



2024 REPORT | PART II.

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



Foreword

Family caregivers are the cornerstone of our healthcare system, yet they often remain overlooked, particularly in the complex world of transplant care. These individuals provide crucial practical, physical, and emotional support to patients before, during, and after lifesaving organ, stem cell, or bone marrow transplants. Their presence is so vital that it's frequently a prerequisite for a recipient to receive a transplant. However, this requirement is not matched with the necessary infrastructure or support to equip caregivers for their immense responsibilities.

This report addresses critical knowledge gaps about the practices and availability of family support programs in transplant centers. It provides our healthcare partners, patient advocates, and policymakers with new, actionable data on:

1. Caregiver needs assessment practices
2. Support and service delivery methods
3. Education and training programs

Our findings reveal that despite efforts by transplant centers, significant gaps persist. The lack of standardized and coordinated practices contributes to disparities and inadequate care for family caregivers across the transplant system. These insights underscore the urgent need for improved caregiver evaluation, support, education, and training practices in transplant centers.

By addressing these gaps, we have the opportunity to enhance not only the experience of transplant caregivers but also improve outcomes for transplant recipients. The data and recommendations in this report will serve as a foundation for creating meaningful improvements in the transplant care ecosystem and in the lives of family caregivers.

As you review this report, I urge you to consider its implications for policy, practice, and research. The challenges highlighted here require a collaborative effort from healthcare providers, policymakers, researchers, and advocates. Together, we can build a more supportive, inclusive, and effective transplant care system that recognizes caregivers as essential partners in healthcare.

The time for transformation is now, and with your engagement, we can make a lasting difference in the lives of family caregivers and the patients they support.



Jason Resendez
President and CEO
National Alliance for Caregiving

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NAC would like to thank everyone who played a role in the creation of this report including:

Advisory Committee

Ira Copperman, Advocate, Transplant Care Partner, Vice-President of Transplant Recipients International Organization (TRIO)

Hailey Hassel, MSW, LICSW, Principal Social Worker & Clinical Supervisor, Patient Support Center Patient & Provider Services, NMDP

Alison Heil, BSN, RN, CCTN, Director, International Transplant Nurses Society

Camilla Nonterah, PhD, Associate Professor of Health Psychology, University of Richmond, School of Arts and Sciences

Cody Reynolds, Transplant Caregiver, United Network for Organ Sharing (UNOS) Region 4 Patient Affairs Committee Representative

Maria Town, President and CEO, American Association for People with Disabilities

Yang Wei, Transplant Caregiver

Authors

Kristi Guillory Reid, JD, MS, Kristi Guillory Reid Enterprises LLC

Hannah-Rose Mitchell, PhD, MPH, Assistant Professor of Clinical Psychology, Health Emphasis, Ferkauf Graduate School of Psychology

Reviewer Committee

Allison Applebaum, PhD, Professor, Geriatrics and Palliative Medicine, Mount Sinai Health System

Anuradha Lala, MD, Associate Professor, Cardiology and Population Health, Mount Sinai Health System

Girish Mour, MBBS, MD, Nephrology, Mayo Clinic in Arizona

National Alliance for Caregiving Staff

Kim Cantor, Chief External Affairs Officer

Fawn Cothran, PhD, RN, GCNS-BC, FGSA, Hunt Research Director

Antoinette 'Toni' Gingerelli, Director of Policy & Advocacy

Yadira Montoya, MSPH, Director of Programs

Melina Piñeyro, MPH, Senior Health Manager, Programs

Jason Resendez, President and CEO

Lauren Tokarewich, MLIS, Senior Manager, Programs

Executive Summary



The current transplant system often overlooks the critical role of family caregivers. These diverse family caregivers provide care for someone waiting to receive an organ, stem cell, or bone marrow transplant, or those who have already received a transplant and they provide assistance at all points during the transplant journey.

The National Alliance for Caregiving's (NAC) Transplant Caregiving Project is seeking to change the narrative around these caregivers through increased research and advocacy.

This report aims to shed light on the experiences and needs of transplant caregivers and advocate for greater support by: 1) sharing findings from a national survey of transplant centers on their family caregiver support practices, programs, and resources; 2) analyzing how current organ transplantation delivery system reform efforts led by the Health Resources and Services Administration (HRSA) and the Centers for Medicare and Medicaid Services (CMS) impact family caregivers; and 3) developing recommendations to prioritize family caregivers in transplant-related care delivery, specifically addressing their roles and needs within these ongoing reforms.

Key survey findings revealed several barriers to comprehensive transplant caregiver support and a lack of standardization in caregiver education and training. The barriers include a limited awareness of caregiver needs, transplant center financial constraints, and the time limitations of transplant staff. A potential gap exists between the recognition of caregivers' needs and the resources available to adequately address these needs.

There is considerable variability in the type and timing of caregiver training across transplant centers. Key education and training topics that are offered at transplant centers include

Key survey findings revealed several barriers to comprehensive transplant caregiver support and a lack of standardization in caregiver education and training.

education on necessary medical procedures required in transplantation and managing the transplant recipient's symptoms. Education and training services on finances and employment, which caregivers have expressed a need for, aren't offered at many transplant centers.

Based on survey findings and a review of current reform proposals and existing research, this report offers six recommendations that seek to improve transplant caregivers' health and well-being:

- 1 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.
- 2 Standardize processes to collect and store caregiver data across transplant centers to assess and document caregiver needs, which can improve care coordination, continuity of care, and inform outcomes-based caregiver research.
- 3 Integrate dedicated caregiver coordinators within transplant teams to identify, address, and support caregivers and their needs along the transplant journey.
- 4 Implement comprehensive, standardized caregiver support programs at transplant centers 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.
- 5 Conduct additional evidence-based research focusing on the diverse needs of transplant caregivers from various demographic and socioeconomic backgrounds to address existing health inequities in the transplant system.
- 6 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.

"[In] November 2017 we started to have a lot of hospital stays. Without leaving my job it's impossible to do the caregiving... It's an understatement to say that [being a transplant caregiver] challenges your work life and family life. I made my decision, and it worked out very well. I wouldn't do anything different otherwise... There's nothing more rewarding than taking care of Justin."

— Yang, Transplant Caregiver (heart)

Transplant caregivers are the nexus of the transplant process. They connect transplant recipients with resources, services, and most of all, provide critical care that help transplant recipients receive and recover from this lifesaving treatment.

Our goal with this report is to increase education, stimulate dialogue, and encourage the development of comprehensive solutions that address the challenges, burdens, and experiences of transplant caregivers.





Introduction

Family caregivers are the backbone of our healthcare system, serving as essential partners to both patients and healthcare providers, yet their expertise and needs are often overlooked by the system they support.

As of 2020, 53 million family caregivers in the United States are caring for another person through sickness or disability, including providing complex care.¹ While family caregivers are diverse and essential across all communities, those from social, economic, and culturally diverse communities face greater challenges and have less access to critical support systems, perpetuating cycles of health and economic disparities.

Recognizing the critical role of family caregivers in transplant care, this report advocates for their greater recognition, support, and integration throughout the transplant process. The report aims to increase education, stimulate dialogue, and encourage the development of comprehensive solutions that address the challenges, burdens, and experiences of family caregivers across transplant care. To achieve this, we will: 1) share findings from a national survey of transplant centers on their family caregiver support practices, programs, and resources; 2) analyze how current organ transplantation delivery system reform efforts led by the Health Resources and Services Administration (HRSA) and the Centers for Medicare and Medicaid Services (CMS) impact family caregivers; and 3) develop recommendations to prioritize family caregivers in transplant-related care delivery, specifically addressing their roles and needs within these ongoing reforms.

Transplant caregivers, those providing care for someone who is waiting to receive or has already received a solid organ, stem cell, or bone marrow transplant, face a myriad of challenges along the transplantation process.² These challenges include extensive time commitments such as assisting patients with ongoing and changing medical requirements, navigating complex healthcare systems, helping the care recipient manage their emotions regarding transplantation, and long-term follow-up care.

Those from social, economic, and culturally diverse communities face greater challenges and have less access to critical support systems.

¹AARP and National Alliance for Caregiving. *Caregiving in the United States 2020*. Washington, DC. Retrieved from <https://www.caregiving.org/research/caregiving-in-the-us/caregiving-in-the-us-2020/>

²National Alliance for Caregiving. (2023). *Transplant Caregiving in the U.S.: A Call for System Change*. Washington, DC. Retrieved from https://www.caregiving.org/wp-content/uploads/2023/11/NAC_TransplantCaregiversReport-FINAL.pdf.

Despite these unique challenges, relatively little is known about the transplant caregiver experience. These “unsung heroes” are underserved and understudied. The National Alliance for Caregiving’s (NAC) Transplant Caregiving Collaborative seeks to change this narrative to recognize, uplift, and support transplant caregivers by focusing on research and advocacy. Through research, we are contributing to current knowledge about the experiences, challenges and needs of transplant caregivers. Our research also aims to understand the availability of education, training, and support for transplant caregivers, and identify potential gaps. In advocacy, assessments of potential policy actions are conducted to engage policymakers, healthcare providers, regulatory bodies, and other stakeholders who work with and support transplant patients and their caregivers.

Project Milestones

Transplant Caregiving Collaborative

In 2022, NAC launched its Transplant Caregiving Collaborative to examine unique experiences of family caregivers supporting transplant recipients.

Transplant Caregiving Report

In 2023, NAC released “*Transplant Caregiving in the U.S.: A Call for System Change*.” This report presented findings from a literature review, a subject matter expert panel, and focus groups with transplant caregivers. It outlined how family caregivers are integral to the transplant recipient’s transplant journey providing critical support, including referral, evaluation, maintaining waitlist status, and well-being post-transplantation. The report also included five recommendations to ensure that transplant caregivers are provided with the necessary support services and resources.

National Survey of Transplant Centers

In May of 2024, NAC commissioned a national survey of transplant centers to understand their policies and practices related to identifying, assessing, and supporting family caregivers.

Champions in Care Transplant Forum

In August of 2024, NAC held its first-ever Champions in Care Transplant Forum. The Forum consisted of an in-depth exploration of reform efforts that seek to change the future of transplant care, including the Organ Procurement Transplantation Network (OPTN) Modernization Initiative and the Organ Transplantation Affinity Group (OTAG), with a focus on how these reforms will impact caregivers. Discussions highlighted the critical role of transplant caregivers, and the valuable role advocacy can play in advancing caregiver needs.

Our research aims to understand the availability of education, training, and support for transplant caregivers, and identify potential gaps.

Understanding the Unique Challenges of Transplant Caregivers

Transplant caregivers are a diverse group of individuals who provide unpaid care to family and friends receiving transplants. They are often solely responsible for a wide range of crucial tasks, including care coordination, provider communication, symptom management, administration of complex medical and nursing tasks like medication regimens, assistance with activities of daily living, and providing emotional support. The scope of the caregiver role is vast and time-consuming, and the transplant caregiver experience is unique and complex.



Transplant caregivers are often asked to closely monitor their care recipients' symptoms, vital signs, and sometimes life-threatening complications.

Transplant caregivers are critical in every aspect of the transplant journey. While the process differs according to the type of transplant, the patient's social support dictates if a patient receives a transplant. Centers will often use a non-legally binding caregiver contract that indicates a caregiver must be available and outlines the wide range of tasks and responsibilities that come with their caregiver role.³ If the patient does not have a full-time caregiver, then the likelihood that they will be able to receive a transplant is low.

For patients undergoing a stem cell transplant, many transplant centers require patients to identify a caregiver who will be available 24 hours a day, seven days a week for between 30 to 100 days post-transplant due to the regimen that patients must adhere to during recovery.⁴ The length requirement varies by center and is in addition to any other support that the caregiver provides before the transplant.

Similarly, verification of social support is a requirement to be waitlisted in most organ transplant programs. Yet, there are no standards by which a transplant recipient's social support is evaluated—either the content or process.⁵⁻⁶ The presence of a caregiver mistakenly places the caregiving focus on the post-transplant period despite the plethora of roles that caregivers must fulfill at all phases along the transplant continuum, such as healthcare system navigation, care coordination, provider communication, and management of complex medical needs at home.

Transplant caregiver experiences are especially profound—they are critical to ensuring transplant success, which increases their own risk for experiencing stress. They are often asked to closely monitor their care recipients' symptoms, vital signs, and sometimes life-threatening complications. These enormous “around the clock” responsibilities continue post-transplantation and may include nutritional needs, maintaining a clean home environment, and adhering to infection prevention recommendations.³ Transplant caregiving is also uniquely isolating compared with caregiving for other illnesses due to the social isolation associated with prolonged hospital stays and the patients' weakened immune systems, which often necessitate limited social contact for both patient and caregiver.⁷

Like other family caregivers, transplant caregivers have a heightened risk of emotional burden, poor quality of life, and mental and physical health consequences. These can include required lifestyle changes, limited time and competing demands, heightened stress, worry

³Amonoo, H. L., Deary, E. C., Harnedy, L. E., Daskalakis, E. P., Goldschen, L., Desir, M. C., Newcomb, R. A., Wang, A. C., Boateng, K., Nelson, A. M., & Jawahri, A. E. (2022). *It Takes a Village: The Importance of Social Support after Hematopoietic Stem Cell Transplantation, a Qualitative Study. Transplantation and cellular therapy, 28*(7), 400.e1–400.e6. <https://doi.org/10.1016/j.jtct.2022.05.007>

⁴Preussler, J. M., Mau, L. W., Majhail, N. S., Bevans, M., Clancy, E., Messner, C., Parran, L., Pederson, K. A., Stickney Ferguson, S., Walters, K., Murphy, E. A., & Denzen, E. M. (2019). *Caregiver availability and patient access to hematopoietic cell transplantation: social worker perspectives inform practice. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer, 27*(11), 4253–4264. <https://doi.org/10.1007/s00520-019-04696-2>

⁵Desalvo, A., & Preussler, J. (2023, April 14). *The Caregiver Impact on Access To alloHCT Treatment. Cell & Gene. https://www.cellandgene.com/doc/the-caregiver-impact-on-access-to-allohct-treatment-0001*

⁶Dew, M. A., DiMartini, A. F., Dobbels, F., Grady, K. L., Jowsey-Gregoire, S. G., Kaan, A., Kendall, K., Young, Q. R., Abbey, S. E., Butt, Z., Crone, C. C., De Geest, S., Doligalski, C. T., Kugler, C., McDonald, L., Ohler, L., Painter, L., Petty, M. G., Robson, D., Schlöglhofer, T., ... Zimbrea, P. C. (2018). *The 2018 ISHLT/APM/AST/ICCA/STSW recommendations for the psychosocial evaluation of adult cardiothoracic transplant candidates and candidates for long-term mechanical circulatory support. The Journal of heart and lung transplantation: the official publication of the International Society for Heart Transplantation, 37*(7), 803–823. <https://doi.org/10.1016/j.healun.2018.03.005><https://pubmed.ncbi.nlm.nih.gov/29709440/>

⁷Applebaum, A., Bevans, M., Son, T., Evans, K., Hernandez, M., DuHamel, K. (2016). *A scoping review of caregiver burden during allogeneic HSCT: lessons learned and future directions. Bone Marrow Transplant, 51*, 1416–1422. <https://doi.org/10.1038/bmt.2016.164>

about the patient's health, feelings of uncertainty, anxiety, depression, post-traumatic stress disorder, neglecting their own needs, poor health behaviors, impaired sleep, and low life satisfaction.⁸ Additionally, transplant caregivers face significant financial strain. Caregivers experience strain because of the costs associated with follow-up appointments, housing during transplant surgery, sometimes paying for the surgery itself, as well as the potential loss of income as a direct result of providing care.²

Despite this enormous load, some transplant caregivers experience a closer relationship with the patient, pride in their ability to provide support to the patient, appreciation for the transplant, gratitude for the patient's improved well-being and quality of life, and a renewed perspective on the priorities in their life.⁸

Changes in the Transplantation Ecosystem

Currently, the organ transplant system in the United States is undergoing significant reforms. The Health Resources and Services Administration (HRSA) and the Centers for Medicare and Medicaid Services (CMS) are spearheading efforts to address longstanding issues within the complex ecosystem of organ donation, procurement, and transplantation.

This ecosystem involves multiple stakeholders, including the Organ Procurement and Transplantation Network (OPTN) Modernization Initiative, United Network for Organ Sharing (UNOS), transplant hospitals, Organ Procurement Organizations (OPOs), and crucially, patients and their family caregivers. Despite facilitating more than 46,000 transplants in 2023, the system faces criticism for underperformance, lack of accountability, and failure to meet growing demand, with more than 100,000 individuals currently on waiting lists.⁹

In response, HRSA launched the OPTN Modernization Initiative in 2023. This initiative aims to strengthen accountability and transparency across five key areas: technology, data transparency, governance, operations, and quality improvement. Notable changes include separating the OPTN Board of Directors from its long-time OPTN contractor to reduce conflicts of interest.¹⁰ For the first time ever, HRSA also transitioned from a single vendor to multiple vendors to support OPTN operations and its plans to modernize the organ transplant system.¹¹

Complementing these efforts, the Organ Transplantation Affinity Group (OTAG), a federal collaborative, is working to improve coordination among government agencies. OTAG's landscape assessment revealed several challenges in the patient journey, including the lack of standardization in waitlist criteria and referral processes.

These reform efforts have significant implications for family caregivers. As the system evolves to become more patient-centric and equitable, caregivers may see changes in their roles throughout the transplantation process. This could include greater involvement in pre-transplant care, the need for education in new processes, and evolving post-transplant care responsibilities.

As these efforts progress, it will be crucial to consider how these changes impact family caregivers and to develop practices and policies that support their vital role. The voice and experiences of transplant caregivers must be visible and strong throughout this process. It is also important to note that these transplant reforms do not impact the bone marrow or stem cell transplant community. This population faces their own unique challenges and caregiving burdens along the journey that should be addressed.



Transplant caregivers are essential to the success of organ transplant reform. Their voices and experiences must be amplified.

⁸Jesse, M. T., Hansen, B., Bruschein, H., Chen, G., Nonterah, C., Peipert, J. D., Dew, M. A., Thomas, C., Ortega, A. D., Balliet, W., Ladin, K., Lerret, S., Yaldo, A., Coco, T., & Mallea, J. (2021). Findings and recommendations from the organ transplant caregiver initiative: Moving clinical care and research forward. *American Journal of Transplantation*, 21(3), 950-957. <https://doi.org/10.1111/ajt.16315>

⁹Energy & Commerce Chair Rodgers. (2024, September 11). Subcommittee Chair Griffith Opening Remarks at Hearing on Organ Procurement and Transplantation Network. Energy & Commerce Chair Rodgers. <https://energycommerce.house.gov/posts/subcommittee-chair-griffith-opening-remarks-at-hearing-on-organ-procurement-and-transplantation-network>

¹⁰U.S. Department of Health and Human Services & Health Resources and Services Administration. (2024, August 29). HRSA Announces Historic Steps to Overhaul the Nation's Organ Transplant System. <https://www.hrsa.gov/about/news/press-releases/historic-overhaul-optn>

¹¹U.S. Department of Health and Human Services. (2024, September 19). In Historic Step, HRSA Makes First Ever Multi-Vendor Awards to Modernize the Nation's Organ Transplant System and End the Current Contract Monopoly. <https://www.hhs.gov/about/news/2024/09/19/hrsa-makes-first-ever-multi-vendor-awards-to-modernize-the-nations-organ-transplant-system.html>

National Survey of Transplant Centers



To gain comprehensive insights into family caregiver support programs at U.S. transplant centers, NAC collaborated with the healthcare market research firm KOLgroups¹² to conduct a national survey of 114 transplant centers.

The survey evaluated the current landscape of family caregiver support across transplant centers across the U.S., assessing both existing practices and the availability of caregiver needs assessments, support programs, education, and training. The findings from this research were used to guide policy recommendations in this report and can inform practice improvements as reform efforts progress across federal agencies and health systems.

To guide this research, NAC established an Advisory Committee and engaged with a Survey Review Committee composed of various subject matter experts in organ transplantation and individuals with lived experience in transplant care.

Methodology and Center Characteristics

From April 30 to May 18, 2024, there were 114 transplant centers throughout the U.S. surveyed to ascertain information about their existing transplant infrastructure related to their family caregiver support programs, including availability, access to and demand for these programs, and barriers to effective support delivery of these programs.

The goal was to obtain a representative sample of transplant centers that reflect the makeup of centers in the U.S. by OPTN region, organ/tissue type, geographic location, race/ethnicity, and socioeconomic status. KOLgroups identified individual respondents to serve as representatives of their transplant centers from their existing database. They searched for respondents from their existing database of contacts using keywords such as “transplant,”

The findings from this research were used to guide policy recommendations in this report and can inform practice improvements as reform efforts progress across federal agencies and health systems.

¹²KOLgroups. (n.d.). Healthcare Market Research. <https://kolgroups.com/>

“administrator,” or “executive” to identify potential survey respondents. Additionally, KOL groups verified some individual respondent information (e.g., institution affiliation and role) using public sources via internet search to ensure respondents’ identities.

Potential respondents were screened to ensure they were qualified to answer the survey questions regarding the availability of caregiver support programs at their site. Eligible respondents were provided with the definitions of family caregiver¹ and caregiver support programs to aid them in completing the survey. Caregiver support programs were defined as “structured, planned, coordinated activities and procedures aimed specifically at supporting caregivers of transplant recipients as a part of routine care in your transplant center.” This definition of a family caregiver’s support program, along with several questionnaire items, were adapted from a prior survey to assess the availability of family caregiver support programs in cancer centers.¹³

The 32-question online survey assessed the following domains:

- **Caregiver Needs Assessment** (e.g., *Does your transplant center have a written process to assess caregivers’ needs for support?*)
- **Support and Service Delivery for Caregivers** (e.g., *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?*)
- **Education and Training** (e.g., *Which caregiver-specific education and training programs are available onsite or through referral from your transplant center?*)

Transplant Center Respondent Characteristics

A total of 114 unique transplant centers were represented, about half of which were academic medical centers. The sample included centers with solid organ transplant programs (kidney, heart, liver, pancreas, lung, and intestine) and bone marrow/stem cell transplants. Most transplant centers performed multiple types of transplants. An analysis of the distribution of transplant program(s) and center types can be found in the table below. For example, 90% of the transplant centers participating in this survey perform kidney transplants.

Transplant Program Types by Center Ownership

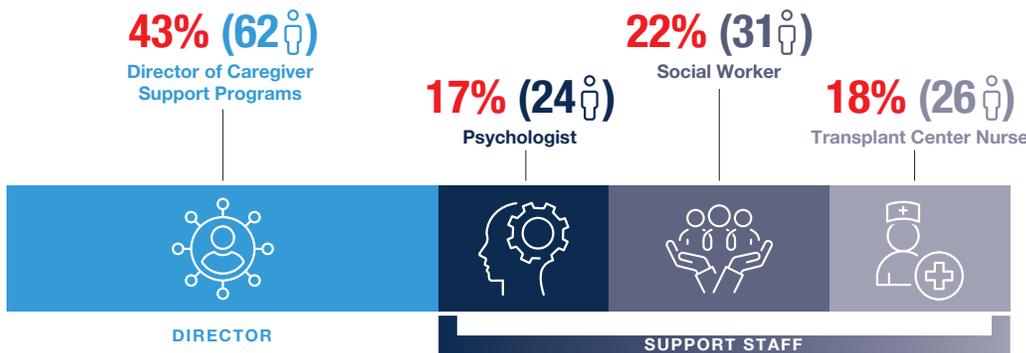
	Kidney	Liver	Heart	Pancreas	Lung	Allogenic Bone Marrow Transplant	Autologous Bone Marrow Transplant	Intestine
Count	103	59	58	48	21	6	5	5
# of Transplant Centers	90%	52%	51%	42%	18%	5%	4%	4%
Academic medical center (i.e., university-based hospital)	50%	61%	48%	54%	71%	83%	100%	100%
Independently owned (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%

¹³ Odom, J. N., Applebaum, A., Bakitas, M. A., Bryant, T., Currie, E., Curry, K., Donovan, H., Fernandez, M. E., Ferrell, B., Azuero, A., Gray, T. F., Hendricks, B. A., Meier, D., Nightingale, C., Reinhard, S., Sannes, T. S., Sterba, K., & Young, H. M. (2023). Availability of Family Caregiver Programs in US Cancer Centers. *JAMA Network Open*, 6(10), E2337250. <https://doi.org/10.1001/jamanetworkopen.2023.37250>

The sample included institutions serving diverse patients and caregivers by socioeconomic background (i.e., low-, medium-, and high-income levels) and geographic location (i.e., rural and urban). Some sites served patients with medium to high-income levels, while some sites served mostly low-income patients, and the remaining centers served patients with varying income levels (e.g., “low,” “medium,” and “high”).

Regarding race and ethnicity, most transplant centers reported they served patients who mostly identified as white. Centers reported primarily serving populations who identified as the following races and ethnicities: 78% white, 62% Black/African American, 50% Asian, 27% Latino, 13% Native Hawaiian or Pacific Islander, and 10% Native American or Alaska Native.

Survey Respondent Roles



A total of 143 individuals were sampled from 114 sites. The sample comprises both support staff and directors of caregiver support programs.

Key Survey Results

Inconsistent Caregiver Evaluation Practices

Survey results revealed inconsistent practices in assessing caregiver circumstances across transplant centers. While individual caregiver reviews are most frequently conducted when the recipient is on the waitlist, only 3% of centers perform these reviews at regular intervals. Notably, caregiver circumstances are evaluated in less than one-third of cases when recipients are initially placed on the waitlist, and in more than 40% of cases during the waiting period. These findings highlight a lack of standardized practices for caregiver screening during the enrollment and waitlist phases, pointing to a significant gap in the transplant preparation process.

Gaps in Caregiver Support Needs Assessment Protocol

Survey findings unveiled significant shortcomings in caregiver support within transplant centers, highlighting a critical need for improvement in standardized processes and integrated services. Notably, more than 40% of respondents reported that their centers either lacked written procedures for assessing caregiver support needs or were unaware of such documentation processes. This absence of standardized assessment underscores a systemic gap in addressing caregiver needs.

Only 32% of centers provide caregiver distress screening. Support services are often reactive, triggered by events like hospitalizations or complications, rather than proactively offered. This inconsistency in support leaves many transplant caregivers underprepared and unsupported throughout the transplant process, highlighting a critical gap in the transplant care ecosystem.

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The top barrier to providing caregiver support, as cited by respondents, was a limited awareness of the need for support.

Barriers to Comprehensive Caregiver Support

While most transplant centers offer some form of caregiver support, the survey revealed a few concerning trends. Most transplant centers offered between 2-4 types of family caregiver support programs; however, 30% had none. There was little consistency in the types of support provided, and there was no standardized program delivery. Caregiver support programs are typically delivered via a combination of on-site, in-system referral and/or referral to a third-party provider—with in-system referral being the most common.

Over two-thirds of survey respondents reported having a designated caregiver coordinator at their center, but key barriers to comprehensive support included limited awareness of caregiver needs (48%), financial constraints of the center (43%), and time limitations of the current staff (42%). This apparent contradiction suggests that despite having designated coordinators, many centers lack an awareness of the experiences and needs of family caregivers as well as sufficient resources and personnel to effectively manage caregiver care and serve as reliable points of contact. These disparities highlight a potential gap between the recognition of caregivers' needs and the resources available to adequately address them.

Transplant Centers Lack Standardized Practices for Caregiver Education and Training

Transplant centers demonstrate a concerning lack of standardization in caregiver education and training. While 58% of centers offer some form of caregiver-specific education and training, there is variability in the type and timing of the training offered. The most common type of education and training focuses on the medical aspects of the transplant process (e.g., necessary medical procedures in transplantation and managing the transplant recipient's symptoms). In terms of the timing of the education and training, most centers indicated that typically the caregiver and transplant recipient receive it simultaneously (42%). At other sites, the caregiver received the education before (34%) or after (24%) the transplant recipient.

Education and training services are also delivered via a combination of on-site, in-system referral, and/or referral to third parties outside the center or healthcare system. Key education and training areas that are frequently delegated to external providers include training on communicating with the transplant team (43% referred within the healthcare system; 35% referred externally), caregiver self-care and wellness education (41% referred within the healthcare system; 35% referred externally), and information on essential medical procedures, tests, and treatments (34% referred within the healthcare system; 34% referred externally). This reliance on outside resources for fundamental education and training services suggests a potential disconnect between transplant centers and comprehensive caregiver services, emphasizing the urgent need for more integrated and standardized approaches to ensure caregivers receive consistent, high-quality education and training throughout the transplant journey.

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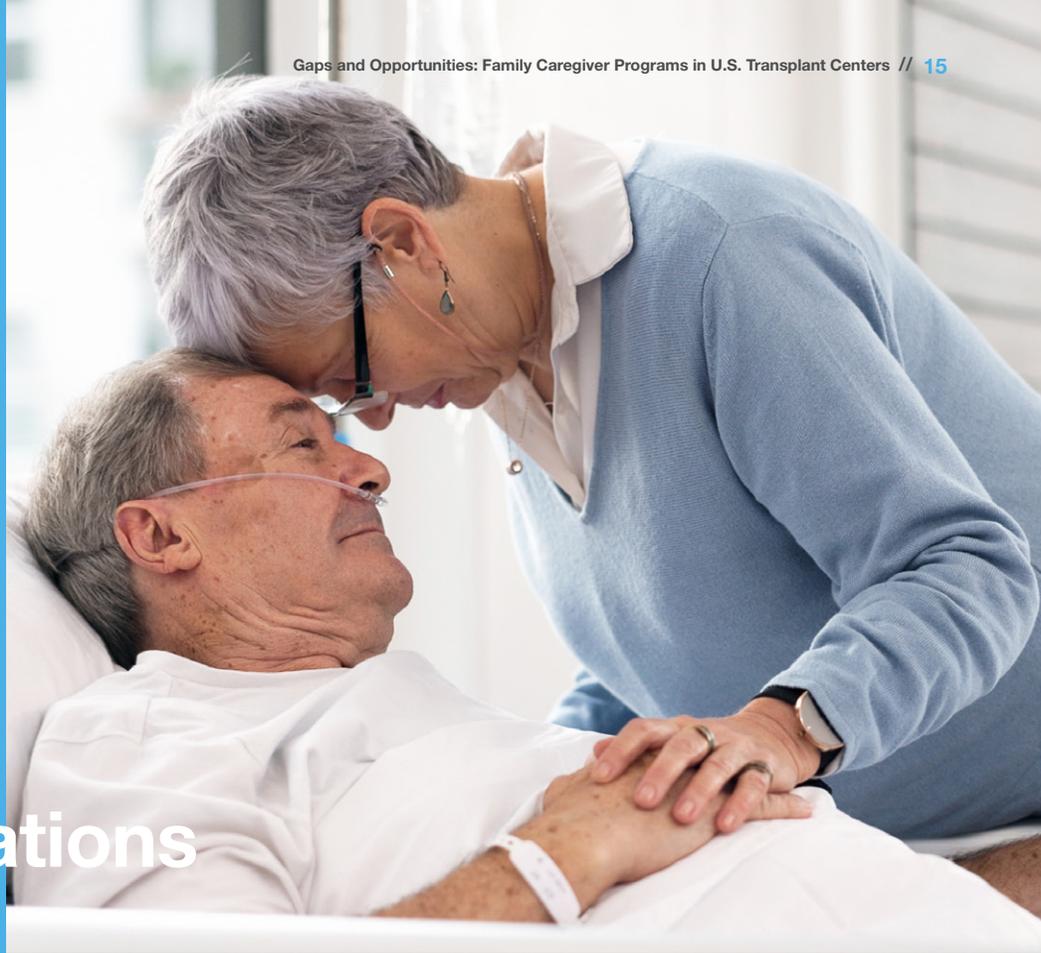
Despite a high awareness (80%) of new Medicare billing codes for Caregiver Training Services (CTS), only a small number of transplant centers (7%) are actively using them.

Disparities in Transplant Caregiver Support Across Demographic Groups

Survey results reveal disparities in the provision of caregiver support programs across racial, ethnic, and socioeconomic lines. Latino, Native American, and Black/African American populations are more likely to be identified as low-income and urban dwelling. These demographics correlate with reduced access to crucial support services such as group psychosocial programs, financial counseling, and complementary health programs. In contrast, centers serving predominantly non-Latino white and Asian populations, often with higher incomes and more diverse geographic distribution, offer more comprehensive support. Furthermore, the cultural responsiveness of existing programs remains questionable because most caregiver interventions have been developed and tested in homogeneous, primarily non-Latino white populations. This disparity highlights a critical need for more inclusive, culturally competent, and equitably distributed caregiver support in transplant centers.

Underutilization of Medicare Billing Codes for Caregiver Training Services in Transplant Centers

Despite a high awareness (80%) of new Medicare billing codes for Caregiver Training Services (CTS), only a small number of transplant centers (7%) are actively using them. This underutilization varies across center types and staff roles. Transplant center directors show higher familiarity and usage (13%) compared to support staff (7%). Academic medical centers lead in the adoption of the billing codes (10%), significantly outpacing other transplant center types (0-2%). The underutilization of CTS billing codes highlights a dual challenge: limited access to essential training for caregivers and missed reimbursement opportunities for healthcare providers. This gap highlights the need for improved implementation strategies of these new reimbursement pathways across all transplant center types.



Recommendations

The following six recommendations build on the policy and practice recommendations in NAC's 2023 *Transplant Caregiving in the U.S.: A Call for System Change* report. The recommendations are expanded and supported by the transplant center survey and seek to ensure the voices of transplant caregivers are included in every step of the transplant journey. These recommendations aim to strengthen the caregiver's role in the transplant process while simultaneously improving the support they receive. By implementing these changes, we can ensure better care for transplant candidates and recipients, as well as enhance the caregivers' ability to maintain their own health and well-being throughout the caregiving journey.

These recommendations aim to strengthen the caregiver's role in the transplant process while simultaneously improving the support they receive.



RECOMMENDATION 1:

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

Challenge Defined

The presence of social support is used to determine transplant eligibility in both organ and bone marrow/stem cell transplants. Social support is, in essence, the presence of a caregiver. Even though this criterion plays a life-changing role for someone in need of a transplant, little is known regarding how many patients are disqualified from organ transplants due to inadequate support and how providers are evaluating social support to determine transplant eligibility.¹⁴

Research shows that the lack of a standardized caregiver identification and evaluation process during the waitlist (solid organ) and referral (bone marrow and stem cell) period leads to bias and inequities for those from medically underserved communities.^{14,15}

¹⁴Ladin, K., Emerson, J., Berry, K., Butt, Z., Gordon, E. J., Daniels, N., Lavelle, T. A., & Hanto, D. W. (2019). Excluding patients from transplant due to social support: Results from a national survey of transplant providers. *American Journal of Transplantation: Official Journal of the American Society of Transplantation and the American Society of Transplant Surgeons*, 19(1), 193–203. <https://doi.org/10.1111/ajt.14962>

¹⁵Bashey, A., Zhang, X., Morris, L. E., Holland, H. K., Bachier-Rodriguez, L., Solomon, S. R., & Solh, M. (2023). Improved access to HCT with reduced racial disparities through integration with leukemia care and haploidentical donors. *Blood Advances*, 7(15), 3816–3823. <https://doi.org/10.1182/bloodadvances.2023009765>

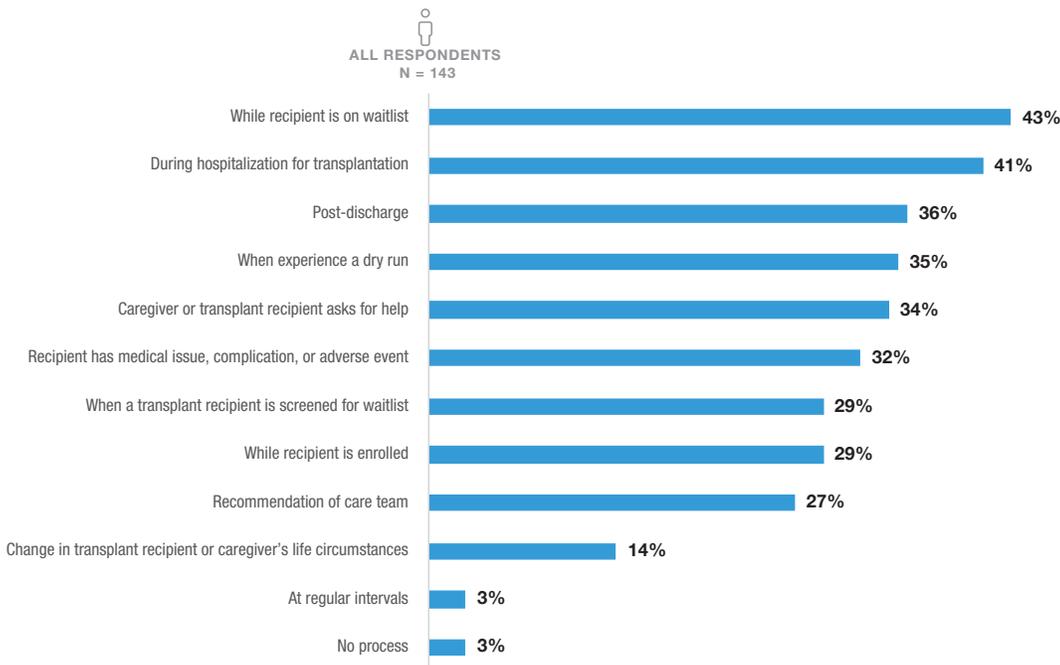
People who are medically underserved may face difficulty demonstrating social support due to challenges regarding their ability to have caregivers accompany them to appointments and an inability to afford home-based care. It is also important to recognize the different caregiving situations and arrangements across diverse populations. For example, instead of a family member, some transplant recipients may have a close friend or family friend who can provide support. One potential way to decrease caregiver burden is to examine these caregiver requirements to determine which requirements are necessary for patient health and safety.

Survey Findings

Survey results revealed that individual caregiver circumstances are reviewed to ensure they are frequently meeting the minimum requirements while the recipient is on the waitlist, with only 3% of centers reviewing circumstances at regular intervals. However, even at this stage their circumstances are reviewed *less than* one-third of the time when the transplant recipient is placed on the transplant waitlist and 43% of the time when the patient is on the waitlist. These results indicate that there is no consistency or standard practice regarding caregiver screening during the enrollment and waitlist phase.

Review of Caregiver Circumstances

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



If situations arise that prompt a review of caregiver circumstances, such as a change in health insurance status or a patient being removed from the waitlist due to health reasons, 54% of transplant centers reported that caregivers tend to not meet their center's minimum requirements to serve as a caregiver upon these reviews.

"[We] went to the library, read books and learned about transplantation. If I had questions, they [transplant team] would answer them... The first time Glenda ever saw a dietitian was when in her hospital bed, two, three, four days... after her transplant. The dietitian said, "I want to go over a list." There was no education pre-transplant [for] recipient or [the] family - none whatsoever... Whenever Glenda had a problem – and that the key – whenever she has had a problem, they always stepped up to the plate and put Glenda first. But there [was] nothing like helping us with references."

– Ira, Transplant Caregiver (kidney)

Proposed Solution

A standardized caregiver identification and social support evaluation process stands to benefit transplant patients and their caregivers by providing them with the opportunity to be added to the waitlist regardless of race, ethnicity, or socioeconomic status. Standardization could also further the development of caregiver criteria applied uniformly across transplant centers.

From the outset, a comprehensive and standardized process for caregiver identification and an evaluation of the caregiver's readiness and willingness to serve in this role could mitigate the potential for events in which caregivers are not prepared or able to provide the necessary care for transplant recipients.

Comprehensive caregiver identification and evaluation during the waitlist/referral period could assess the following topics:¹⁶ 1) past experiences and comfort with the caregiving role; 2) physical health; 3) mental health; 3) cognitive ability; 4) identification of existing resources and social determinants of health to determine how the transplantation team can support the family; and 5) cultural factors that may impact home-based care post-transplantation.

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.



RECOMMENDATION 2:

Standardize processes to collect and store caregiver data across transplant centers to assess and document caregiver needs, which can improve care coordination, continuity of care, and inform outcomes-based caregiver research

Over 40% of survey respondents reported that their transplant centers lacked written processes to assess transplant caregiver support needs or that they were not aware of a written process for documenting these needs.

Challenge Defined

Practices for collecting and documenting caregiver information and support needs are not standardized across the healthcare system. Transplant caregivers must navigate complex systems of care, which often operate in silos. Inconsistent practices in documenting and sharing caregiver information across systems can lead to unrecognized care needs, exacerbated inequities, lack of interoperability of care systems, and a lack of wide scale data on caregiver health outcomes.¹⁷

There have been recent efforts to augment hospital information systems to better document and support the care provided by family caregivers, such as the documentation of family caregivers in a hospital's electronic health record (EHR). This is required as part of the Family Caregiver Advise, Record, Enable (CARE) Act, which has been enacted in more than 40 states.¹⁷ Ideally, this information would be recorded in a separate caregiver-specific record.¹⁸

Survey Findings

Survey findings revealed that transplant centers lack standardized processes for assessing and documenting caregiver needs.

¹⁶Applebaum, A. J., Sannes, T., Mitchell, H. R., McAndrew, N. S., Wiener, L., Knight, J. M., Nelson, A. J., Gray, T. F., Fank, P. M., Lahijani, S. C., Pozo-Kaderman, C., Rueda-Lara, M., Miran, D. M., Landau, H., Amonoo, H. L. (2023). *Fit for Duty: Lessons Learned from Outpatient and Homebound Hematopoietic Cell Transplantation to Prepare Family Caregivers for Home-Based Care*. *Transplantation and Cellular Therapy*, 29(3), 143-150. <https://doi.org/10.1016/j.jtct.2022.12.014>

¹⁷Griffin, J. M., Kaufman, B. G., Bangert, L., Holland, D. E., Vanderboom, C. E., Ingram, C., Wild, E. M., Dose, A. M., Stiles, C., & Thompson, V. H. (2022, February 13). *Improving Transitions in Care for Patients and Family Caregivers Living in Rural and Underserved Areas: The Caregiver Advise, Record, Enable (CARE) Act*. *Journal of Aging & Social Policy*, 36(4), 581-588. <https://doi.org/10.1080/08959420.2022.2029272>

¹⁸Applebaum, P. A., Kent, P. E., & Lichtenhal, P. W. (2021, May 4). *Documentation of Caregivers as a Standard of Care*. *Journal of Clinical Oncology*, 39(18). <https://doi.org/10.1200/JCO.21.00402>

Proposed Solution

Caregiver advocates and researchers would like to see additional caregiver documentation by recommending that caregivers' roles, needs, and requests for support are documented in their own caregiver-specific EHR. Documentation of caregiver-specific information in EHR could lead to a clearer understanding of the services that transplant caregivers need and use. This change could improve care coordination among clinicians who provide caregiver services at multiple sites. Caregiver-specific EHRs can also inform future transplant caregiver research using data collected across centers.¹⁸

The OPTN Modernization Initiative and OTAG efforts could be further strengthened by explicitly recognizing the unique role of family caregivers in helping improve patient outcomes and advancing health equity. Improving the process and collection of caregiver data, an effort to improve the waitlist and referral processes for organ transplants, is one important step toward the integration of family caregivers into care teams. Moreover, a significant change would be to create an infrastructure that allows for coordinated and efficient methods of sharing or updating caregiver information.

Transplant caregiver outcomes should be documented so that information sharing and services between clinicians at various locations can be easily coordinated. Transplant centers should use consistent and more expansive language to categorize caregivers. This language should clearly delineate caregiver roles and their involvement on the care team, without using terms like "other," which places caregivers in a "catch-all" category and reduces the contributions of caregivers.

Standardize processes to collect and store caregiver data across transplant centers to assess and document caregiver needs, which can improve care coordination, continuity of care, and inform outcomes-based caregiver research.



"Most of the focus was on the patient. But I think in terms of me- to be transparent- as the caregiver. I don't think they [transplant team], especially after discharge, I don't think there was much time spent on me. She recovered nicely and rapidly in the timely fashion. But again, if it's a long-term thing, and there was no checkpoint as to how I'm doing mentally, now you are going to have two patients instead of one."

– Georgette, Transplant Caregiver (heart and kidney)



RECOMMENDATION 3:

Establish a Coordinator on the Transplant Team Dedicated to the Family Caregiver

Challenge Defined

The transplant process has many steps that require patients and their caregivers to navigate. At each stage of the journey, transplant recipients depend on the practical, emotional, and financial support and assistance of their transplant caregivers. Coordinating care and communicating with the transplant team are key tasks that family caregivers perform. Transplant teams are usually composed of these members:¹⁹

- **Clinical Transplant Coordinators:** Typically nurses or other professionals who help to arrange the patient's evaluation, treatment, and follow-up care.
- **Transplant Physicians:** Doctors who manage the patient's medical care, tests, and medications. These physicians do not perform the surgery but work with the transplant coordinator to care for the patient until the transplant occurs.
- **Transplant Surgeons:** Doctors who perform the transplant surgery and may provide follow-up care.

¹⁹U.S. Department of Health and Human Services. (n.d.). The Transplant Team. <https://optn.transplant.hrsa.gov/patients/about-plantation/the-transplant-team/>

- **Financial Coordinators:** Professionals who work with others on the team, insurers, and administrative personnel to clarify the financial aspect of the patient's care during the transplant process.
- **Social Workers:** Professionals who help the patient and their family understand and cope with transplant-related issues, including potential side effects related to transplant surgery.

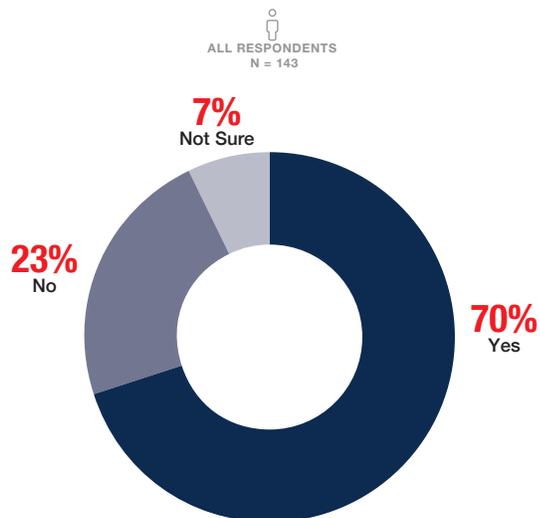
Depending on the specific transplant procedure, the transplant team may include other members such as a psychologist, physical therapist, and dietitian.²⁰

Survey Findings

More than two-thirds of survey respondents reported that their centers had a designated coordinator for caregivers. However, 42% of respondents reported that “the limitations of current staff” were a primary barrier to their transplant center providing caregiver support programs, which suggests that there may be a lack of individuals available to coordinate caregiver care and to serve as a designated point of contact for caregivers.

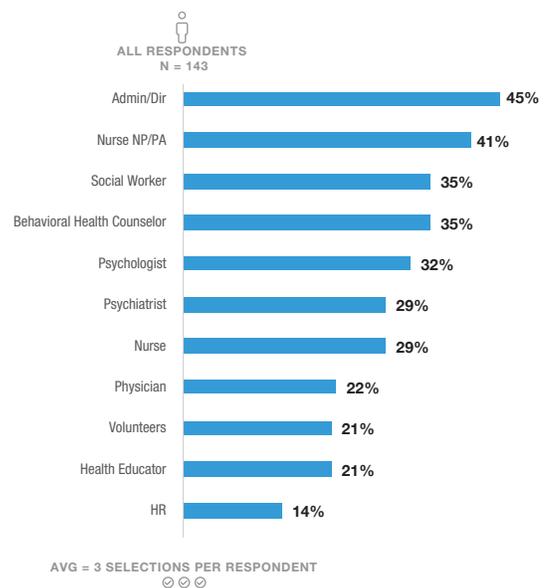
Dedicated Caregiver Support Staff

Does your transplant center have a care coordinator, social worker, nurse, or other health care professional on the transplant team dedicated to supporting caregivers?



Staff Responsible for Providing Support to Caregivers

Who is responsible at your transplant center for providing support to caregivers of transplant recipients? (Select all that apply)



Many different types of professionals are responsible for providing caregiver support. These range from administrators/directors to human resource professionals, who are likely to have variable training, background, and knowledge. The differences in the types of roles may also suggest that transplant centers may value different components of the caregiver experience. For example, a center with a psychologist or counselor who is designated as being responsible for caregiver support might emphasize the mental and behavioral health needs (e.g., medication adherence, substance use prevention) of the caregivers. Whereas a center with a nurse responsible for caregiver support might emphasize the skills-based training in nursing tasks. Finally, it is likely that individuals in these various roles have varying amounts of time available to dedicate to caregiver support. Directors may be bogged down with other responsibilities and volunteers might not always be available. Together, the survey results suggest a lack of dedicated point people with the time and training to optimally support caregivers.

²⁰United Network for Organ Sharing. (n.d.). People you should know. <https://transplantliving.org/after-the-transplant/people-you-should-know/>

Proposed Solution

A dedicated professional for transplant caregivers is missing from the transplant team. A “family caregiver champion” would make these teams complete. This individual, such as a nurse or social worker, would serve as a primary point of communication for caregivers. A family caregiver champion could fill in the gaps related to screening by being responsible for initial family caregiver consent, caregiver distress screening, and follow-up screening throughout the transplant process.¹⁶ This individual could also deliver needed education, training, and support to family caregivers pre- and post-transplantation, deliver psychosocial interventions, or refer caregivers to these services. A caregiver coordinator can also facilitate open lines of communication between the caregiver and the many individuals involved in the transplant process.

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



RECOMMENDATION 4:

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

Challenge Defined

Without a comprehensive assessment of caregivers’ multidimensional needs and concerns, transplant centers may fail to effectively identify caregivers and provide them with the necessary support. Due to the dynamic and varied nature of the care recipient and caregivers’ needs throughout the transplant care trajectory, the routine screening of caregivers’ health-related social needs (e.g., transportation, housing, financial) and psychosocial needs should be conducted enabling targeted support services to be provided. In terms of psychosocial needs, caregiver distress screening is a recommended practice to evaluate overall distress and identify the physical, emotional, or practical issues that contribute to distress.^{16,21}

Education and training are fundamental services that almost all caregivers require. Medical education and training resources are particularly relevant during the acute transplant phase when caregivers assume vast responsibilities and are quickly trying to learn complex, novel tasks. Caregivers may require education and training long after they initiate caregiving as their responsibilities can change. Providing education and training early, and at more regular intervals, can improve a caregivers’ ability to care for the patient and mitigate their own mental and physical health consequences.^{2,13}

Caregiver support programs can extend beyond medical education and training and are sources of emotional and practical assistance. Such programs typically have multiple components, including peer mentorship, psychosocial support, and self-care. Studies reviewing the evidence on the feasibility and effectiveness of organ¹³ and stem cell transplant²² caregiver interventions reveal caregiver openness and willingness to participate in nonpharmacological, psychosocial support interventions. However, there is limited evidence for the interventions’ efficacy in improving caregiver psychosocial outcomes. Moreover, the rationale for how or why caregiver support programs are developed at each site is not always clear or informed by research and best practices.¹³

“I used my own initiative to make things work... The hepatologist was talking with me about her medication. I told him that sometimes she did take her medicine on her own and other times, I would have to give it to her. He’s like, ‘Well how do you know that she’s that she’s taking it?’ and I explained I can bring you what I’ve done. I made a spreadsheet with the name of the prescription, date, and the time it was taken. I would audit [the spreadsheet] every single, every single day... And then on the next visit I took him one of the completed sheets to him and showed it to him.”

– Lorrinda, Transplant Caregiver (liver)

²¹Reynolds, S. (2023, October 27). Study Finds Shortcomings in Monitoring Caregivers’ Emotional Health. National Cancer Institute. <https://www.cancer.gov/news-events/cancer-currents-blog/2023/cancer-caregivers-distress-screening>

²²Bangertner, L. R., Griffin, J. M., Langer, S., Hasan, B., Kim, W. S., Murad, M. H., & Khara, N. (2018). The Effect of Psychosocial Interventions on Outcomes for Caregivers of Hematopoietic Cell Transplant Patients. *Current hematologic malignancy reports*, 13(3), 155–163. <https://doi.org/10.1007/s11899-018-0445-y>

Survey Findings

The survey assessed the intervals and rationale supporting caregiver screening and the types of support services offered. Specifically, it examined the availability and content of caregiver-specific training and education programs that are critical for caregivers to fulfill their tasks.

Findings revealed that transplant centers do not routinely offer screening, caregiver support services, or education and training. The survey results revealed a lack of transplant center standardization regarding screening, education and training, and support services.

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 there is a change in the caregiver's or transplant recipient's life circumstances (34%)
- When the caregiver or transplant recipient requests assistance (31%)

The survey also assessed the types of education and training topics that respondents' transplant centers provided. Fifty-eight percent of transplant centers offered caregiver-specific education and training. Education and training tend to be offered to patients and caregivers in tandem (42% of the time). In other cases, the caregiver receives training separately—either before or after the transplant. Caregiver specific education and training are slightly more common in pediatric centers (63%) compared to adult-only transplant centers (54%).

Different types of caregiver-specific education and training services are offered at various intervals during the transplant continuum:

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%)

"I really wasn't told of the support that we can get being in the hospital, being able to perhaps get institutional Medicaid... I didn't find out about that until gosh until a year and half, two years later. Meanwhile the bills were all stacking up and coming in. I had insurance through my job, but it wasn't enough for the co-pays on medications. I mean it was a nightmare. I was shocked that I wasn't better prepared for that stuff via the hospital... the support at that level I think was really really bad. It was a huge financial burden to find out about it until after the fact. I was like wow... That would have made such a big difference in our lives. I don't know it would have solved all our problems, but it certainly would have made a significant difference and taken some stress away."

— Jeanne, Living Donor & Pediatric Transplant Caregiver (heart)

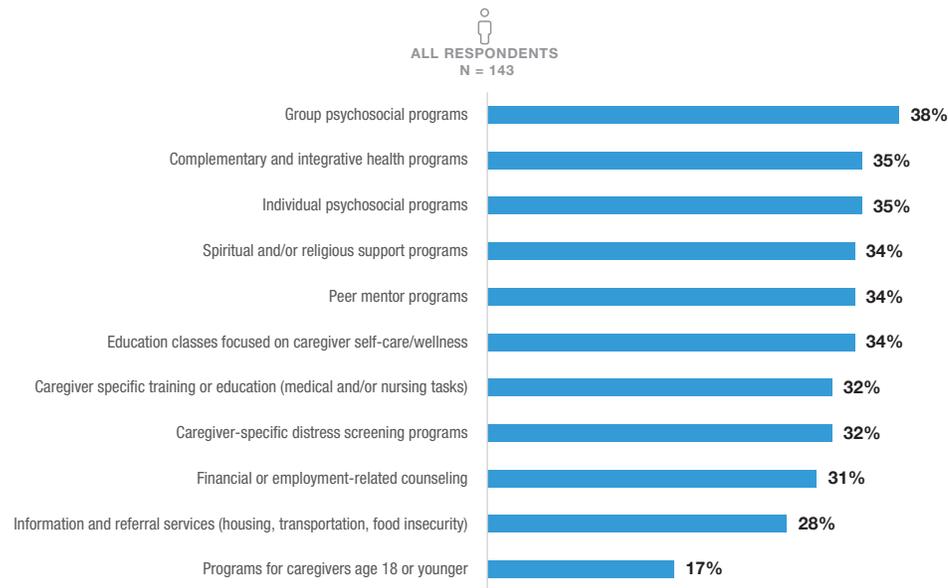
The most common type of education and training category focused on the medical aspects of the transplant process. The second most common category focused on communication, coordination, and planning. Education and training in social determinants of health (e.g., finances, transportation, housing) and caregiver health were the least common categories. These results suggest that while transplant centers may be equipped to provide some

caregiver education, offerings are quite limited as most of these critical services were offered at less than half the sites surveyed.

In addition to education and training services, the survey asked about a range of possible support programs offered. Most respondents indicated that their sites offered between 2-4 types of programs to transplant caregivers. The figure below displays the types of programs offered. These programs were largely focused on psychosocial concerns, but also touched on topics related to education and training.

Types of Support Programs Offered

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)



When support, education, and training are offered, they are focused on the medical aspects of the process and not the caregiver's health and well-being.

Though most transplant caregiver support programs were offered within transplant centers, respondents reported that critical caregiver services are often provided by a third party (i.e., outside the transplant center and/or healthcare system). The types of services that are usually referred to external third parties include:

- Training related to communicating with the transplant team (43%)
- Training related to caregiver self-care and wellness, physical and mental health (41%)
- Education on necessary medical procedures, tests, and treatments required in transplantation (34%)

Overall, there was little consistency in the types of support provided and there was no standardized program delivery. The top barriers to providing caregiver support included limited awareness of the need for support (48%), financial limitations of the transplant center (43%), and time limitations of the transplant center (42%).

Proposed Solution

Survey results coupled with existing research suggest that while transplant centers, to a limited extent, recognize the importance of caregiver screening, support, education, and training, they face significant barriers to the routine provision of these services and the implementation of standardized practices surrounding these services. Moreover, when support, education, and training are offered they are focused on the medical aspects of the

process and not the caregiver's health and well-being. These barriers create a significant gap in support for transplant caregivers, leaving them ill-equipped and unsupported throughout the transplant process.

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.



“Fortunately, our employer is great. We have great leave benefits and great medical benefits. After Elaina’s transplant we were off work for I guess almost two months... I burned through all my sick leave and annual leave about a week before I was supposed to come back to work. So, I had to use catastrophic leave which you get eighty percent of your pay. Our work has been great working with us to ensure that we can get our 80 hours in but working a more flexible schedule. If something comes up with Elaina, we can step out for a bit and do what we need to do to care for her.”

– Cody, Pediatric Transplant Caregiver (liver)



RECOMMENDATION 5:

Raise a Greater Awareness of the Health Inequities in the Transplant Donation and Transplant Process

Challenge Defined

The current transplant system is fraught with inequities that disproportionately affect patients and caregivers who are from low income and/or racially and ethnically diverse groups. These challenges include obstacles in getting on the waitlist/being referred for a transplant, being matched with a medically suitable organ/donor, and barriers accessing and navigating the healthcare system. A recent article addressing organ donation and health equity noted “in few domains of healthcare is the unequal weighting of a Black/African American life versus a white life so clear as in our organ donation system.”²³ Reforming the current system should also be viewed as a health equity issue to ensure equitable access to this lifesaving treatment.

Transplant candidates and recipients who are from racially and ethnically diverse groups are more likely to need new organs.²⁴

- Native American individuals are 4 times, Black/African American individuals are 3 times, and Latino individuals are 1.5 times more likely to have kidney failure than non-Latino whites.
- Asian individuals are 4 times more likely to have a common indicator that places them at higher risk for liver transplants.

These disparities extend to bone marrow and stem cell transplants, for which Black/African American patients face less donor availability, encounter obstacles in accessing care, and experience poorer outcomes as compared to other races.²⁵ Evidence also suggests that stem cell transplants are less likely to occur in areas where there is a greater proportion of Black/African American individuals, which may be linked to rates of residential racial segregation.²⁵

Transplant caregivers also face significant economic burdens along the caregiving journey. In a study evaluating patients and their caregivers two years post-transplantation, 80% of caregivers indicated that the transplantation procedure had a “moderate to great impact” on their finances.²⁶ Patients and their caregivers are often unaware of future caregiving-related costs, or the time commitments associated with providing care once treatment begins. Unexpected high costs and office visit co-payments can lead to medication noncompliance, which can result in a lower quality of life for both the patient and caregiver.²⁶

²³Jealous, B., Locke, J., & Segal, G. (2020). *New Organ Donation Rule is a Win for Black Patients And Health Equity*. *Health Affairs Forefront*. <https://www.healthaffairs.org/content/forefront/new-organ-donation-rule-win-black-patients-and-health-equity>

²⁴Arnold Ventures, Schmidt Futures, Organize & Federation of American Scientists. (n.d.). *Inequity in Organ Donation*. <https://costlyeffects.organdonationreform.org/Inequity/>

²⁵Majhail, N., Nayyar, S., Burton Santibañez, M., Murphy, E., & Denzen, E. (2011). *Racial disparities in hematopoietic cell transplantation in the United States*. *Bone Marrow Transplantation*, 47, 1385-1390. <http://doi.org/10.1038/bmt.2011.214>

²⁶Meehan, K. R., Meehan, J. M., Hill, J. M., Brighton, S., Hayes, C. A., Lowrey, C. H., & Lowrey, C. H. (2020, September). *Caregivers' Out-of-Pocket Expenses and Time Commitment Following Hematopoietic Stem Cell Transplantation at a Rural Cancer Center*. *Transplantation and Cellular Therapy*, 26(9), 277-231. <https://doi.org/10.1016/j.bbmt.2020.06.015>

The transplant center survey is an initial step in evaluating the extent to which transplant centers are addressing the needs of racially diverse caregivers and the impacts of the financial burden in providing care.

Survey Findings

Survey respondents reported the patient population of their centers served by race/ethnicity, income, and geographic location. The survey results revealed that minority groups, especially Latino, Native American, and Black/African American populations, were more likely to be identified as “low income” and lived in urban areas. While white and Asian populations reported higher incomes and lived in more even rural-urban geographic distribution areas.

- White: 59% served in both rural and urban areas; 12% classified as low income.
- Black/African American: 40% served in both rural and urban areas; 47% classified as low income.
- Asian: 75% served in urban areas; 32% classified as low income.
- Native Hawaiian or Pacific Islander: 56% served in urban areas; 47% classified as low income.
- Latino: 65% served in urban areas; 80% classified as low income.
- Native American/Alaskan Native: Evenly split between being served in urban and rural areas; 60% classified as low income.

Program Availability by Race/Ethnicity Served at Transplant Centers

Programs Available	ALL CENTERS (N = 114)	Centers Serving Exclusively Low Income (N=9)	Centers Incl any Black / AA population (N=95)	Black / AA - Exclusively Low Income (N = 43)	Centers Incl any Hispanic / Latino (N=44)	Hispanic/Latino Exclusively Low Income (N = 29)	Centers incl 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%



The survey revealed disparities in caregiver support programs by race/ethnicity, which were magnified by income level. For example, group psychosocial programs, financial counseling, and complementary health programs are less available at centers serving primarily low-income populations, particularly Black/African American patients and their caregivers. Even when caregiver support programs are offered, it is unknown if these programs are culturally responsive. There are few evidence-based transplant caregiver interventions.¹³ Moreover, most caregiver support interventions have been developed and tested in mostly homogenous settings that primarily serve white caregivers, which can limit their applicability and effectiveness in more diverse populations.

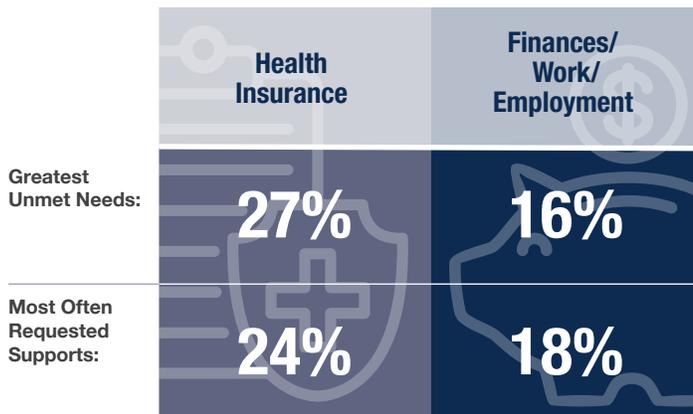
Economic Burden of Transplant Caregiving

To gain a better understanding of the financial challenges facing caregivers and transplant centers, the survey asked respondents to report the “greatest unmet needs” at their centers and the “most often requested supports.” Concerns about insurance and finances, work, and/or employment were identified as the greatest unmet needs and were some of the most common reasons for financial support requests by caregivers. To address these unmet needs and requested support, 31% of the transplant centers provided financial or employment-related counseling for caregivers.

At the transplant-center level, financial limitations were also identified and frequently reported as the “main perceived barrier to providing caregiver support”:

- The transplant center’s financial limitations (15%)
- Inconsistent or low reimbursement rates from government or third-party payers (11%)

Top Caregiver Unmet Needs and Requested Supports



“There was no [education or training] for me, per say. I know they spent a lot of time with her [transplant recipient] before the discharge. There was a long, extensive session - because as you can imagine - there was a long list of Whitney’s medications. They [transplant team] did go through those things and they reviewed each one what it was about how to use it. But it’s a lot of information, right? It’s a lot to digest in a short period of time.”

– Georgette, Transplant Caregiver (heart and kidney)

Providers can play a role in educating caregivers on financial requirements. They can discuss the time and financial commitments with caregivers before initiating treatment, given that costs and time can increase dramatically during the transplant process.

Proposed Solution

Persistent racial and ethnic inequities in healthcare affect access, quality, and ultimately, trust in the healthcare system by communities of color. To address the inequities in the organ transplant system, increased evidence-based research is needed to understand the unique needs of diverse transplant caregivers. This type of research could aid in the development of culturally responsive caregiver services and support. Additionally, policies and practices that address the financial burdens associated with caregiving need to be developed with an emphasis on developing educational tools so caregivers can learn about health insurance and the impact of caregiving on employment. The development of culturally responsive programs for transplant caregivers of color can also help to increase knowledge and develop a sense of community among diverse caregivers.



To address existing health inequities in the organ transplant system, it is imperative to conduct additional evidence-based research focusing on the diverse needs of transplant caregivers from various demographic and socioeconomic backgrounds.



RECOMMENDATION 6:

Promote Payment Reform to Increase Coverage of Transplant Caregiver Education, Training, and Supports

Challenge Defined

The 2024 Medicare Physician Fee Schedule (PFS) introduced new billing codes for caregiving training services (CTS). The CTS billing codes allow eligible providers to bill Medicare for offering individual and group CTS for patients with a mental or physical health diagnosis who need help with their daily activities. Traditionally, CMS did not reimburse practitioners under Medicare Part B to deliver these services to individuals other than the patient, especially if the patient was not present.

These billing codes are a significant step in recognizing the essential role that caregivers play within healthcare teams and for maintaining the health of millions of people living with a chronic disease or disability. They enhance patient care by equipping family caregivers with the knowledge and skills needed to support their care recipients and manage their conditions more effectively.²⁷

Survey Findings

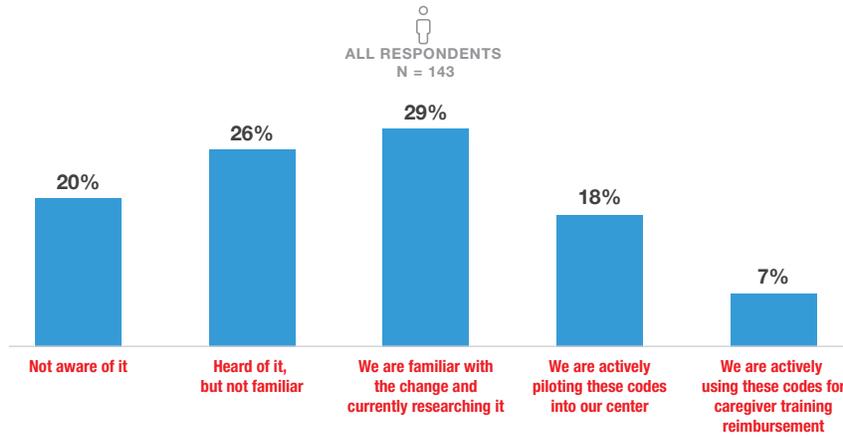
There was variability in terms of awareness of these new CTS billing codes and the types of centers that have begun utilizing these codes. While 80% of transplant centers are aware of the new Medicare billing codes for reimbursement related to caregiver training services, only 7% of centers actively use them.

Only 7% of transplant centers actively use the caregiver training services (CTS) billing codes.

²⁷National Alliance for Caregiving Act on RAISE. (2023). Policy Brief: How the 2024 Medicare Physician Fee Schedule Advances Supports for Family Caregivers. https://www.actonraise.org/wp-content/uploads/2023/12/NAC_Physician-Fee-Rule-Briefing_120723.pdf

Use of Caregiver Training Services (CTS) Billing Codes

Is your transplant center aware of new Medicare billing codes to receive reimbursement for caregiver training services?

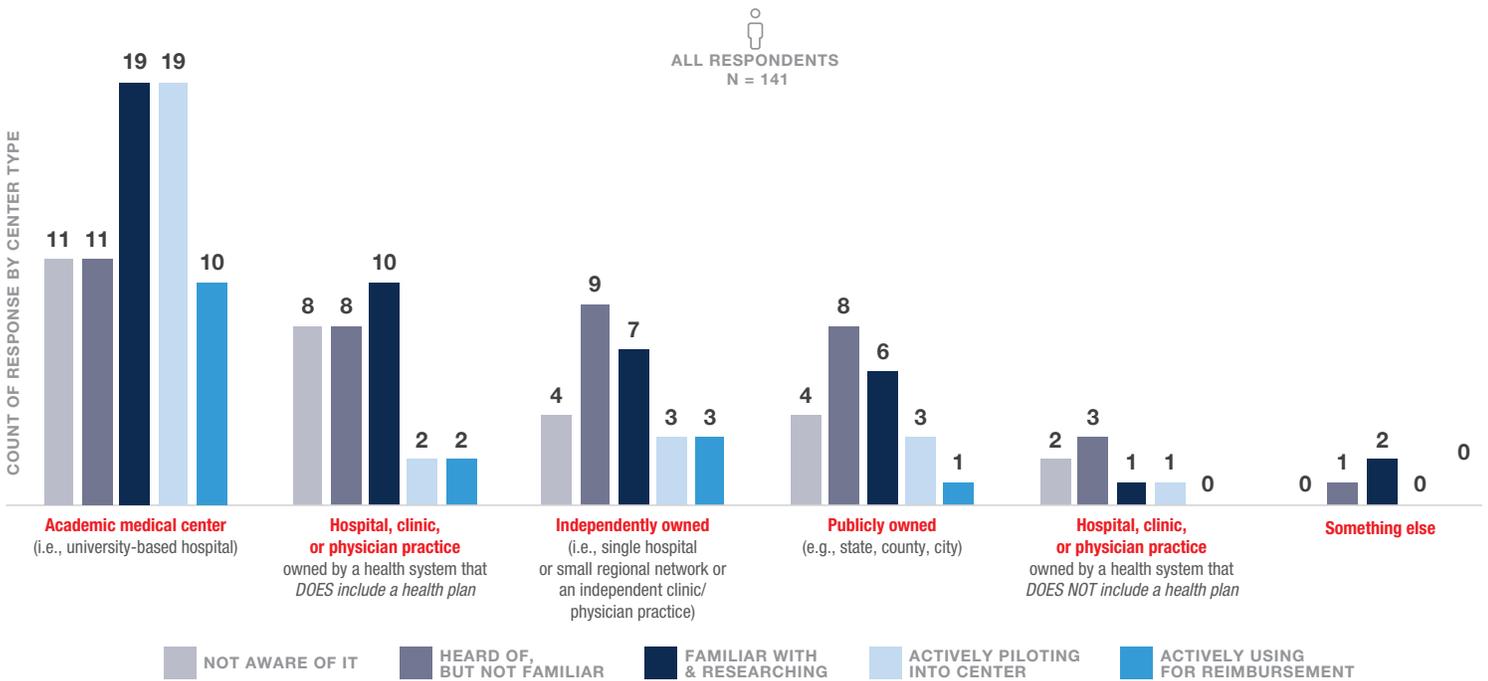


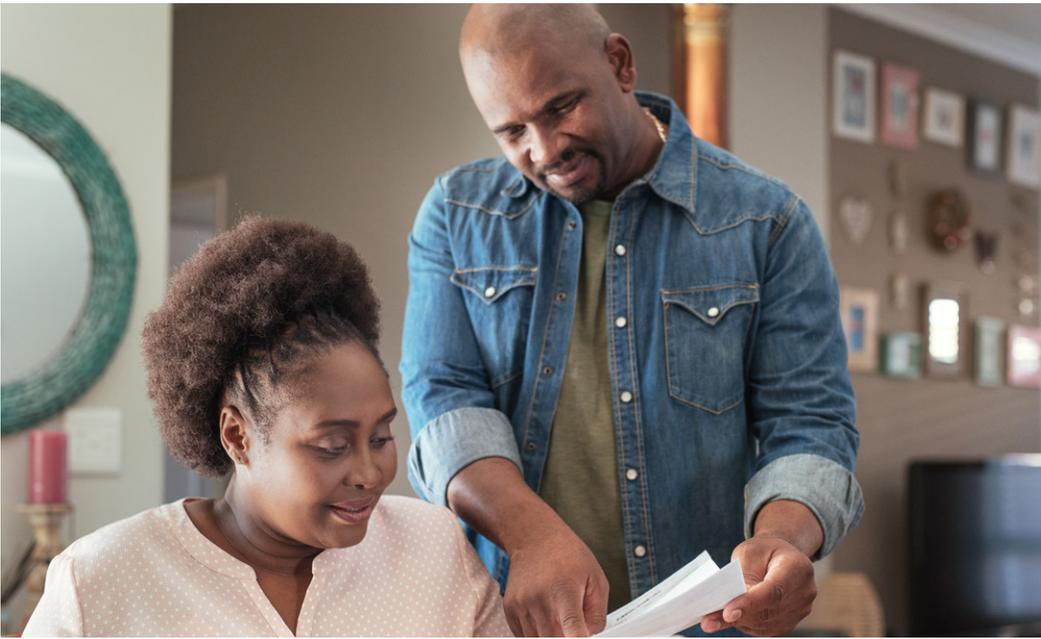
We urge CMS to take a multifaceted approach to improve the utilization of caregiver support billing codes in transplant centers.

The level of awareness varies significantly depending on the respondent’s role, which points to a gap in communication within transplant centers. Transplant center directors generally are more familiar with the codes compared to support staff—13% of directors reported actively using the codes compared to 7% of support staff. Academic medical centers are leading in the adoption and utilization of these billing codes (10%) as compared to other types of transplant centers (0-2%).

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

Level of awareness based on CENTER TYPE.





Proposed Solution

The low rates of awareness, adoption, and utilization of the CTS Medicare billing codes suggests a need for increased communication geared toward transplant centers regarding how these codes can be implemented and optimized to provide caregiver education, training, and support.

NAC is supportive of the CMS 2025 Medicare Physician Fee Scheduled Proposed Rule that would expand the CTS billing codes to include training for direct care services, such as specific clinical skills aimed at enabling caregivers to provide hands-on treatment, infection care, and patient monitoring. This provision is critical given the prevalence of family caregivers assisting with medical and nursing tasks. Additionally, the proposed rule would also establish new coding and a payment allowance for caregiver behavior management and modification services that are allowable in individual and group settings.

We urge CMS to take a multifaceted approach to improve the utilization of CTS billing codes in transplant centers. This approach should include developing and transparently collecting performance indicators related to code usage, as well as convening a diverse learning community of healthcare providers, family caregivers, transplant center staff, and community service providers. This community would work to understand real-time experiences, identify barriers to code utilization, and advance practical solutions. Additionally, CMS should create and disseminate best practices for integrating CTS billing codes into transplant center operations, with a particular focus on providing targeted education and support to non-academic and smaller transplant centers. By addressing the current disparities in CTS billing code usage and fostering a collaborative environment for improvement, CMS can significantly enhance the financial support for caregiver training programs across all types of transplant centers.

“I got no [training and education]. What they did give us, which was a mandatory marital course... But zero on how to keep a stoma bag on or when your kid gets a hole in their head because they’ve been laying on the ventilator for so long. Which she did... Just nothing. Nothing. No training on any of this. Some of the tips that I actually figured out how to keep the stoma bag on from not leaking and flying off I learn from other moms on the floor when I was in the hospital... It was really trial and error... I still have to this day, stacks and stacks of meticulous notes that I took of every single nurse, their name, what they administered to her, how much they administered to her at the time, and the exact time and day. That’s what you have to do. And I came to just take these, memorize every single thing... There was no support.”

– Hailey, Pediatric Transplant Caregiver (intestine)

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.



Conclusion

Family caregivers play a vital but often overlooked role in the transplant care continuum. While transplant centers continue to make efforts to support caregivers, a lack of standardized and coordinated practices leaves caregivers behind and perpetuates inequities across racial, ethnic, and socioeconomic lines. This report offers recommendations to improve the health and well-being of family caregivers, which is crucial to ensure positive transplant patient outcomes and quality of life.

The findings from our national survey of transplant centers reveal significant gaps in caregiver support programs and highlight the urgent need for systemic change. By addressing these gaps and implementing evidence-based practices, we can create a more inclusive and effective transplant care system that truly values the indispensable contributions of family caregivers.

Transforming the transplant care ecosystem to fully support caregivers requires collaboration among policymakers, healthcare providers, researchers, and advocates. As reform efforts progress across federal agencies and health systems, it is critical that the voices and experiences of transplant caregivers remain at the forefront. By working together to implement the recommendations in this report, we can enhance the quality of care, reduce caregiver burden, and ultimately improve outcomes for transplant recipients.

Transforming the transplant care ecosystem to fully support caregivers requires collaboration among policymakers, healthcare providers, researchers, and advocates.



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About the National Alliance for Caregiving

Since 1996, the National Alliance for Caregiving (NAC) has been a catalyst for change, transforming how the United States recognizes, supports, and values our 53 million family caregivers providing complex care. Through our nationally recognized research and our advocacy for the first-ever National Strategy to Support Family Caregivers, we drive the policy, system, and culture change needed to make family caregivers a national priority. With more than 50 members, we build partnerships across aging, disability, healthcare, philanthropy, and the private sector to make caregiving more sustainable, equitable, and dignified. Learn more at www.caregiving.org.

National Alliance for Caregiving
1730 Rhode Island Avenue NW
Suite 812
Washington, DC 20036

202.918.1013 phone
202.918.1014 fax
info@caregiving.org