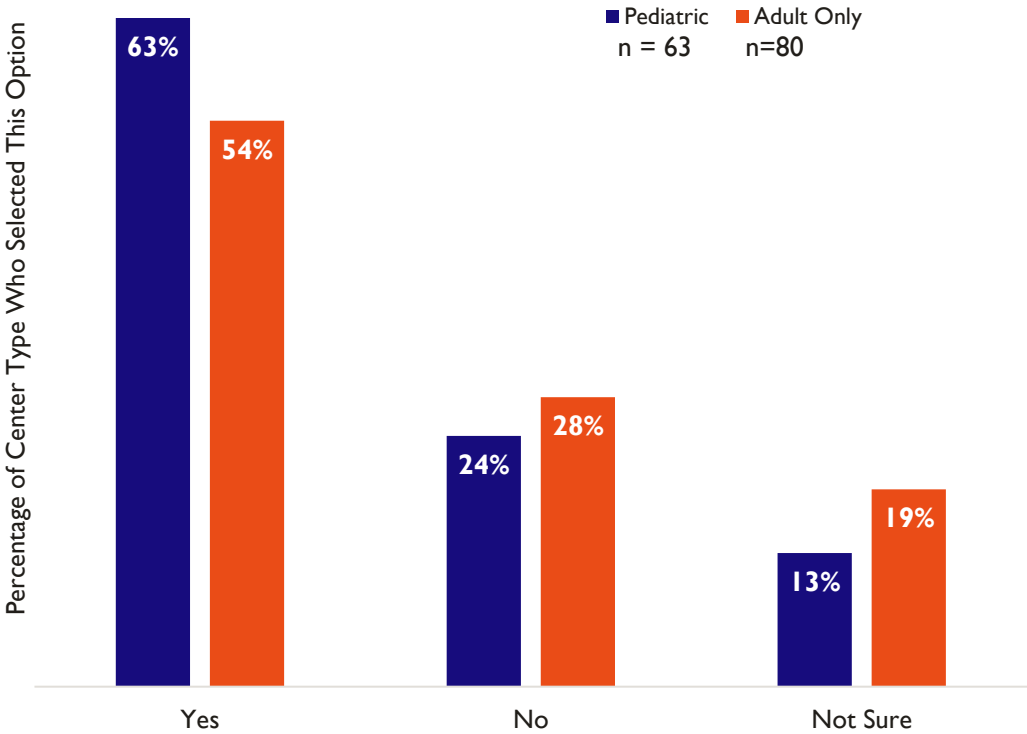
Just over half of centers provide caregiver-specific education and training, leaving nearly half with none.

This specific type of education and training is slightly more common in pediatric centers compared to adult-only transplant centers.

Does your transplant center provide caregiver-specific education and training?



All respondents
n = 143

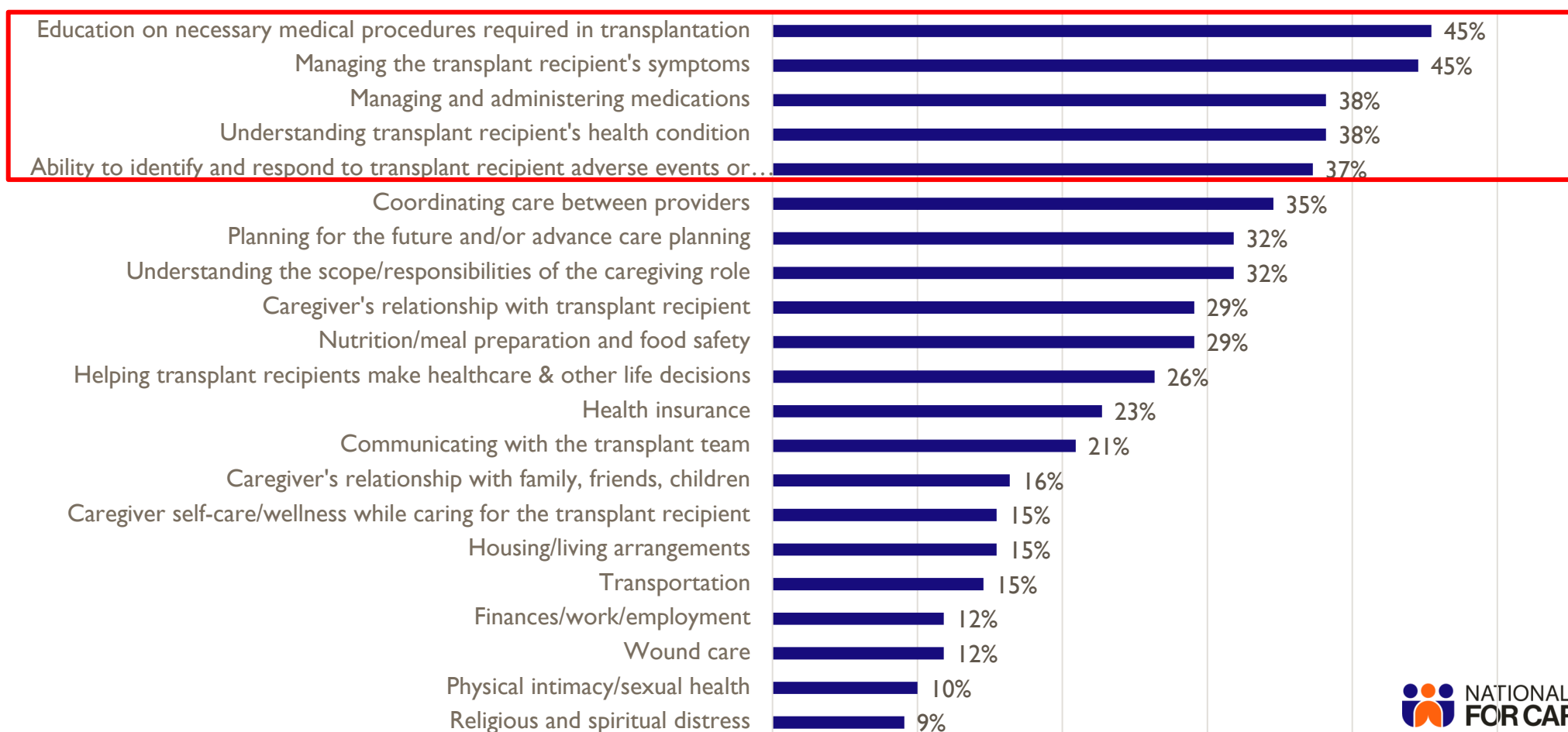


Training centers on the patient: the two most common topics are medical procedures in transplantation and managing the recipient's symptoms.

Which caregiver-specific education and training are available on-site or through referral from your transplant center?

Does your transplant center provide caregiver-specific education and training? = "Yes"

n = 110



Caregivers are usually trained alongside the patient, not for their own role

The caregiver and transplant recipient usually receive education and training at the same time in **42%** of transplant centers.



42%

TRAINED TOGETHER
Most transplant centers educate caregivers and recipients together.

When do transplant recipients and caregivers receive education and/or training?

1

34%

**CAREGIVER
BEFORE**



In most cases, the caregiver receives education and training **before** recipient.

2

42%

**SAME TIME
TIME**



In most cases, the caregiver and recipient receive education and training **together**.

3

24%

**CAREGIVER
AFTER**

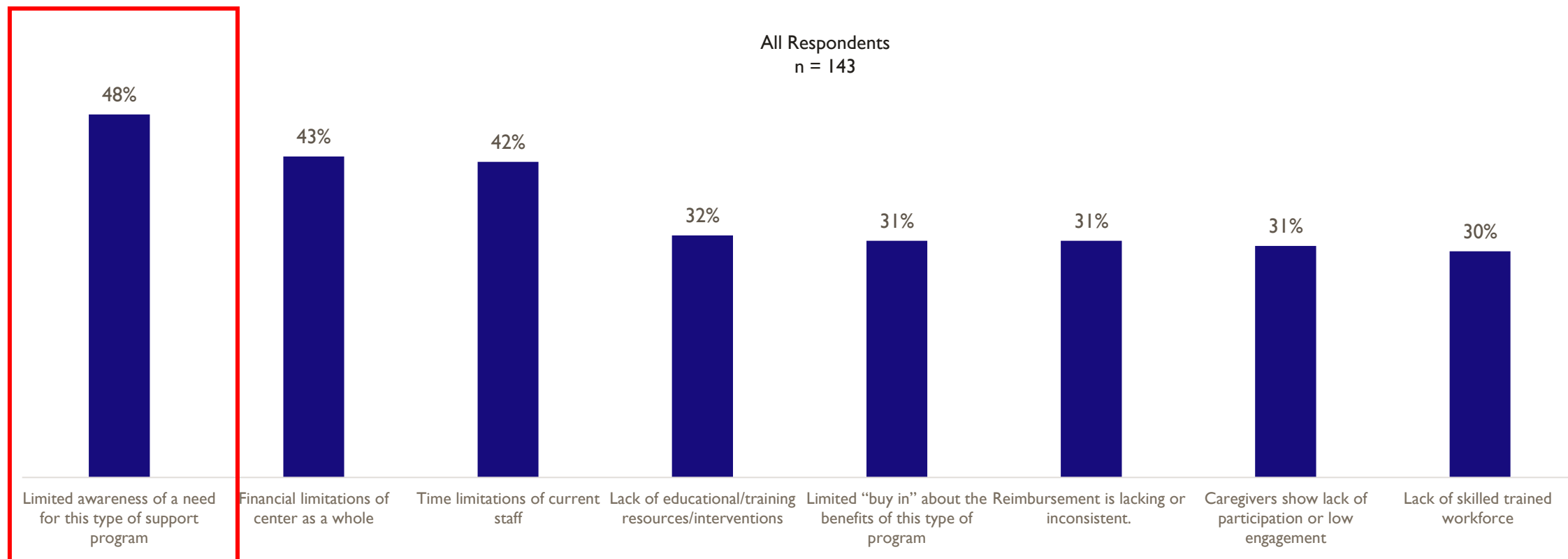


In most cases, the caregiver receives education and training **after** recipient.

Excluded respondent answers = "Not sure"
n = 128

The barriers are perceived, not structural: limited awareness of the need for caregiver support, followed by financial and time constraints.

What are the main perceived barriers to your center providing caregiver support programs?



Continue Exploring Our Research



2023 REPORT

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



bitly



2024 REPORT | PART II.

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



THE FAMILY CAREGIVER GAP

**Disparities
and Missed
Opportunities in
Support Services
Across U.S.
Transplant Centers**



In chat, please share:

In the chat, share what surprised you most about the availability of caregiver support in transplantation?

Poll Question

What caregiver support service would have the greatest impact if available at every transplant center?

Thank you to our Funders!

