



THE FAMILY CAREGIVER GAP

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



Executive Summary

Family caregivers are central to the transplant system, yet they are often overlooked and lack adequate support. Existing services typically prioritize transplant recipients, creating a significant gap for family caregivers. Research conducted by the National Alliance for Caregiving (NAC)—including a literature review, subject matter expert panel, focus groups with family caregivers, and a national survey of transplant centers—highlights the crucial role of transplant caregivers and provides six recommendations to improve their health and well-being through education, training, and support.

Drawing on NAC’s 2024 transplant center survey data, this brief provides new insights on the state of existing caregiver support programs, the extent to which they are adopted, and key facilitators and barriers. Primary insights include:

- Varied program adoption across centers
- Moderate utilization with clear preferences
- Limited caregiver needs assessment
- Disparities in access

These insights inform our practice and policy change recommendations to guide the development, implementation, and expansion of caregiver support programs (Table 1).

“This field is so specific that without a dedicated caregiver resource, it’s hard to be both the transplant recipient’s caregiver and their advocate.”

– Yang, Transplant Caregiver



Scan to learn more about Yang and other transplant caregivers’ stories.

TABLE 1. RECOMMENDATIONS AND APPLICATION TO FAMILY CAREGIVER SUPPORT PROGRAMS

Implementing a standardized screening process during the transplant waitlist period can reduce bias and health inequities and can help to identify caregivers needing additional support at the onset of transplant care.	<i>Standardized screening protocols should assess and triage specific caregiver support needs during the waitlist period.</i>
Transplant centers need standardized processes to collect caregiver data to assess and document caregiver needs, which can improve care coordination, continuity of care, and inform outcomes-based caregiver research.	<i>Collecting standardized data on caregiver experiences can inform the development of support programs and align them with caregiver needs.</i>
Dedicated caregiver coordinators are missing but are critically needed on transplant teams to identify, address, and support caregivers and their needs along the transplant journey.	<i>Dedicated care coordinators should identify caregiver needs and ensure they are addressed via referrals made to appropriate services at all stages.</i>
Caregiver support programs provided at transplant centers should be targeted, consistent, evidence-based, standardized, and provided throughout the transplant continuum.	<i>Support programs should be embedded across all phases of care and adapted to caregivers’ dynamic needs.</i>
Health inequities are present in the current organ transplant system, but these inequities can be addressed through additional evidence-based research on the needs of diverse transplant caregivers.	<i>Support programs must address issues related to social determinants of health and develop services tailored to caregivers with diverse needs.</i>
Greater awareness and adoption of the Medicare Caregiver Training Services billing codes are ways to bolster access to training and support services for family caregivers across different types of transplant centers.	<i>Policymakers and payers should prioritize mechanisms that reimburse caregiver support services and incentivize the integration of caregiver support into routine transplant care.</i>

Introduction

The U.S. healthcare system relies on 63 million family caregivers to provide critical patient care needs.¹ As care increasingly shifts from inpatient to outpatient, ambulatory, and home-based settings, family caregivers are taking on significantly more responsibilities.² Family caregivers are diverse, from varied social, economic, and cultural communities, bringing a range of experiences and responses to the role.¹ Yet, it has been increasingly recognized that many will experience significant challenges, including poor mental and physical health, diminished quality of life, and socioeconomic hardship.³⁻⁵

Caregivers play a particularly essential role in the transplant system.^{6,7} Fortunately, medical and technological advances have enabled U.S. transplant centers to provide life-saving treatment to an estimated 60,000 solid organ (e.g., kidney, liver, heart, lung), stem cell, and bone marrow recipients per year.⁶ However, transplant care relies tremendously on caregivers who provide care coordination, symptom management, emotional and financial support, and even carry out complex nursing tasks—often for 24-hours a day, 7-days a week.^{7,8} Transplant caregiving is particularly isolating, as prolonged hospital stays and the patient's impaired immunity requires limited social contact for both the patient and caregiver.⁹

Due to the intense demands of their role, transplant caregivers face heightened risk for outcomes like anxiety, depression, loneliness, post-traumatic stress, sleep disturbances, pain, reduced immune functioning, and financial strain.^{6,7,9} To mitigate these outcomes, support systems within transplant centers must prioritize family caregivers and deliver caregiver-specific services.

Examples include individual or group psychotherapy, education, and complementary medicine—all of which are designed to reduce emotional burden and improve resilience. Comprehensive programs also target practical challenges such as navigating healthcare systems, managing finances, and coordinating care. Recent policy developments, such as the Caregiver Advise, Record, Enable (CARE) Act, requires healthcare systems to identify, document, and involve family caregivers,¹⁰ and the introduction of Medicare billing codes for caregiver health risk assessments, and caregiver training services (CTS),¹¹ offers new mechanisms for facilitating caregiver support. Additionally, researchers have developed evidence-based interventions to reduce caregiver distress.^{6,9,12,13} However, it remains unclear whether these interventions and other offerings meet caregivers' holistic needs.

This report aims to describe the use of transplant programs, current gaps, and future directions for transplant centers to expand services to caregivers to improve patient and caregiver quality of life and health outcomes.

Method

The National Alliance for Caregiving's (NAC) Transplant Caregiving Collaborative,⁶ seeks to recognize and uplift transplant caregivers through research and advocacy. Its first report, *Transplant Caregiving in the U.S: A Call for System Change*, highlighted transplant caregivers' vital role and existing knowledge gaps. Next, to understand transplant centers' efforts to identify, assess, and support family caregivers, NAC commissioned a survey of 114 transplant centers nationwide from April 30 to May 18, 2024. The survey methods are described in *Gaps and Opportunities: Family Caregiver Programs in U.S. Transplant Centers*,¹⁴ which revealed limitations in standardized and coordinated practices that contribute to inconsistent support and disparities for caregivers. The current brief augments survey results and focuses on support and service delivery for caregivers, evaluating questions like: *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?* and *At your transplant center, what percent of caregivers of transplant recipients actually receive this type of support?*

The 114 centers included a mix of academic and non-academic sites, serving diverse patient populations across urban and rural areas, with income levels ranging from predominantly low-income to mixed- or high-income. Centers reported serving mostly White patients (78%), with centers also serving Black/African American patients (62%), Asian patients (50%), Latino/x/e patients (27%), Native Hawaiian or Pacific Islander patients (13%), and Native American or Alaska Native patients (10%). There were 143 individual providers that represented these centers who responded and they accounted for both support staff (i.e., transplant center nurse [18%], social worker [22%], psychologist [17%]) and program directors (43%)—all of whom engage in caregiver support.

Survey Findings

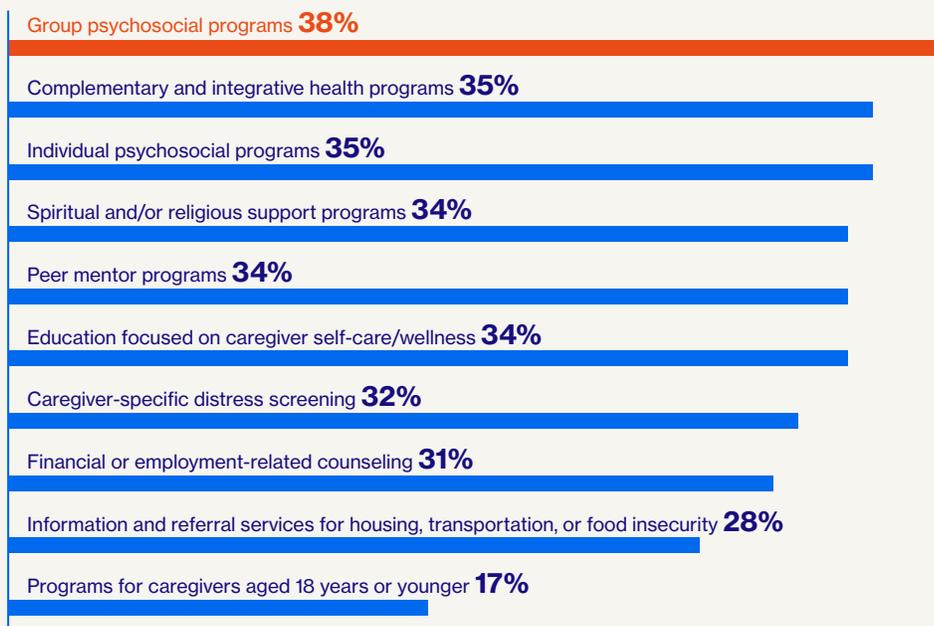
Service Delivery and Utilization Trends

KEY TAKEAWAYS

- **Heavy reliance on referrals:** Critical services are frequently outsourced, including financial counseling (66–70% referred), distress screening (52–70% referred), and medical education (57–70% referred), rather than being delivered onsite.
- **Moderate but varied utilization:** Most programs see ~60% utilization when available, with group psychosocial (50–90%) and peer mentoring (50–80%) programs showing highest use, while SDOH and youth services (50–60%) showing lowest engagement.
- **“All or nothing” access patterns:** Significant disparities exist between centers, with some caregivers receiving comprehensive support while others have limited or no access to services.

Offerings and Delivery Modes. Most transplant centers offered a few different forms of caregiver support: 70% of centers offered two to four types of support programs for caregivers of transplant recipients or candidates. The available programs were offered at similar frequencies (Figure 1). Psychosocial programs were the most offered and youth caregiver services were the least offered. The specific components of the group psychosocial programs, complementary and integrative health programs, and individual psychosocial programs were not assessed, but interventions like yoga and mindfulness-based stress reduction^{15,16} psychoeducation, problem solving, and cognitive behavioral therapy¹⁷ have shown promise in reducing caregiver stress and anxiety, suggesting value in the frequently offered psychosocial and integrative support programs.

FIGURE 1. CAREGIVER SUPPORT SERVICE OFFERINGS



Caregivers are typically referred to programs either within the center's greater healthcare system or to third-party providers (Table 1). In some cases, onsite programs are offered. Referrals are often relied on for critical services addressing material needs like financial or employment-related counseling (66–70%), as well as for specialized services like complementary and integrative health programs (70–76%) or youth caregiver programming (72–84%). Despite being a time-sensitive clinical assessment, distress screening was only delivered onsite in 41% of centers and typically referred to a third party (52–70%), and although caregivers provide critical nursing tasks, medical education is offered onsite at less than half of centers.

TABLE 2. PROGRAM DELIVERY MODE

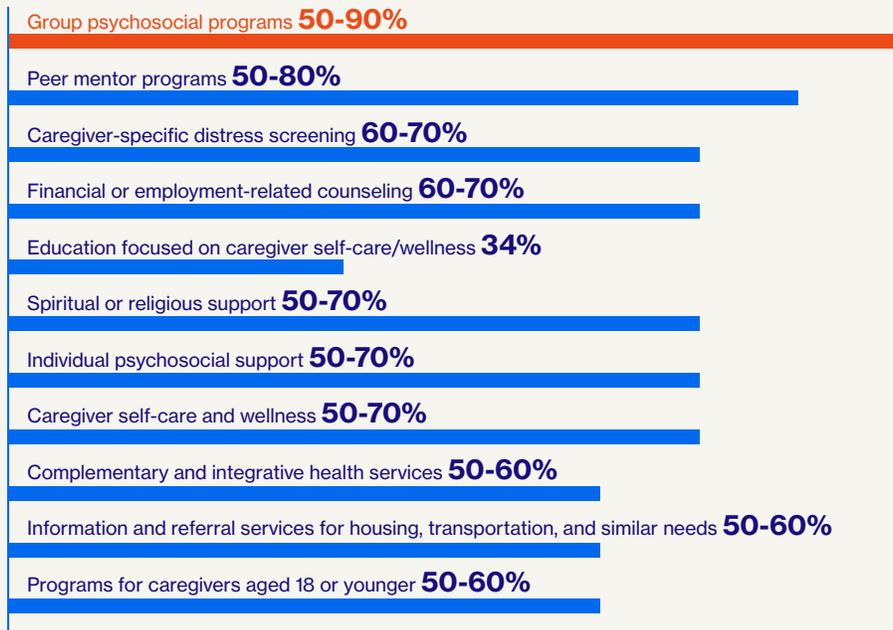
Program	Onsite		Referred within the system		Referred to a third party	
	Count	Percentage	Count	Percentage	Count	Percentage
Group Psychosocial	31	(56%)	31	(56%)	33	(60%)
Individual Psychosocial	27	(54%)	39	(78%)	36	(72%)
Integrative Health	17	(34%)	38	(76%)	35	(70%)
Spiritual/Religious Support	22	(46%)	36	(75%)	34	(71%)
Peer Mentor	22	(45%)	29	(59%)	33	(67%)
Self-Care/Wellness Education	19	(40%)	37	(77%)	37	(77%)
Training or Education: Medical/Nursing	22	(48%)	26	(57%)	32	(70%)
Distress Screening	19	(41%)	24	(52%)	32	(70%)
Financial or Employment-related Counseling	20	(45%)	31	(70%)	29	(66%)
Information/Referral Services	18	(45%)	28	(70%)	29	(73%)
Youth Caregiver Programs	8	(32%)	21	(84%)	18	(72%)

Centers that offer certain programs are more likely to offer others in tandem. Individual psychosocial support services are highly correlated with training or education classes, complementary and integrative health services, and peer mentor programs. It is possible that these programs are overseen by some of the same personnel (e.g., social workers, psychologists) and thus clustered together. Distress screening programs were not strongly clustered with other support services (except spiritual and/or religious support programs), despite the need for a robust referral system when elevated distress and unmet needs are identified.^{18,19} A gap persists for youth-focused and SDOH programming, which tend to be less commonly offered alongside other programs, suggesting that youth caregiver needs might still get overlooked (even for systems that provide other types of support services).

There is an “all or nothing,” pattern of uneven access, with some caregivers receiving robust comprehensive support, and others with limited resources. We found that while various support programs exist, their adoption is inconsistent and varies by center. Centers provide fewer services for practical/financial needs and for younger caregivers; highlighting gaps. Programs are clustered, with centers that offer one type being more likely to offer others—but not necessarily assessment or distress screening, which ideally should be paired with referrals to support programs. Necessary, time-sensitive services like medical education, financial support, and distress screenings are often outsourced.

Utilization. Most available caregiver support programs have a utilization rate of around 60%. The most-used services are group psychosocial programs and peer mentor programs, while those addressing SDOH—like housing and transportation referrals—and youth-focused support are the least utilized.

FIGURE 2. CAREGIVER SUPPORT SERVICE UTILIZATION



Caregiver use of programs is overall moderate, with some programs more often adopted, like group psychosocial programs and peer mentoring, suggesting that caregivers desire social support and emotional connection with those with shared experiences and they are willing to use programs that can potentially integrate evidence-based interventions. In contrast, programs targeting SDOH, such as material resource referrals and youth-focused support, are less frequently utilized. This may reflect access barriers or limited integration into the transplant center workflows and referral system, leaving the most vulnerable caregivers to face unmet needs that must be addressed before any other support needs can be adequately met.

Drivers and Barriers

KEY TAKEAWAYS

- **Reactive, not proactive approach:** Only 3% of centers conduct regular reviews of family caregiver support needs, with most assessments triggered by specific milestones like patient waitlist (49%), dry run (43%), or crises (38%) (i.e., medical issue, complication, or adverse event).
- **Self-advocacy drives support access:** The most utilized services (peer mentoring, psychosocial support) are primarily accessed when family caregivers ask for help themselves (47–57% of centers), placing the burden on already stressed caregivers.
- **Awareness is the top barrier:** Nearly half of centers (48%) cite limited awareness of family caregiver support needs as their primary barrier, followed by financial limitations (43%), and staff time constraints (42%).

Barriers to centers providing caregiver support most often included limited awareness for the need for caregiver support (48%), followed by financial limitations of centers (43%), and time limitations of staff (42%).

Very few centers indicated conducting reviews of caregiver support needs at regular intervals (3%), suggesting a lack of standard screening practices. Most centers review support needs at selected milestones like while the patient is on the waitlist (49%), in the case of a “dry run” (43%), during the hospitalization for a transplant procedure (41%), when a recipient has a medical issue, complication, or adverse event (38%), and post-hospitalization or discharge of the recipient (38%). Support needs are also often reviewed if there is a change in life circumstances, which most frequently includes changes to health insurance status or loss of income.

The most offered and utilized types of support (peer mentor programs [57%], group [47%], and individual [48%] psychosocial support programs) were most frequently considered for referrals when the caregiver or transplant recipient asked for help themselves. The less commonly offered and utilized types of support (information and referral services for housing, transportation, and similar needs [55%]) tended to be considered when a recipient had a medical issue, complication or adverse event. Youth-focused support for caregivers aged 18 years old or younger was most often considered when there was a change in the caregiver’s life circumstances (56%), examples of which included changes in family structure, childcare circumstances, and insurance status. Barriers to centers providing caregiver support most often included limited awareness for the need for caregiver support (48%), followed by financial limitations of centers (43%), and time limitations of staff (42%). Limited “buy in” about the benefits of such programs (31%) and lack of reimbursement were also significant barriers (31%).

Centers appear to take a reactive, rather than proactive, approach to evaluating and addressing caregiver support needs. When caregivers receive support, especially psychosocial support, it is often because they advocate for it directly or experience an acute medical event. Critical needs, especially among vulnerable populations and youth caregivers, may go unnoticed until there is a crisis. Awareness of the caregiver support needs tends to be limited, and financial and staffing/resource availability presents another significant barrier to support provision. Increased screening, evaluation, and early intervention should triage caregiver needs and prioritize service delivery, especially in resource-limited settings. Center awareness and financial barriers can be addressed with improved documentation and potentially with CTS billing codes.

Disparities and Gaps

KEY TAKEAWAYS

- **Racial disparities in service availability:** Centers serving mostly Black/African American patients offer significantly fewer support programs across all categories, with offerings dropping to 21–28% compared to ~33% at centers overall.
- **Income disparities:** Centers serving exclusively low-income patients are least likely to offer financial counseling (22% vs. 31% overall) and other critical services, despite serving those with the greatest material needs.
- **Youth caregivers overlooked:** Only 18% of centers offer youth-specific programs, with this dropping to just 11% at centers serving low-income patients, leaving a growing and vulnerable caregiver population without targeted support.

Fewer support programs are available at centers serving minority race/ethnicity patients, with centers serving mostly Black/African American individuals much less likely to offer integrative health services (23%), peer mentor programs (28%), caregiver distress screening (26%), financial assistance counseling (23%), and information and referral services to address issues of housing, transportation, food insecurity (21%), compared to offerings in around one-third of centers overall. For centers serving exclusively low-income individuals, complementary/integrative health programs, caregiver-specific training/education on medical or nursing tasks, and programs for caregivers aged 18 years or younger were significantly less likely to be offered: just 11% of the time compared to 35%, 34%, and 17% in centers overall. Centers serving mostly low-income patients were less likely to offer financial or employment-related counseling programs (22%) compared to centers overall (31%), despite that they likely see the greatest need for such services. Centers often refer patients to programs that address SDOH needs, perpetuating access barriers for those with the greatest support and specifically, material needs. Finally, youth programs are rarely offered (only 18% of centers), despite the fact that youth caregivers are growing in numbers and require unique support.²⁰

Minority and low-income caregivers have less access to support services. Programs targeting SDOH are far less common and not necessarily more likely to be offered to minority or low-income patient populations. Youth caregivers may be one group especially at risk, yet they are overlooked. These data underscore the disparities in caregiver experiences and outcomes and point to critical areas for targeted intervention and resource allocation.

Summary and Recommendations

The national survey of 114 transplant centers reveals a troubling paradox: While transplant care fundamentally depends on family caregivers who provide round-the-clock medical care, emotional support, and care coordination, the system consistently fails to meet their needs. The data paints a clear picture of systemic gaps, reactive approaches, and stark disparities that undermine both caregiver well-being and patient outcomes.

Three critical failures emerged from our findings. First, the heavy reliance on referrals for essential services—with 70% of financial counseling and medical education occurring offsite—creates dangerous delays and access barriers for family caregivers managing life-or-death responsibilities. Second, the near absence of proactive support (only 3% of centers regularly assess caregiver needs) means problems escalate to crises before intervention occurs. Third, profound disparities leave underserved populations—minority, low-income, and youth caregivers—with the least access to support, perpetuating health inequities throughout the transplant system.

Despite these failures, the data also reveals a path forward. The high utilization of peer support and group psychosocial programs (up to 90%) suggests that family caregivers actively seek and benefit from support when it's accessible. This finding, combined with policy developments like the CARE Act and Medicare's CTS billing codes, creates an unprecedented opportunity for transformation.

To bridge the gap between current practice and caregiver needs, transplant centers must move from reactive to proactive support models. This requires implementing standardized screening protocols during the waitlist period, embedding dedicated caregiver coordinators within transplant teams, and ensuring equitable access to evidence-based support programs throughout the care continuum. Most urgently, centers must recognize that supporting family caregivers isn't optional—it's essential infrastructure for a better functioning transplant system. Without systematic change, we risk the collapse of the very foundation upon which transplant success depends—the family caregivers who make life-saving care possible.

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ABOUT THE NATIONAL ALLIANCE FOR CAREGIVING

The National Alliance for Caregiving (NAC) is a catalyst for change, transforming how the United States recognizes, supports, and values its more than 63 million family caregivers providing complex care for older adults, people with a serious illness, or a disability. Through their nationally recognized caregiving research and advocacy, NAC drives policy, system, and culture change to elevate family caregivers as a national priority. NAC fosters partnerships across aging, disability, healthcare, philanthropy, and the private sector with the goal of making family caregiving more sustainable, equitable, and dignified.

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