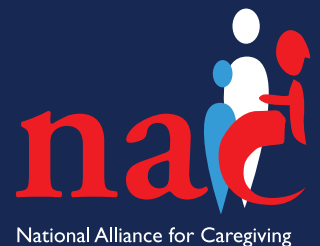




2023 REPORT

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



## Foreword

It is my pleasure to present *Transplant Caregiving in the U.S.: A Call for System Change*. This report highlights the experiences of an often-unseen community of family caregivers—those who provide care for someone waiting to receive an organ, stem cell, or bone marrow transplant, or who have received these life saving procedures.

Transplant caregivers play a vital role in the lives of organ transplant patients. They provide essential physical and emotional support before, during, and after surgery, and their contributions are critical to the success of the transplant process.

Despite the importance of transplant caregivers, relatively little attention is paid to their experiences and needs. This report aims to address this gap by providing a comprehensive overview of the transplant caregiver role, the challenges and rewards of caregiving, the impact of caregiving on caregivers' lives, and recommendations for improving support for caregivers.

The report is based on a review of existing research and interviews with transplant caregivers, healthcare professionals, and subject matter experts. The findings reveal that transplant caregivers face many challenges, including:

- **Significant time and effort commitment:** Transplant caregiving can be very demanding, both physically and emotionally. Caregivers often provide around-the-clock care and may have to juggle caregiving with other responsibilities, such as work and family.
- **High levels of stress and anxiety:** Transplant caregiving can be a very stressful experience, as caregivers worry about the health and well-being of those they're caring for. Caregivers may also experience anxiety about the transplant process itself and the potential for complications.
- **Lack of support:** Many transplant caregivers feel that they do not have enough support from others, including family members, friends, and healthcare professionals. This can lead to feelings of isolation and overwhelm.

As one caregiver told us, “it was a nightmare and I was shocked that I wasn’t better prepared via the hospital. And when you leave, it’s like the door gets shut. They’re so busy with the patients they have that there’s no one. There’s really no one. And you can’t call the state level... the support on that level is really bad.”

By centering the experiences of family caregivers across transplant care and treatment, we outline recommendations to address the systemic failures that contribute to caregiver strain and hardship.

It is our hope that health system leaders, policy makers, and patient advocacy organizations, will use this report to inform, develop, and implement solutions that will address the challenges transplant caregivers face.



Jason Resendez  
President and CEO  
National Alliance for Caregiving

Every ten minutes,  
a person is added  
to the national  
transplant waitlist.<sup>1</sup>  
This report expands  
on the experiences of  
transplant caregivers  
who provide invaluable  
support throughout the  
transplant process.

<sup>1</sup>UNOS. *Caring for Patients. Transplant Living.* <https://transplantliving.org/before-the-transplant/caring-for-transplant-patients/>.

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We would also like to extend gratitude to and honor the memory of Jim Gleason, late former president of Transplant Recipients International Organization and a member of this advisory committee.

# Executive Summary



**Rapid advancements in medicine and technology have expanded access to life-saving transplant surgeries, including solid organ, bone marrow, and stem cell transplants. Transplant can be a very long and stressful procedure, from waitlist to months or years post-transplant.**

Although most patients recover and resume active lives after a transplant, there is risk of complications and side-effects that require a significant need for care. Caregivers, or the unpaid individuals providing care to family, friends, and those in need with illness and disability, are critical to transplant care. In fact, the transplant system heavily relies on caregivers, as transplant recipients are typically required to identify an available caregiver who will provide support during and after transplant.

It is well-recognized that caregivers tend to experience negative consequences to their health and well-being due to grappling with a family member's illness while simultaneously adopting the role of caregiver and the associated responsibilities.<sup>2</sup> Transplant caregivers tend to report numerous unmet needs and a lack of resources necessary to meet the demands of their role. This not only affects the caregivers' day-to-day functioning but can also impair their ability to carry out caregiving responsibilities and possibly jeopardize the success of the transplant patient. Due to the intensity of the transplant experience, family caregivers of the estimated 60,000 transplant patients in the United States face significant consequences to their health, emotional, and financial well-being.

This report explores the experiences of family caregivers of transplant patients to shine a light on this area of unmet need in transplant care and caregiving. Findings are drawn from varied sources including a literature review, a subject matter expert panel, and focus groups and oral histories with family caregivers.

**Caregivers, or the unpaid individuals providing care to family, friends, and those in need with illness and disability, are critical to transplant care.**

<sup>2</sup>National Alliance for Caregiving & AARP. (2020, May). *Caregiving in the U.S. 2020*. Retrieved November 1, 2023 from [https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316\\_RPT\\_CaregivingintheUS\\_WEB.pdf](https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316_RPT_CaregivingintheUS_WEB.pdf).

*“When caregivers feel informed and supported, when they receive education and training on the medical and nursing tasks they need to perform, they are better able to carry out their caregiving responsibilities with minimal detriment to themselves and ensure the best medical outcomes for patients. This is true across all caregiving settings, but perhaps is most powerfully seen among caregivers of patients recovering from Hematopoietic cell transplantation outside of the hospital, whose lives are literally in their caregivers’ hands.”*

*Dr. Allison Applebaum,  
Associate Attending Psychologist and Director of the Caregivers  
Clinic at the Memorial Sloan Kettering Cancer Center*



## Key Insights:

- Research on the experiences of transplant caregivers and interventions for transplant caregivers is limited.
- The burden of transplant caregiving is inequitable, with caregivers from socioeconomically disadvantaged and diverse racial and ethnic background facing exacerbated challenges, yet most of what we know about transplant caregiving is from studies conducted in non-Latino white, formally-educated caregivers.
- Transplant caregiver support is not sustained for as long as caregivers are facing the consequences of caregiving and risk for burden.
- Transplant caregivers face risks of psychosocial consequences that can impact their long-term well-being and their transplant recipient’s success post-transplant. In some cases, caregivers report benefits and growth.
- Transplant caregivers and those they care for interact with multiple transplant centers to find a transplant match. The lack of universal screening processes is inequitable, makes the transplant process more difficult to navigate, and creates barriers to support.
- Educational and supportive psychosocial interventions (e.g., stress management, peer-support) can help improve a caregiver’s health and well-being but these support mechanisms rarely follow caregivers several years out when they are still very vulnerable to psychosocial distress.

Together, these findings suggest that, despite their crucial role in the transplant care continuum, transplant caregivers are generally under-studied, under-resourced, and under-supported. Transplant system barriers and challenges were mentioned most often by caregivers as a source of stress. The challenges brought up consistently were: getting information, the waitlist process, the post-transplant period, and issues of access and quality of care throughout the process. Caregiver interviewees also reported financial strain and a lack of resources. As evidenced by the literature review and focus groups, transplant caregivers face psychosocial consequences that can impact their long-term well-being and their patients’ success of transplant.

**The burden of transplant caregiving is inequitable, with caregivers from socioeconomically disadvantaged and diverse racial and ethnic background facing exacerbated challenges**

Based on these findings, we recommend that transplant centers implement the following:

### **A Standardized Screening Process and Caregiver Identification**

A standardized screening process would provide both transplant patients and their caregivers with the opportunity to be added to a waitlist regardless of race, ethnicity, or socioeconomic status. It would also delineate necessary and measurable requirements to be applied across transplant centers. Caregiver identification is a critical first step toward documenting, understanding, and addressing the challenges of transplant caregivers.

### **Caregiver-Specific Data Sharing & Coordination Among Transplant Centers**

Caregiver-specific data collection, sharing, and coordination among transplant centers would save time and stress for both caregivers and transplant recipients. Collecting and sharing caregiver data across centers will provide the information necessary in the creation, refinement, and evaluation of caregiver support best practices.

### **A Coordinator on the Transplant Team Dedicated to the Family Caregiver**

A family caregiver coordinator would serve as the point person for communicating with caregivers throughout the pre- and post-transplant process while supporting the caregiver's health and well-being.

### **Routine Family Caregiver Screenings and Delivery of Support Services to Respond to Unmet Needs at Critical Points Along the Transplant Journey**

Caregivers are not consistently nor comprehensively linked to support resources. There is a need for transplant centers and health care teams to assess and deliver support services that provide caregivers with resources to reduce distress and bolster positive outcomes.

### **Policies that Provide Financial Assistance and Workplace Protection and Appropriate Medical Coverage for Transplant Caregivers**

Federal policies, such as the Family Medical Leave Act (FMLA) are helpful, but they do not address the unique care needs in end-stage organ disease and transplantation. Comprehensive paid family and medical leave is needed to help transplant caregivers and patients balance care and work responsibilities. Further, implementing financial assistance for transplant caregivers and ensuring adequate health coverage would allow them to care for the transplant recipient without jeopardizing their current or future financial situation.

Ultimately, transplant caregiving is an enormous responsibility that can come with great cost to the caregiver but is also incredibly valuable with benefits to both transplant recipients and caregivers. Health care providers and researchers as well as policy makers should consider these findings and recommendations to mitigate the burden of caregiving and maximize its benefits.



**Ultimately, transplant caregiving is an enormous responsibility that can come with great cost to the caregiver but is also incredibly valuable with benefits to both transplant recipients and caregivers.**

# Introduction



**As of late 2023, there are 53 million family caregivers in the United States who provide unpaid care to family members and friends who are aging, or who are living with a serious medical condition, illness, or disability.<sup>3</sup>**

Caregivers face enormous challenges due to the prolonged distress and uncertainty associated with illness and disability in the family and from witnessing a family member's suffering, and the often long-term and numerous responsibilities that come with the caregiver role while also often feeling unrecognized, unprepared, and under-resourced.

This report focuses on a unique subset of caregivers who provide care for someone waiting to receive an organ, stem cell or bone marrow transplant or who have already received a transplant. Transplant caregivers—like other caregivers—provide a range of emotional, instrumental, and financial support to the transplant recipient. In general, they go uncompensated for the time they spend providing this care and receive limited support to maintain their own health and well-being.

**Who is a family caregiver? According to the National Strategy to Support Family Caregivers, family caregivers are “people of all ages, from youth to grandparents; people with and without disabilities; people providing care from a distance; and people meeting a wide variety of needs, such as supporting people with intellectual and developmental disabilities (ID/DD) across the lifespan, caring for people with serious and/or progressive illnesses like dementia and cancer, and assisting with daily tasks that can be challenging for older people and people with disabilities.”<sup>4</sup>**

**Transplant caregivers are uncompensated for the time they spend providing this care and receive limited support to maintain their own health and well-being.**

<sup>3</sup>National Alliance for Caregiving & AARP. (2020, May). Caregiving in the U.S. 2020. Retrieved November 1, 2023 from [https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316\\_RPT\\_CaregivingintheUS\\_WEB.pdf](https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316_RPT_CaregivingintheUS_WEB.pdf).

<sup>4</sup>Administration for Community Living. (2020, September). 2022 national strategy to support family caregivers. Retrieved November 1, 2023 from [https://acl.gov/sites/default/files/RAISE\\_SGRG/NatlStrategyToSupportFamilyCaregivers.pdf](https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyToSupportFamilyCaregivers.pdf).

In 2022, over 42,000 solid organ transplants<sup>5</sup> and almost 23,000 stem cell transplants<sup>6</sup> were performed in the United States. At the end of 2023, the national transplant waitlist currently has over 100,000 names.<sup>7</sup> Caregivers provide a vital role across the entire transplant process. This includes referral, evaluation, maintaining waitlist status, and providing pre- and post-surgery support. This is due to transplant centers requiring verification of social support to be wait-listed for most solid and nonsolid organ transplants.<sup>8</sup> This requirement means that, to receive life-saving procedures, transplant recipients are required to identify someone available to provide care and support around the clock. There are many points during the transplant process where caregivers need additional support services. Education and training on transplant complications, infection risk, medication adherence, and medical/ nursing tasks are some of the areas that have direct and important implications for the transplant recipient's recovery and quality of life.<sup>9</sup>

Despite the critical role caregivers play in the transplant process, we have limited knowledge of the experience and needs of caregivers in transplantation. This knowledge gap is even bigger for transplant caregivers of racially and ethnically diverse backgrounds, as the research on transplant caregiving has largely been conducted in mostly non-Latino white populations.

## Transplant Experiences

Transplant caregiving is a difficult and demanding journey; however, it does not impact all caregivers or their transplant recipients equally. Transplant caregiving experiences and outcomes vary due to a variety of factors, including the type of transplantation (stem cell vs. bone marrow vs. solid organ), underlying reason for transplantation, degree of transplantation success, and the quality of life and life expectancy post-transplant.

Socioeconomically disadvantaged caregivers tend to have less access to the resources (e.g., health insurance, employer benefits, flexible work schedules) required to meet the

demands of caregiving, leading to disproportionate levels of stress and burden. For example, individuals from diverse racial and ethnic groups are less likely to be listed on the transplant waitlist, and when they are listed, they are less likely than non-Latino white recipients to receive a transplant.<sup>10</sup> The caregivers waiting alongside these patients are required to provide prolonged care to patients who are less likely to have successful outcomes.

While it's possible to experience positive outcomes as a transplant caregiver,<sup>11</sup> research most often cites the negative effects on their mental, physical, and financial health.<sup>12</sup> Across the entire transplant process, caregivers feel a high level of emotional burden, including stress, anxiety, depression, and even post-traumatic stress disorder (PTSD),

**At the end of 2023, the national transplant waitlist currently has over 100,000 names.<sup>7</sup> Caregivers provide a vital role across the entire transplant process.**



<sup>5</sup>Health Resources and Services Administration. (2023, March). Organ donation statistics. Organ Donor. <https://www.organdonor.gov/learn/organ-donation-statistics>.

<sup>6</sup>Health Resources and Services Administration. (2023, June). Donation and transplantation statistics. Transplants Performed. <https://bloodstemcell.hrsa.gov/data/donation-and-transplantationstatistics>.

<sup>7</sup>UNOS. Caring for patients. Transplant Living. <https://transplantliving.org/before-the-transplant/caring-for-transplant-patients/>

<sup>8</sup>Dew, 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., Geest, S.D., Doligaski, C.T., Kuglar, C., McDonald, L., Ohler, L., Painter, L., Petty, M.G., Robson, D., Schlöglhofer, T., Schneekloth, T.D., Singer, J.P., Smith, P.J., Spaderna, H., Teutenberg, J.J., Yusen, R.D., & Zimbren, P.C. (2018). The 2018 ISHLT/APM/AST/ICCAC/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>.

<sup>9</sup>Applebaum, 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), 143–50. <https://doi.org/10.1016/J.JTCT.2022.12.014>.

<sup>10</sup>Bratton, C., Chavin, K., & Baliga, P. (2011). Racial disparities in organ donation and why. *Current Opinion in Organ Transplantation*, 16(2). Doi: 10.1097/MOT.0b013e3283447b1c.

<sup>11</sup>Harvey, J., & Berndt, M. (2021). Cancer caregiver reports of post-traumatic growth following spousal hematopoietic stem cell transplant. *Anxiety, Stress, and Coping*, 34(4), 397–410. <https://doi.org/10.1080/010615806.2020.1845432>.

<sup>12</sup>Applebaum, A. J., Bevans, M., Son, T., Evans, K., Hernandez, M., Giralt, S., & DuHamel, K. (2016). A scoping review of caregiver burden during allogeneic HSCT: Lessons learned and future directions. *Bone Marrow Transplantation*, 51(11), 1416–22. <https://doi.org/10.1038/bmt.2016.164>





**Transplant caregiving is a difficult and demanding journey; however, it does not impact all caregivers or their transplant recipients equally.**

all of which have been linked to physical health outcomes.<sup>13,14</sup> Roles and relationships often change, leaving caregivers feeling socially isolated, and sometimes exacerbating mental and physical health consequences.<sup>15</sup>

Experiencing financial stress during the transplant journey is also common. This is due to the costs associated with getting a transplant, follow-up appointments, staying in the area during transplant surgery, sometimes paying for the surgery itself, and the potential loss of work.<sup>16</sup>

Caregiver experiences and the associated stress and burden tend to be prolonged. Caregivers often report feeling stress and strain for months to years after the transplant has occurred.<sup>17</sup> For example, caregivers may need to pay for costly post-transplant medications and hospital follow-up visits, and then have new, added expenses associated with required post-transplant lifestyle changes (e.g., new dietary restrictions) for years to come. Considering the growing body of research documenting the burden felt among transplant caregivers, their experience warrants further investigation, as well as identifying practice improvements and policies that will provide better support.

## A Call for Improving Support Services for Transplant Caregivers

The findings and recommendations in this report add to other recent national efforts to increase awareness about transplant caregivers and address the challenges they face. For example, the Organ Transplant Caregiver Initiative published a preliminary action plan to improve education, research, and advocacy for organ transplant caregivers.<sup>18</sup> In addition, in early 2023, the Health Resources and Services Administration (HRSA), launched a Modernization Initiative, which includes several actions to strengthen accountability and transparency in the Organ Procurement and Transplantation Network. While transplant caregivers are not the focus of this HRSA initiative, it does have important implications for both transplant caregivers and their recipients.<sup>19</sup>

Overall, this report aims to provide a better understanding of the experiences and challenges of transplant caregivers and outlines opportunities to develop infrastructure within the transplant system to be more responsive to their urgent needs. Using the current practices of transplant centers, this report explores ways centers can better support patients and their caregivers. Most importantly, the final section of this report offers insights on how the transplant system can implement and improve policies and practices to ensure caregivers are recognized, identified, and receiving the level of support and assistance they need.

<sup>13</sup>Beattie, S., & Lebel, S. (2011). *The experience of caregivers of hematological cancer patients undergoing a hematopoietic stem cell transplant: A comprehensive literature review*. *Psycho-oncology*, 20(11), 1137–50. Doi: 10.1002/pon.1962.

<sup>14</sup>Bevans, M. F., Ross, A., Wehrlen, L., Klagholz, S. D., Yang, L., Childs, R., Flynn, S.L., Remaley, A.T., Krumlauf, M., Reger, R.N., Wallen, G.R., Shamburek, R., & Pacak, K. (2016). *Documenting stress in caregivers of transplantation patients: Initial evidence of HPA dysregulation*. *Stress*, 19(2), 175–184. Doi: 10.3109/10253890.2016.1146670.

<sup>15</sup>Beattie, S., & Lebel, S. (2011). Doi: 10.1002/pon.1962.

<sup>16</sup>Glaze, J., Brooten, D., Youngblut, J., Hannan, J., & Page, T. (2021). *The lived experiences of caregivers of lung transplant recipients*. *Progress in Transplantation*, 31(4), 299–304. Doi: 10.1177/15269248211046034.

<sup>17</sup>Wulff-Burchfield, E.M., M. Jagasia, & B.N. Savani. (2013). *Long-term follow-up of informal caregivers after allo-SCT: A systematic review*. *Bone Marrow Transplantation*, 48(4), 469–473. Doi: 10.1038/bmt.2012.123.

<sup>18</sup>Jesse, 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: Official Journal of the American Society of Transplantation and the American Society of Transplant Surgeons*, 21(3), 950–957. <https://doi.org/10.1111/ajt.16315>.

<sup>19</sup>Health Resources and Services Administration. (2023, March). *HRSA Announces Organ Procurement and Transplantation Network Modernization Initiative*. <https://www.hrsa.gov/about/news/press-releases/organ-procurement-transplantation-network-modernization-initiative>.

# Methodology

To further understand the needs of transplant caregivers NAC conducted: (1) a literature review, (2) a subject matter expert panel, (3) focus groups with family caregivers, and (4) oral histories with family caregivers. A description of each method and a visualization of the process follows.

## Literature Review

NAC conducted a review of the existing literature on transplant caregivers by extracting and integrating information from peer-reviewed original articles and systematic reviews. Findings were then analyzed to identify cross-cutting themes (see Appendix B).

## Subject Matter Expert Panel

NAC gathered 10 subject matter experts representing various transplant organizations, including: advocacy, professional societies, healthcare systems, and academic institutions. Participants were experienced patient advocates, social workers, nurses, pharmacists, psychologists, financial coordinators, and physicians.

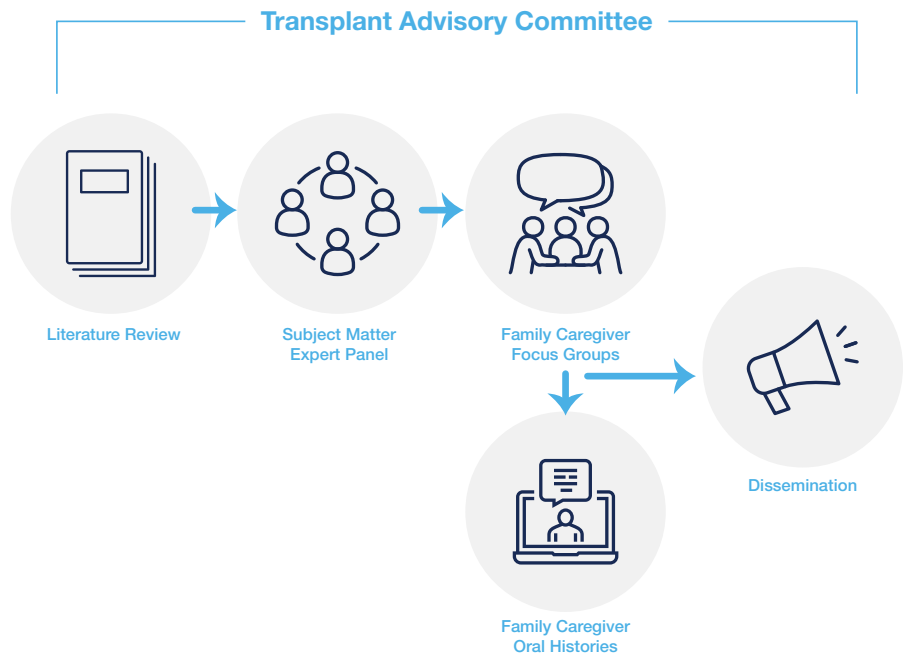
Experts were then engaged in two activities: a survey and a panel. The purpose of the survey was to understand expert perspectives surrounding pre-transplant practices including screening, resources, and supports. The panel aimed to understand post-transplant resources and support.

## Family Caregiver Focus Groups

In partnership with Schlesinger Group, five, two-hour focus groups were conducted to examine transplant caregivers' experiences, difficulties, support received, perceptions of support, perceptions of support barriers, and suggested solutions to barriers. Participants (N=30) were represented across age, race/ethnicity, income status, geographic location, sexual orientation, gender identity, stage of transplant process, and relationship with transplant recipient.

## Oral Histories with Transplant Family Caregivers

NAC frequently conducts oral histories with family caregivers. For this project, NAC spoke to twelve caregivers for 60 minutes each about their day-to-day experience of being a transplant caregiver. Caregivers represented diverse race/ethnicity, gender, age, relationship with the transplant recipient, and type of transplant. These oral histories were summarized into written vignettes. This report weaves three of these vignettes (Brian, Yang, and Jeanne) to offer further insights into the challenges that affect transplant caregivers, and the supports and services they hope to see implemented to make the process easier for future caregivers. All other vignettes are provided in Appendix D, or they can be watched on the [National Alliance for Caregiving's YouTube channel](#).



**Participants (N=30) were represented across age, race/ethnicity, income status, geographic location, sexual orientation, gender identity, stage of transplant process, and relationship with transplant recipient.**

# Literature Review



**The purpose of the literature review was to gain an understanding of the transplant caregiver landscape by examining transplant caregivers' experiences and any interventions that have been developed and evaluated to assist them. Two persistent and cross-cutting themes emerged from the literature: mental health and well-being and equity.**

This analysis of the literature reveals the significant mental health and well-being and equity challenges that persist due to the ongoing nature of transplant caregiving and the individual and contextual needs of transplant recipients and caregivers. However, it also identifies opportunities to reduce such challenges so that clinicians and care teams can optimally support transplant caregivers.

## Mental Health and Well-Being

Transplant caregivers face risks for mental, emotional, and social health (e.g., psychosocial) consequences that can impact their long-term well-being and their transplant recipient's success post-transplant. In some cases, caregivers report benefits and growth. There is a need to provide caregivers with resources to reduce distress and bolster positive outcomes.

Caregivers may notice distress at many points during the transplant journey, from diagnosis, the waiting period, or leading up to and after transplantation; the time right around the transplant is thought to be most stressful. This phase appears to be characterized by anxiety, depression, and PTSD. However, very few studies have followed caregivers beyond the one-year post-transplant point despite evidence that suggests caregiver distress may be highest in the months to years following transplant.<sup>20</sup> For example, one study found

**Transplant caregivers face risks for mental, emotional, and social health (e.g., psychosocial) consequences that can impact their long-term well-being and their transplant recipient's success post-transplant.**

<sup>20</sup>Wulff-Burchfield, E. M., Jagasia, M., & Savani, B. N. (2013). Doi: 10.1038/bmt.2012.123.

that when reassessing caregivers 4–10 years after transplantation, burden, stress, and depression significantly increased from baseline. It is often the case that caregivers only recognize the distress associated with their family member's illness experience after the height of their treatment, since during treatment they are focused on the patient's needs rather than their own. Thus, there is a critical need to support transplant caregivers long after the initial treatment.

Caregivers of transplant recipients report psychological distress at the same levels as—or even higher than—patients. Specific mental health challenges include stress, burden, fatigue, anxiety, depression, worry, and PTSD.<sup>21,22,23,24,25</sup> This distress not only has a negative impact on the caregivers' day-to-day functioning but can also impair their ability to carry out caregiving responsibilities, thus potentially affecting patient outcomes too. Increases in stress over time can transform from solely psychological to physical manifestations.<sup>26</sup> Indeed, caregivers are at risk for physical health consequences as their psychological dysfunction is associated with poor physical health and quality of life including sleep difficulties,<sup>27,28</sup> fatigue,<sup>29</sup> cardiovascular disease,<sup>30</sup> and increased mortality risk.<sup>31</sup>

Yet, caregiver and patient experiences appear to relate to each other. For example, psychological distress and burden have been correlated longitudinally in transplant patients and their caregivers where higher distress among caregivers, including anxiety and depression, has been shown to predict inferior quality of care provided to patients leading to poor patient health outcomes.<sup>32</sup> Higher distress among caregivers, including anxiety and depression, has been shown to predict inferior quality of care provided to patients and subsequently leads to poor patient health outcomes. Similarly, patient outcomes are associated with caregivers' anxiety, depression, and quality of life. To illustrate, transplant caregiver depression was associated with their patient's quality of life.<sup>33</sup> Additionally, better sleep quality in transplant caregivers has been related to earlier neutrophil engraftment, a marker of faster stem cell transplant success in patients,<sup>34</sup> suggesting that caregiver experiences may even relate to transplant outcomes.



**Caregivers of transplant recipients report psychological distress at the same levels as—or even higher than—patients.**

<sup>21</sup>Applebaum, A. J., Bevans, M., Son, T., Evans, K., Hernandez, M., Giral, S., & DuHamel, K. (2016). <https://doi.org/10.1038/bmt.2016.164>.

<sup>22</sup>Beattie, S., & Lebel, S. (2011). Doi: 10.1002/pon.1962.

<sup>23</sup>Bevans, M. F., Ross, A., Wehrlen, L., Klagholz, S. D., Yang, L., Childs, R., Flynn, S.L., Remaley, A.T., Krumlauf, M., Reger, R.N., Wallen, G.R., Shamburek, R., & Pacak, K. (2016). Doi: 10.1002/pon.1962.

<sup>24</sup>Langer, S., Lehane, C., & Yi, J. (2017). Doi: 10.1007/s11899-017-0391-0.

<sup>25</sup>Liang, J., Lee, S.J., Storer, B.E., Shaw, B.E., Chow, E.J., Flowers, M.E., Krakow, E.F., Bar, M., Syrjala, K.L., Salit, R.B., Kurukulasuriya, C.E., & Jim, H.S.L. (2019). Rates and risk factors for post-traumatic stress disorder symptomatology among adult hematopoietic cell transplant recipients and their informal caregivers. *Biology of Blood and Marrow Transplantation*, 25(1), 145-150. Doi: 10.1016/j.bbmt.2018.08.002.

<sup>26</sup>Virches, A., Miyazaki, E. T., dos Santos Junior, R., Duca, W. J., da Silva Fucuta, P., Ferreira da Silva, R., de Cássia Martins Alves da Silva, R., Basso, B. P., Micelli Domingos, N. A., & de Oliveira Santos Miyazaki, M. C. (2021). Burden, stress, and depression in informal caregivers of patients pre and post liver transplant. *Transplantation Proceedings*, 53(1), 233–238. <https://doi.org/10.1016/J.TRANSPROCEED.2020.02.072>.

<sup>27</sup>Ross, A., Yang, L., Klagholz, S. D., Wehrlen, L., & Bevans, M. F. (2016). The relationship of health behaviors with sleep and fatigue in transplant caregivers. *Psycho-Oncology*, 25(5), 506–12. Doi: 10.1002/pon.3860.

<sup>28</sup>Sannes, T.S., Mikulich-Gilbertson, S.K., Natvig, C.L., Brewer, B.W., Simoneau, T.L., & Laudenslager, M.L. (2018). Caregiver sleep and patient neutrophil engraftment in allogeneic hematopoietic stem cell transplant. *Cancer Nursing*, 41(1), 77–85. Doi: 10.1097/NCC.0000000000000447.

<sup>29</sup>Ibid.

<sup>30</sup>Myaskovsky, L., Posluszny, D. M., Schulz, R., DiMartini, A. F., Switzer, G. E., Dabbs, A. D., McNulty, M.L., Kormos, R.L., Toyoda, Y., & Dew, M. A. (2012). Predictors and outcomes of health-related quality of life in caregivers of cardiothoracic transplant recipients. *American Journal of Transplantation*, 12(12), 3387–97. Doi: 10.1111/j.1600-6143.2012.04243.x.

<sup>31</sup>Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *Jama*, 282(23), 2215–19. Doi: 10.1001/jama.282.23.2215.

<sup>32</sup>Sannes, T. S., Ranby, K. W., Yusuf, M., Brewer, B. W., Jacobs, J. M., Callan, S., Ulrich, G.R., Pensak, N.A., Natvig, C., & Laudenslager, M. L. (2022). More often than not, we're in sync: patient and caregiver well-being over time in stem cell transplantation. *Health and Quality of Life Outcomes*, 20(6), 1-10. <https://doi.org/10.1186/s12955-021-01909-3>.

<sup>33</sup>Sannes, T. S., Simoneau, T. L., Mikulich-Gilbertson, S. K., Natvig, C. L., Brewer, B. W., Kilbourn, K., & Laudenslager, M. L. (2019). Distress and quality of life in patient and caregiver dyads facing stem cell transplant: Identifying overlap and unique contributions. *Supportive Care in Cancer*, 27(6), 2329-2337. Doi: 10.1007/s00520-018-4496-3.

<sup>34</sup>Sannes, T.S., Mikulich-Gilbertson, S.K., Natvig, C.L., Brewer, B.W., Simoneau, T.L., & Laudenslager, M.L. (2018). Doi: 10.1097/NCC.0000000000000447.

Another source of stress during the post-transplant phase surrounds financial strain—time off work, lost wages, exhausting PTO, insurance coverage challenges, and uncertainty about the future.<sup>35,36,37</sup> Hidden sources of financial stress, such as hospitalization costs, parking, legal, and medication costs, including refills, also contribute to feelings of anxiety, depression, and worry.<sup>38,39,40</sup> In fact, 45 percent of caregivers who had to limit their work hours experienced higher levels of depression and anxiety related to lost income. Interestingly, while caregivers reported receiving managerial support related to work absence due to caregiving, this was juxtaposed with frequent inquiries about when the caregiver would be returning to work and no change in workload, which ultimately exacerbated stress.<sup>41</sup>

Underrecognized challenges to the mental health experience of transplant caregivers can also include a shift in social roles, changes in relationships, and an increase in isolation. For transplant caregivers who are parents, the added challenge of being both a parent and supportive caregiver is a source of conflict that creates stress and causes feelings of overwhelm.<sup>42</sup> Due in part to the vulnerability of transplant patients, caregivers also report social isolation.<sup>43</sup> Caregivers may even feel isolated from the care team and the type of informational support they need, which creates a recurring dynamic of stress when caregivers are unsure who to contact when unexpected needs or complications arise, or when they need to navigate coordinating appointments across multiple specialty departments.<sup>44</sup>

Despite varied mental health challenges for transplant caregivers, not all experiences are detrimental. Some transplant caregivers report satisfaction with their level of care, feelings of preparation, having someone to talk to, as well as varied levels of emotional support.<sup>45</sup> Some caregivers even report positive mental health outcomes and benefits as a result of caregiving.<sup>46</sup> For example, transplant caregivers experience post-traumatic growth as indicated by enhanced ability to live in the moment, feelings of honor and pride, and personal and/or spiritual connection.<sup>47</sup>

## Equity

The burden of transplant caregiving is inequitable, with caregivers from socioeconomically disadvantaged and diverse racial and ethnic background facing exacerbated challenges, yet most of what we know about transplant caregiving is from studies conducted in non-Latino white, formally-educated caregivers.

While the impact of transplant caregiving is a difficult and demanding journey, not all caregivers or transplant recipients experience the same challenges. For example, the fact that African American/Black patients receive fewer transplants despite similar preferences<sup>48</sup>



**45 percent of caregivers who had to limit their work hours experienced higher levels of depression and anxiety related to lost income.**

<sup>35</sup>Ibid.

<sup>36</sup>Wadhwanii, S. I., Barrera, A. G., Shifman, H. P., Baker, E., Bucuvalas, J., Gottlieb, L. M., Kotagal, U., Rhee, S. J., Lai, J. C., & Lyles, C. R. (2022). <https://doi.org/10.1002/LT.26498>.

<sup>37</sup>Yagelniski, A., Rosaasen, N., Cardinal, L., Fenton, M. E., Tam, J., & Mansell, H. (2020). A qualitative study to explore the needs of lung transplant caregivers. *Progress in Transplantation* 30(3), 243–48. <https://doi.org/10.1177/1526924820933842>.

<sup>38</sup>Cushman, G. K., Rich, K. L., Rea, K. E., Quast, L. F., Stolz, M. G., Gutierrez-Colina, A. M., Eaton, C. K., Lee, J. L., Mee, L. L., George, R., & Blount, R. L. (2020). <https://doi.org/10.1093/JPEPSY/JSAA023>.

<sup>39</sup>Pawlow, P. C., Blumenthal, N. P., Christie, J. D., Matura, L. A., Aryal, S., & Ersek, M. (2021). <https://doi.org/10.1016/J.JPAINSYMMAN.2021.05.004>.

<sup>40</sup>Wadhwanii, S. I., Barrera, A. G., Shifman, H. P., Baker, E., Bucuvalas, J., Gottlieb, L. M., Kotagal, U., Rhee, S. J., Lai, J. C., & Lyles, C. R. (2022). <https://doi.org/10.1002/LT.26498>.

<sup>41</sup>Ibid.

<sup>42</sup>Cushman, G. K., Rich, K. L., Rea, K. E., Quast, L. F., Stolz, M. G., Gutierrez-Colina, A. M., Eaton, C. K., Lee, J. L., Mee, L. L., George, R., & Blount, R. L. (2020). Caregivers' barriers to facilitating medication adherence in adolescents/young adults with solid organ transplants: Measure development and validation. *Journal of Pediatric Psychology*, 45(5), 498–508. <https://doi.org/10.1093/JPEPSY/JSAA023>.

<sup>43</sup>Wadhwanii, S. I., Barrera, A. G., Shifman, H. P., Baker, E., Bucuvalas, J., Gottlieb, L. M., Kotagal, U., Rhee, S. J., Lai, J. C., & Lyles, C. R. (2022). Caregiver perspectives on the everyday medical and social needs of long-term pediatric liver transplant patients. *Liver Transplantation: Official Publication of the American Association for the Study of Liver Diseases and the International Liver Transplantation Society*, 28(11), 1735–46. <https://doi.org/10.1002/LT.26498>.

<sup>44</sup>Pawlow, P. C., Blumenthal, N. P., Christie, J. D., Matura, L. A., Aryal, S., & Ersek, M. (2021a). The supportive care needs of primary caregivers of lung transplant candidates. *Journal of Pain and Symptom Management*, 62(5), 918–926. <https://doi.org/10.1016/J.JPAINSYMMAN.2021.05.004>.

<sup>45</sup>Harvey, J., & Berndt, M. (2021). <https://doi.org/10.1080/10615806.2020.1845432>.

<sup>46</sup>Chen, Y. H., Lee, W. C., Kao, Y. Y., Chen, L. C., Ho, L. H., & Shih, W. M. (2022). The post-traumatic growth of primary caregivers of patients after liver transplantation. *Healthcare*, 10(9), 1617. Doi: 10.3390/healthcare10091617.

<sup>47</sup>Harvey, J., & Berndt, M. (2021). <https://doi.org/10.1080/10615806.2020.1845432>.

<sup>48</sup>Cascino, T. M., Colvin, M. M., Lanfer, D. E., Richards, B., Khalatbari, S., Mann, D. L., Taddei-Peters, W. C., Jeffries, N., Watkins, D. C., Stewart, G. C., & Aaronson, K. D. (2023). Racial inequities in access to ventricular assist device and transplant persist after consideration for preferences for care: A report from the REVIVAL study. *Circulation: Heart Failure*, 16(1), E009745. <https://doi.org/10.1161/CIRCHEARTFAILURE.122.009745>.



**A lack of access to information because it is not available, not in an appropriate language, or at a higher literacy level may also impede caregivers' ability to carry out care tasks.**

reinforces inequities and typifies barriers of access that impact racially and ethnically diverse caregivers who support patients.<sup>49</sup> In a study that revealed positive experiences throughout the transplant process, caregivers of color were not represented, and participants were primarily retired.<sup>50</sup> It is unknown how much access diverse racial and ethnic groups and socioeconomically disadvantaged caregivers have to positive experiences and benefits. Moreover, most studies evaluating interventions in caregivers (described below) were overwhelmingly conducted among white, female, and often highly educated patients and caregivers.<sup>51</sup> It is unclear whether the existing research can be applied to more diverse populations.

Another area of inequality is the cost of transplant, especially for caregivers who may be on a limited or fixed income. Housing, transportation, and medication expenses quickly accumulate and contribute to caregiver financial strain. These are particularly relevant when transplant centers are an average of seven hours away from patients' and caregivers' homes.<sup>52,53</sup> Additionally, adopting the caregiver role can hinder the ability to work, resulting in substantial lost income.

A lack of access to information because it is not available, not in an appropriate language, or at a higher literacy level may also impede caregivers' ability to carry out care tasks. Thus, the challenges associated with following complex medication regimens (for which caregivers are primarily responsible) may negatively influence the patient's medication adherence. Given the physical isolation that is often required in the post-transplant period, caregivers are likely to face even greater challenges staying connected to the support and information necessary to provide an optimal level of care for their transplant recipient and themselves. Recommendations for hematopoietic cell transplantation demonstrate promise to screen, educate, train, refer to psychosocial intervention, and ultimately better support caregivers across the transplant space.<sup>54</sup>

Studies suggest that socioeconomic challenges (i.e., low socioeconomic status and lower levels of formal education) mediate longer-term mental health and well-being of caregivers. For example, socioeconomic status has been linked to transplant caregiver quality of life, with caregivers of lower educational status reporting poorer quality of life and higher burden.<sup>55,56</sup> These results suggest interventions should aim to target socioeconomically

**Educational and supportive interventions have been shown to help improve transplant caregivers' mental and physical health. These must be flexibly delivered to caregivers with barriers to accessing care.**

<sup>49</sup>Wadhwanii, S. I., Barrera, A. G., Shifman, H. P., Baker, E., Bucuvalas, J., Gottlieb, L. M., Kotagal, U., Rhee, S. J., Lai, J. C., & Lyles, C. R. (2022). <https://doi.org/10.1002/LT.26498>.

<sup>50</sup>Yagelniski, A., Rosaasen, N., Cardinal, L., Fenton, M. E., Tam, J., & Mansell, H. (2020). <https://doi.org/10.1177/1526924820933842>.

<sup>51</sup>Langer, S., Lehane, C., & Yi, J. (2017). Doi: 10.1007/s11899-017-0391-0.

<sup>52</sup>Wadhwanii, S. I., Barrera, A. G., Shifman, H. P., Baker, E., Bucuvalas, J., Gottlieb, L. M., Kotagal, U., Rhee, S. J., Lai, J. C., & Lyles, C. R. (2022). <https://doi.org/10.1002/LT.26498>.

<sup>53</sup>Yagelniski, A., Rosaasen, N., Cardinal, L., Fenton, M. E., Tam, J., & Mansell, H. (2020). <https://doi.org/10.1177/1526924820933842>.

<sup>54</sup>Applebaum, 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). <https://doi.org/10.1016/J.JTCT.2022.12.014>.

<sup>55</sup>Jamani, K., Onstad, L. E., Bar, M., Carpenter, P. A., Krakow, E. F., Salit, R. B., Flowers, M.E.D., & Lee, S. J. (2018). Quality of life of caregivers of hematopoietic cell transplant recipients. *Biology of Blood and Marrow Transplantation*, 24(11), 2271-2276. Doi: 10.1016/j.bbmt.2018.06.015.

<sup>56</sup>Shrestha, D., Rathi, S., Grover, S., Taneja, S., Duseja, A., Chawla, Y. K., & Dhiman, R. K. (2020). Factors affecting psychological burden on the informal caregiver of patients with cirrhosis: Looking beyond the patient. *Journal of Clinical and Experimental Hepatology*, 10(1), 9-16. Doi: 10.1016/j.jceh.2019.06.002.

disadvantaged caregivers and clinicians; healthcare teams must ensure screening tools and educational materials are an appropriate literacy level, as well as linguistically and culturally responsive.

## Interventions

Educational and supportive interventions have been shown to help improve transplant caregivers' mental and physical health. These must be flexibly delivered to caregivers with barriers to accessing care.

There is an opportunity for targeted educational, behavioral, and supportive interventions for transplant caregivers and patients. Interventions can prepare recipients and their caregivers for the transplant experience, which can prevent poor psychosocial (i.e., mental, emotional, and social health) outcomes. Additionally, interventions can teach coping skills and provide support for caregivers managing emotional distress from their family member's illness and transplant and their caregiver role. Most transplant caregiver interventions focus on providing transplant-related education to the patient and caregiver.<sup>57,58</sup> For example, some evidence suggests that educational and psychosocial interventions for caregivers can reduce negative outcomes such as psychological distress and fatigue and decreased mental health service use.<sup>59</sup> Others have aimed to provide mental health support, including empirically-supported stress management interventions,<sup>60,61,62</sup> problem-solving,<sup>63</sup> and peer-support interventions.<sup>64</sup>

Stress management interventions show evidence for reducing distress, depression, and anxiety three months post-hematopoietic stem cell transplantation,<sup>65</sup> and even stress biomarkers modification, an indication of better physiological adaptation to illness.<sup>66</sup> Cognitive behavioral stress management was linked to lower distress, depression, and anxiety three months post-transplant.<sup>67</sup> However, the overall support for these interventions is not robust and some of the interventions deemed feasible or accepted failed to reduce distress.<sup>68</sup> With these results in mind, it has been proposed that caregivers routinely and standardly receive education prior to interventions on symptom management, medication adherence, how to monitor for complications and side effects, and how to safely conduct nursing tasks.<sup>69</sup>

Some evidence suggests that educational and psychosocial interventions for caregivers can reduce negative outcomes such as psychological distress and fatigue and decreased mental health service use.<sup>6</sup>



<sup>57</sup>Bangerter, L. R., Griffin, J. M., Langer, S., Hasan, B., Kim, W., Murad, M. H., & Khera, N. (2018). The effect of psychosocial interventions on outcomes for caregivers of hematopoietic cell transplant patients. *Current Hematologic Malignancy Reports*, 13, 155-163. Doi: 10.1007/s11899-018-0445-y.

<sup>58</sup>Jesse, M. T., Gartrelle, K., Brusichweine, H., Hug, G., LeTarte, B., Lerret, S., & Dew, M. A. (2022). Doi: 10.1111/ctr.14611.

<sup>59</sup>Bangerter, L. R., Griffin, J. M., Langer, S., Hasan, B., Kim, W., Murad, M. H., & Khera, N. (2018). Doi: 10.1007/s11899-018-0445-y.

<sup>60</sup>Laudenslager, M. L., Simoneau, T. L., Mikulich-Gilbertson, S. K., Natvig, C., Brewer, B. W., Sannes, T. S., Kilbourn, K., Gutman, J., & McSweeney, P. (2019). A randomized control trial of stress management for caregivers of stem cell transplant patients: Effect on patient quality of life and caregiver distress. *Psycho-oncology*, 28(8), 1614-23. Doi: 10.1002/pon.5126.

<sup>61</sup>Pensak, N. A., Joshi, T., Simoneau, T., Kilbourn, K., Carr, A., Kutner, J., & Laudenslager, M. L. (2017). Development of a web-based intervention for addressing distress in caregivers of patients receiving stem cell transplants: Formative evaluation with qualitative interviews and focus groups. *JMIR Research Protocols*, 6(6), e7075. Doi: 10.2196/resprot.7075.

<sup>62</sup>Ravyts, S. G., Sannes, T. S., Dzierzewski, J. M., Zhou, E. S., Brewer, B. W., Natvig, C., & Laudenslager, M. L. (2021). Check your sleep before you start: A secondary analysis of a stress management intervention for caregivers of stem cell transplant patients. *Psycho-Oncology*, 30(6), 936-45. Doi: 10.1002/pon.5680.

<sup>63</sup>Bevans, M., Wehrlen, L., Castro, K., Prince, P., Shelburne, N., Soeken, K., Zabora, J., & Wallen, G. R. (2014). A problem-solving education intervention in caregivers and patients during allogeneic hematopoietic stem cell transplantation. *Journal of Health Psychology*, 19(5), 602-617. Doi: 10.1177/1359105313475902.

<sup>64</sup>Giordano, T., Esq, J. L. W., & Nathan, H. M. (2018). Assessing the impact of an online support group on the emotional health of transplant caregivers. *Transplantation*, 102, S309. Doi: 10.1097/01.tp.0000543027.85949.6c.

<sup>65</sup>Laudenslager, M. L., Sannes, T. S., Phillips, S. J., Simoneau, T. L., Lin, J., Epel, E., & Blackburn, E. (2015). Telomere length in caregivers of allogeneic hematopoietic stem cell transplant patients: Relationship to psychological distress and aging. *Brain, Behavior, and Immunity*, 49, e25. <https://doi.org/10.1016/j.bbi.2015.06.104>.

<sup>66</sup>Laudenslager, M. L., Simoneau, T. L., Phillips, S., Benitez, P., Natvig, C., & Cole, S. (2016). A randomized controlled pilot study of inflammatory gene expression in response to a stress management intervention for stem cell transplant caregivers. *Journal of Behavioral Medicine*, 39(2), 346-54. Doi: 10.1007/s10865-015-9709-3.

<sup>67</sup>Laudenslager, M. L., Simoneau, T. L., Mikulich-Gilbertson, S. K., Natvig, C., Brewer, B. W., Sannes, T. S., Kilbourn, K., Gutman, J., & McSweeney, P. (2019). Doi: 10.1002/pon.5126.

<sup>68</sup>Langer, S. L., Kelly, T. H., Storer, B. E., Hall, S. P., Lucas, H. G., & Syrjala, K. L. (2012). Expressive talking among caregivers of hematopoietic stem cell transplant survivors: acceptability and concurrent subjective, objective, and physiologic indicators of emotion. *Journal of Psychosocial Oncology* 30(3), 294-315. Doi: 10.1080/07347332.2012.664255.

<sup>69</sup>Applebaum, 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). <https://doi.org/10.1016/J.JTCT.2022.12.014>.

Lastly, the COVID-19 pandemic underscored the necessity of remote interventions. Remote interventions are especially relevant in transplant patients and their caregivers who tend to be isolated. A tele-education intervention showed promise in teaching caregivers important nursing, medication management, and nutrition information.<sup>70</sup> Remotely-delivered mobile health interventions based in cognitive behavioral therapy are promising in transplant patients and require assessment in the transplant recipient and caregivers.<sup>71,72</sup> A peer-support group was delivered virtually for solid organ transplant caregivers and these caregivers reported comfort in engaging with the support group, reduced distress, and perceived support from other caregivers despite not being co-located.<sup>73</sup>



While most interventions have been delivered directly to the caregivers,<sup>74</sup> it is possible to include patients and caregivers in dyadic interventions.<sup>75</sup> A dyadic problem-solving intervention that included both patients and caregivers found that stress management skills, health behaviors, and caregiver confidence improve caregiver symptoms of emotional distress.<sup>76</sup> A family-focused intervention showed improved cohesion in the family unit but no effect on caregiver coping skills.<sup>77</sup> It is unclear whether models that engage both patient and caregiver at once are superior to patient or caregiver-only interventions. However, it is imperative that both patients and caregivers are offered education and support intervention referrals when appropriate.

Despite transplant caregivers' intervention being generally favorable, caregiver attrition tended to be high largely due to patient morbidity and mortality.<sup>78</sup> Moreover, interventions have generally not followed caregivers several years out from their transplant experience when they are still very vulnerable to psychosocial distress. There is also a need to examine strengths-based and meaning-centered interventions in transplant caregivers as potential modalities to foster posttraumatic growth and meaning-making.<sup>79</sup> Other targets of intervention may include coping and health behaviors, as poor health behaviors also contributed to poor sleep quality, more distress, and fatigue in caregivers.<sup>80</sup> Transplant caregivers' impaired sleep also contributed to their own psychological distress and fatigue,<sup>81</sup> supporting delivery of sleep interventions such as cognitive behavioral therapy for insomnia.

**A peer-support group was delivered virtually for solid organ transplant caregivers and these caregivers reported comfort in engaging with the support group, reduced distress, and perceived support from other caregivers despite not being co-located.<sup>6</sup>**

<sup>70</sup>Amonoo, H. L. (2023). <https://doi.org/10.1016/J.JTCT.2022.12.014>.

Wickham, S. K., Solle, J. C., Emmert, A., Daniels, L., Pullo, A., & Close, S. (2021). Learning at home: Implementing an adaptable tele-education model for autologous transplant caregivers amidst a global pandemic. *Transplantation and Cellular Therapy*, 27(3), S185-S186. [https://doi.org/10.1016/S2666-6367\(21\)00228-1](https://doi.org/10.1016/S2666-6367(21)00228-1).

<sup>71</sup>DuHamel, K. N., Mosher, C. E., Winkel, G., Labay, L. E., Rini, C., Meschian, Y. M., Austin, J., Greene, P.B., Lawsin, C.R., Rusiewicz, A., Grosskreutz, C.L., Isola, L., Moskowitz, C.H., Papadopoulos, E.B., Rowley, S., Scigliano, E., Burkhalter, J.E., Hurley, K.E., Bollinger, A.R., & Redd, W. H. (2010). Randomized clinical trial of telephone-administered cognitive-behavioral therapy to reduce post-traumatic stress disorder and distress symptoms after hematopoietic stem-cell transplantation. *Journal of Clinical Oncology*, 28(23), 3754. Doi: 10.1200/JCO.2009.26.8722.

<sup>72</sup>Mitchell, H. R., Smith, S. K., Gebert, R., & Applebaum, A. J. (2022). Mobile cognitive behavioral therapy for posttraumatic stress: Diving back in after hematopoietic stem cell transplant. *Psycho-oncology*, 31(10), 1802. Doi: 10.1002/pon.6022.

<sup>73</sup>Giordano, T., Esq, J. L. W., & Nathan, H. M. (2018). Doi: 10.1097/01.tp.0000543027.85949.6c.

<sup>74</sup>Bangerter, L. R., Griffin, J. M., Langer, S., Hasan, B., Kim, W., Murad, M. H., & Khera, N. (2018). Doi: 10.1007/s11899-018-0445-y.

<sup>75</sup>Langer, S., Lehane, C., & Yi, J. (2017). Doi: 10.1007/s11899-017-0391-0.

<sup>76</sup>Bevans, M. F., Castro, K., Wehrlen, L., Prince, P., Prachenko, O., Zabora, J., & Wallen, G. (2010). Healthy lifestyles may improve transplant caregiver outcomes. *Biology of Blood and Marrow Transplantation*, 16(2), S193. <https://doi.org/10.1016/j.bbmt.2009.12.127>.

<sup>77</sup>Fife, B.L., Von Ah, D.M., Spath, M.L., Weaver, M.T., Yang, Z., Stump, T., & Farag, S. (2017). Preliminary efficacy of a brief family intervention to prevent declining quality of life secondary to parental bone marrow transplantation. *Bone Marrow Transplant*, 52(2), 285-291. Doi: 10.1038/bmt.2016.267.

<sup>78</sup>Bangerter, L. R., Griffin, J. M., Langer, S., Hasan, B., Kim, W., Murad, M. H., & Khera, N. (2018). Doi: 10.1007/s11899-018-0445-y.

<sup>79</sup>Applebaum, A. J., Bevans, M., Son, T., Evans, K., Hernandez, M., Giralt, S., & DuHamel, K. (2016). <https://doi.org/10.1038/bmt.2016.164>

<sup>80</sup>Ross, A., Yang, L., Klagholz, S. D., Wehrlen, L., & Bevans, M. F. (2016). The relationship of health behaviors with sleep and fatigue in transplant caregivers. *Psycho-Oncology*, 25(5), 506-12. Doi: 10.1002/pon.3860.

<sup>81</sup>Bevans, M. F., Castro, K., Wehrlen, L., Prince, P., Prachenko, O., Zabora, J., & Wallen, G. (2010). <https://doi.org/10.1016/j.bbmt.2009.12.127>.



Overall, reviews of the studies on transplant caregiver interventions have identified a scarcity of literature and a need for more research on interventions.<sup>82,83</sup> Nonetheless, there is promise for stress management and education as modalities to increase caregiver confidence and reduce their psychosocial distress. Treatment centers should be prepared to refer caregivers of transplant patients to psychosocial support.

**Providers should deliver interventions flexibly to caregivers who are often physically isolated.**



## Brian

*Brian was the caregiver for his wife, who needed a kidney transplant a few years ago. Brian and his wife went through extreme challenges to get her a kidney. They were on the waitlist in Minnesota and were called almost immediately, but the kidney wasn't viable. Because they had gotten the first call so fast they assumed another kidney would quickly be found, so they left their lives in Connecticut to live in Minnesota. They eventually moved back to Connecticut when no kidney was found. In Minnesota, they experienced about 10–15 calls for non-viable kidneys, reducing their morale and resulting in feelings of helplessness and hopelessness.*

*Brian and his wife faced constant setbacks while waiting for a kidney transplant call. His wife experienced medical complications like falls or mini strokes that would cause her to be removed from the waitlist. Brian would nurse her back to an acceptable health to be re-listed for a kidney.*

*Brian did not receive any help from the transplant medical team. Becoming his wife's caregiver and care coordinator became Brian's full-time job, and he ended up taking a layoff from work. He learned a lot about caregiving "on the fly" and through 9-1-1 calls. Based on his experience, Brian believes there needs to be some coordination among transplant centers. As someone who had to take care of all his wife's paperwork moving through multiple centers and waiting for a kidney, he thinks there could have been better communication that would have reduced his workload. He also believes caregivers need workplace protection and financial support, especially when it comes to travel.*

*Brian's experience highlights the need to provide caregivers with a roadmap describing the transplant process and the relevant members of the care team and sources of support so they know what to expect and where they can go to for support. See Appendix D for Brian's full story.*

<sup>82</sup>Jesse, M. T., Gartrelle, K., Bruschein, H., Hug, G., LeTarte, B., Lerret, S., & Dew, M. A. (2022). Doi: 10.1111/ctr.14611.

<sup>83</sup>Langer, S., Lehane, C., & Yi, J. (2017). Doi: 10.1007/s11899-017-0391-0.

# Subject Matter Expert Panel



NAC surveyed and spoke to a panel of subject matter experts in the transplant field to gain an understanding of the resources and supports currently available to caregivers pre- and post-transplant, as well as opportunities for potential improvements. The expert panelists illustrated the challenge of the transplant journey with two primary takeaways:




1. Resources that support both caregivers and transplant patients (e.g., meetings with the transplant/health care team, services, education) are accessible and available during the pre-transplant phase but decline dramatically after transplantation.

The panel spoke about the need to raise awareness surrounding the caregiver role during the entire transplant process, allowing for more caregiver specific preparation and a readied mindset.

The table on the next page maps the resources the panel identified as available along with suggestions for additional supports and services for caregivers. The panel spoke about the need to raise awareness surrounding the caregiver role during the entire transplant process, allowing for more caregiver specific preparation and a readied mindset.

	Education & Information Resources		Financial Resources		Caregiver Mental & Social Health	
	AVAILABLE	NEEDED	AVAILABLE	NEEDED	AVAILABLE	NEEDED
<b>PRE-Transplant</b>	<p>Educational information provided to the caregiver alongside the patient.</p> <p>Transplant coordinator and/or social worker available to both the transplant recipient and caregiver.</p>	<p>A care package geared specifically towards the caregiver.</p> <p>Increased awareness about the need for a caregiver during the process.</p> <p>Meetings between the caregiver and the transplant team to inform, prepare, and set expectations for the transplant caregiver.</p>	None available	Financial assistance options through grants and donations from hospitals.	<p>Little to no resources dedicated to caregiver’s physical and mental health.</p> <p>Peer support programs in some centers.</p>	<p>An increased awareness and focus on the needs (e.g., mental health, social) of caregivers.</p> <p>Evaluation and coordination to connect caregivers to mental health resources within the transplant center/ health system.</p> <p>Referrals and linkages to external resources and support.</p> <p>Implementing palliative care programming into the process.</p>
<b>POST-Transplant</b>	<p>Little to no specific resources planned post-transplant unless requested by the caregiver.</p> <p>When available, educational resources focused on simulations of medication regimes and medical tasks training.</p>	<p>Family meetings</p> <p>Resources to help caregivers adapt into their new way of living.</p>	None available	Financial assistance options through grants and donations from hospitals.	Peer connect programs*	<p>Centers integrating routine, standardized assessments and screening aimed at the caregiver’s mental health.</p> <p>Normalize palliative care.</p>

\*Some centers and many organizations also offer peer connect programs, in which caregivers and patients connect with other caregivers and patients further along in their transplant journey who can answer questions and offer advice.



**2. The transplant system can and should play a bigger role in establishing caregiver support and resources.**

Understandably, the current emphasis is on the transplant recipient; however, this also means that caregivers are offered “what’s available.” This broad approach isn’t individualized or intentional, resulting in limited and declining support unless a patient speaks up on behalf of their caregiver, or the patient misses an appointment because of unmet caregiver need(s). Adopting a multidisciplinary focus on caregivers would allow transplant teams to provide support to both transplant patients and caregivers at each step of the process. Examples of specific caregiver support programs and services could include:

- Developing and disseminating caregiver specific educational and information resources (e.g., caregiving packets) that acknowledge the critical role of the caregiver and adequately prepare caregivers for the complex and ongoing requirements of being a transplant caregiver.

**Adopting a multidisciplinary focus on caregivers would allow transplant teams to provide support to both transplant patients and caregivers at each step of the process.**

- A 24-hour hotline to a care coordinator, social worker, or nurse. It would allow a designated space for caregivers to get information from knowledgeable parties. A 24-hour hotline model is already in place in a pediatric transplant center represented in the panel.
- Coordination and connections to external support and services for both the patient and caregiver. For example, Be the Match is an organization that works with stem cell and bone marrow transplant patients and their caregivers, often filling in education gaps with resources a transplant center does not provide. This includes tools like an online library of resources organized by topic.

System-wide change is needed to better support transplant caregivers. For example, all panelists agreed that additional resources (e.g., time, staff) would have to be dedicated to caregivers to support their mental health needs. With these additional resources, centers could incorporate psychological evaluations, provide wide access to counselors with expertise in transplant or caregiving, and connect caregivers to religious or spiritual supporters. Interestingly, pediatric transplant programs seem to have the most support for caregivers, likely because in cases of children receiving a transplant, the caregiver is often a parent or guardian.

It is important to note that the panelists also highlighted policy barriers to providing or expanding support for transplant caregivers. Like most caregivers, many transplant caregivers are working while providing care, further increasing their stress and burden. Sixty-one percent of caregivers report working while providing care; however, they are forced to make adjustments to their work situation as a result of caregiving, including going late, leaving early, and taking time off.<sup>84</sup> Policy changes could be made to ensure caregivers keep their job if they must take a leave of absence and that they continue to be reimbursed for a defined period. These reimbursements could possibly come through the transplant patient's health insurance.

**System-wide change is needed to better support transplant caregivers.**

<sup>84</sup>National Alliance for Caregiving & AARP. (2020, May). Caregiving in the U.S. 2020. Retrieved November 1, 2023 from [https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316\\_RPT\\_CaregivingintheUS\\_WEB.pdf](https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316_RPT_CaregivingintheUS_WEB.pdf).

## Jeanne

*Jeanne has been caring for her daughter since she was very young. As a child, a viral infection attacked her daughter's heart, causing her to need a heart transplant; in 2020 as a young adult, Jeanne's daughter needed a kidney transplant as well. Jeanne has been her daughter's caregiver since the heart transplant, and she was the living donor for her daughter's kidney transplant.*

*Much of the time Jeanne felt like she was flying by the seat of her pants. She did not get much education from the healthcare team, except on the medication her daughter would need after her 9-month stay in the hospital post heart transplant. When doctors told Jeanne her daughter was ready to go home, she was terrified about her ability to continue to heal without medical machines and professionals.*

*While pre-transplant seems like a blur now, post-transplant was the hardest time for Jeanne as a caregiver. It took her a year or two post-transplant to address and realize what she had gone through while her daughter was in the hospital. Jeanne had to resign from her job to fully care for her daughter, a huge financial hit for her family. She was not offered financial support services from the hospital and the assigned social worker did not communicate with her about options. She believes the hospital may not have thought they looked like a family who needed help, and that the door was shut on her when they left the hospital.*

*Jeanne feels the medical team could have done more to support her. She suggested that transplant centers have a separate department just for caregivers to ensure they know there is information and support available to them. This department could provide relationships, financial and workplace support, and information. See Appendix D for Jeanne's full story.*

# Focus Groups With Transplant Caregivers



**NAC conducted focus groups with 30 transplant caregivers of both pre- and post- transplant recipients from diverse backgrounds of race/ethnicity, income status, geographic location, sexual orientation/gender identity, and age. Caregivers were asked about available support, access, and experiences with these supports.**

The experiences shared by caregivers in the focus groups were reflective of the literature and subject matter expert panel observations. Though there are some supports available to help ease the transplant caregiving process, caregivers are under-resourced and under-supported throughout the transplant and are certainly not provided enough information to prepare them for the years post-transplant.

The lived experiences of transplant caregivers highlight several areas for support, including: education and information resources; navigating the waitlist process; support drop-off; access and quality of care; the impact of caregiving on their mental and physical health; and financial strain. However, caregivers in these focus groups also provided suggestions to address their challenges. As caregivers are the ones living this journey, it is imperative that their voices are amplified, and that we listen and provide them with the support, tools, and resources they have requested.

**The lived experiences of transplant caregivers highlight several areas for support, including: education and information resources; navigating the waitlist process; support drop-off; access and quality of care; the impact of caregiving on their mental and physical health; and financial strain.**

## Key Insights

Transplant system barriers and challenges were mentioned most often by caregivers. The specific challenges that were consistently raised are: getting information, the waitlist process; post-transplant support; and access and quality of care throughout the entire process.

## Education and Information Resources

Caregivers said they found it difficult to receive both timely and relevant information, especially related to navigating the confusing and complicated transplant process. Often, they did not know what next to expect as their recipient moved through the system.

Caregivers also mentioned a lack of information around understanding their insurance coverage. They did not know what their insurance covered, why some costs were denied, or when they would receive pending reimbursements.



## Waitlists

Caregivers reported that the requirements, information, and communication surrounding waitlists were confusing and frustrating. Patients must be put on a waitlist to have a chance of receiving a transplant, and the ability to be on multiple waitlists means a higher chance of more quickly finding a viable organ or stem cell/marrow match. Waitlist requirements are different across transplant type, centers, regions, and states. Caregivers said these different rules and inconsistencies caused confusion and barred them from possible options they otherwise would have pursued. In addition, being on multiple waitlists meant a high number of appointments that were impractical to try to attend. Some caregivers said that they didn't even know their care recipient could be placed on multiple waitlists until much later in the process, causing feelings of frustration and regret over the possible lost time and what could have been.

Waitlists have strict health requirements to ensure patients are healthy enough to undergo a transplant. Caregivers reported they found it difficult to maintain their recipients' health and meet these requirements and were confused about what needed to be done to keep them on the waitlist, resulting in feelings of distress. The lack of updates and information during the waitlist process resulted in caregivers left wondering what was happening. They also reported persistently having to ask the medical team for a status report on when a transplant might take place, all while struggling to maintain their recipient's health.

**Caregivers reported they found it difficult to maintain their recipients' health and meet these requirements and were confused about what needed to be done to keep them on the waitlist, resulting in feelings of distress.**

## Drop-off in Support Post-Transplant

Caregivers shared that transplant teams were helpful early on with comprehensive support in appointment scheduling, and training (including access to social workers and/or mental health professionals). Information was provided for navigating the transplant process and at key moments, most noticeably while on, or attempting to get on, the waitlist. Once in the system, their care recipient's team was communicative and would make them aware of the transplant process and expectations. However, caregivers noticed a drop-off in support from the healthcare team ranging anywhere from 3 months to 1.5 years post-transplant. They would find that their medical team was smaller, with less resources available to them, and they were receiving fewer medical updates.

## Yang

*Yang has been caring for her son who was diagnosed with chronic heart failure at a young age. After several surgeries as a child, her son received a heart transplant in 2018 at the age of 15. Yang believes that caring for his chronic heart condition prepared her somewhat for being a transplant caregiver, although not completely. Even though the heart transplant was successful, Yang will be a caregiver for her son for life.*

*Once they left the Ronald McDonald House where they stayed during the transplant, Yang felt an acute support drop-off. Post-transplant, she did not know medical terms, and it was a time of great uncertainty for both her and her son. She felt like they were expected to go from beginner mode to expert mode immediately. When her son switched from pediatric to adult care, the support from the healthcare team became even more scarce. Yang was not provided any information or support on this transition and was completely overwhelmed by the system and what she should be doing.*

*Yang is grateful for the opportunity to care for her son, and for how close the experience has brought them. She has joined Transplant Recipients International Organization (TRIO) in the hope that she can help guide transplant caregivers through some of the challenges she has faced. As for the support she believes should be given to transplant caregivers, she states that there needs to be more casual support, not necessarily with medical advice but professionals reaching out and asking caregivers how they are doing. She also understands the importance of self-care through her own experience and hopes to see more respite and retreat options for transplant caregivers. See Appendix D for Yang's full story.*

## Access and Quality of Care

Similar to other caregivers, transplant caregivers' responsibilities included interacting, communicating, and advocating with various healthcare professionals on their care recipient's behalf.<sup>85</sup> They reported medical logistics to be a barrier to accessing care and a source of frustration. Scheduling appointments was difficult for caregivers who worked a 9-to-5 job and were unable to get in touch with anyone because the doctor's office closed at 5. Although online scheduling was sometimes an option, caregivers said it didn't always work the way it should.

The transplant process requires many appointments, all of which cost money to attend. Traveling requires finances for gas and parking, and given the frequency of visits, these costs can quickly add up. Rural caregivers also pointed out the time that these appointments can cost them. One appointment alone could mean traveling over an hour each way, making multiple appointments very difficult to juggle.

Overnight stays also proved to be a challenge to caregivers as they tried to be near the transplant recipient while in the hospital. They would find that Medicare did not cover medical lodging or long hospital stays. One caregiver described how they slept in a sleeping bag on the floor of their recipient's hospital room because the hospital did not have a dedicated place for caregivers to sleep.

Caregivers of a family member with Medicaid insurance shared they perceived the quality of care they received was lower, making the process even more difficult for the caregiver as

**“If you're not assertive, things won't get done, because there's a lot of people that need help or attention and you can get lost.”**

– Transplant Caregiver

<sup>85</sup> Ibid

they struggled to get their recipient everything they needed. Income and insurance, race, class, and zip code all play a role in donor selection and transplantation, and these systemic inequities place even more stress and burden on the caregiver as they attempt to navigate and understand the process.

## Mental and Physical Health

Transplant caregivers' mental, financial, and physical health are all compromised throughout the transplant process. As well, managing social relationships was also revealed as a challenge for the caregivers we spoke to. Caring for their patient meant deprioritizing caring for themselves, and their health often fell by the wayside, even when they were ill. Something as simple as planning a trip to the movies became difficult as they had to plan around their recipient and their own needs, and sometimes even required coordination with doctors. Additionally, maintaining emotional stability was exhausting for caregivers as they were also managing interpersonal frustrations, illness challenges, appointments, and the lack of systemic support.

Caregivers said it was very hard to find others who could relate to their experiences and relationships to their care role and their recipient. The relationship between the caregiver and the care recipient can drastically evolve as they experience loss of boundaries and the changes that come with new role definitions. Finding somebody else who can understand and relate to these changes was a challenge for caregivers.

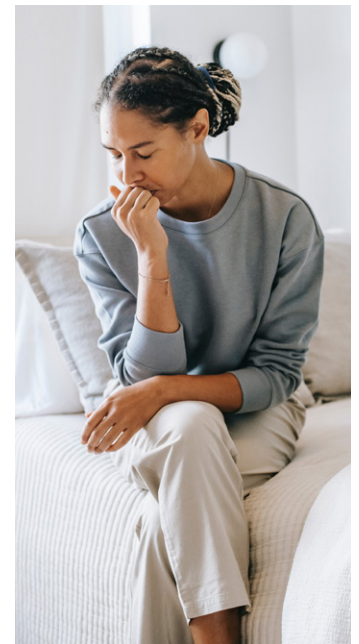
## Financial Strain

While most participants in these focus groups were fully or partially employed, the transplant caregiving process presents a challenge to maintaining employment and impacts income in terms of either total lost income or having to pull from retirement or savings accounts. In the instance of spousal care, income was severely impacted—the recipient was unable to work, and the caregiver found it hard to maintain a full-time job. Middle-class caregivers could not afford the costs associated with the transplant process but did not qualify for the financial support they needed.

Applying for disability requires a minimum threshold of assets that is unrealistic for caregivers who must take care of and provide for a family, meaning they lose out on a benefit they desperately need. Family Medical Leave is also a limited benefit that may not cover the entire duration of leave the caregiver needs, jeopardizing both their employment and employee benefits.

**“Had to be a caregiver and significant other—loss of boundaries and not knowing the outcomes of the efforts. I was supposed to be building the rest of my life with that person, now feels like I’m becoming the parent.”**

– Transplant Caregiver



**“I try and keep my job. If I don’t have a job, a lot of people in my family are in trouble and I’m kind of stuck between a rock and a hard spot because I’ve been off work with FMLA and trying to take care of family members, but I’ve got to go back to work. I’m trying to figure out how to apply for disability. It’s a depressing thing to deal with while you’re trying to keep someone else from being depressed.”**

– Transplant Caregiver



## Emotional Support Groups

Emotional support groups, whether virtual or in-person, provided emotional support for caregivers and were seen as safe spaces where they could value time with others going through the same experience. Support groups were the most widely cited form of emotional support available. Friends and family were also seen to be supportive, although some caregivers found that friends and family did not support them in the way they expected or hoped, such as helping them with their caregiving duties or spending time with the transplant patient. Some participants observed that if their recipient was currently on a waitlist, friends and family would eventually stop reaching out or visiting them in the hospital after learning the initial diagnosis.

When available, caregiver-specific support—within the transplant system or outside of it—is a critical lifeline.

The caregiver focus groups recommended additional support and resources that could be offered throughout the transplant process:

1. Awareness and recognition from the transplant team/medical team about their role as a caregiver.
2. Transplant waitlist training to provide caregivers with education and information on the different states and transplant centers waitlist requirements, how to get on the transplant waitlist, and the ability to track their progress once on the waitlist.
3. A dedicated transplant team member to caregivers, such as a therapist or social worker, to help them navigate the process and provide connections and referrals to resources, such as caregiver support groups.
4. Strengthening post-transplant process. This can include a peer mentorship program where caregivers in the post-transplant stage can speak to those in the pre-transplant stage.
5. A respite service for caregivers that allows them to take a break from their caregiver role and to take time for themselves.

**“The caregiver group was a huge lifesaver for me. I could scream in the group and people would write back, ‘yeah, we’ve been there,’ and it was just good to know that it’s okay to scream.”**

– Transplant Caregiver

When available, caregiver-specific support—within the transplant system or outside of it—is a critical lifeline.





# Recommendations To Support Transplant Caregivers

**NAC's literature review, consultation with subject matter experts, and conversations with transplant caregivers revealed the limited data on their caregiving experience and impact of caregiving in transplantation.**

While having a caregiver is a requirement to be waitlisted in most transplant programs, there appears to be no consistent practices for screening, training, or providing resources and support to caregivers across transplant centers. This finding points to a strong need to establish awareness of the gaps in support for transplant caregivers among health system leaders, policy makers, and the patient advocacy community.

We have developed the following recommendations to help ensure that caregivers of transplant patients are provided necessary and deserved supports, services, and resources throughout the transplant journey.

These recommendations dovetail with both the Organ Transplant Caregiver Initiative<sup>86</sup> and HRSA's Modernization Initiative mentioned at the beginning of the report.<sup>87</sup> Additionally, each of these recommendations are aligned with the five goals of the 2022 National Strategy to Support Family Caregivers:<sup>88</sup>

***Goal 1: Increase awareness and outreach to family caregivers.***

***Goal 2: Advance partnerships and engagement with family caregivers and care teams.***

***Goal 3: Strengthen services and supports for family caregivers.***

***Goal 4: Ensure financial and workplace security for family caregivers.***

***Goal 5: Expand data, research, and evidence-based practices to support family caregivers.***

**This finding points to a strong need to establish awareness of the gaps in support for transplant caregivers among health system leaders, policy makers, and the patient advocacy community.**

<sup>86</sup>Jesse, M. T., Hansen, B., Bruschwein, 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). <https://doi.org/10.1111/ajt.16315>.

<sup>87</sup>Health Resources and Services Administration. (2023, March). HRSA Announces Organ Procurement and Transplantation Network Modernization Initiative. <https://www.hrsa.gov/about/news/press-releases/organ-procurement-transplantation-network-modernization-initiative>.

<sup>88</sup>Administration for Community Living. (2020, September). 2022 national strategy to support family caregivers. Retrieved November 1, 2023 from [https://acl.gov/sites/default/files/RAISE\\_SGRG/NatlStrategyToSupportFamilyCaregivers.pdf](https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyToSupportFamilyCaregivers.pdf).



### Recommendation 1: Standardized Screening Process and Caregiver Identification

Patients must be in good health to receive a transplant, and transplant centers have screening processes to determine eligibility and allow patients to submit their name and information to the appropriate transplant waitlist(s). In many centers, this screening process also ensures that the patient has a caregiver available. Unfortunately, the screening process varies by center. The lack of standard criteria necessary for a transplant receipt leads to bias and opens the door for additional inequities, especially for socioeconomically disadvantaged communities. Overall, non-Latino white individuals are more likely to be rejected for transplant before they reach the waitlist.<sup>89</sup> A standardized screening process would provide both transplant patients and their caregivers with the opportunity to be added to a waitlist regardless of race, ethnicity, or socioeconomic status. A standardized process would also delineate necessary and measurable requirements that are applied across transplant centers.

Further, caregiver identification in the screening process will help determine who is meeting the criteria as a caregiver, who is being turned away, and why. Transparent and consistent data collection will allow centers to recognize bias and discrimination, eliminate such practices, and add more patients and their caregivers to the transplant waitlist. While HRSA's Organ Donation and Transplantation Dashboard<sup>90</sup> makes data available on transplant recipient demographics and transplant waitlist candidates, registrations, and outcomes, it does not include collect any data on their caregivers.

**The lack of standard criteria necessary for a transplant receipt leads to bias and opens the door for additional inequities, especially for socioeconomically disadvantaged communities.**



### Recommendation 2: Caregiver-Specific Data Sharing and Coordination Among Transplant Centers

Transplant centers should standardize their processes for data sharing and coordination to ease the complexities caregivers face when coordinating care. Transplant caregivers and patients are more likely to interact with several centers at the same time in an attempt to more quickly locate a viable transplant. Coordinated, efficient, and simple mechanisms of sharing or updating information internally across transplant centers would save time and stress for both caregivers and patients. This would be especially beneficial when trying to re-list a patient who had been removed due to poor health.

Additionally, centers need to ensure expansive and inclusive data collection categorization beyond using the term "other" as a catch-all to help characterize caregivers. Collecting and sharing caregiver data across centers will provide centers information necessary in the creation, refinement, and evaluation of caregiver support best practices.

**Coordinated, efficient, and simple mechanisms of sharing or updating information internally across transplant centers would save time and stress for both caregivers and patients.**



### Recommendation 3: A Coordinator on the Transplant Team Dedicated to the Family Caregiver

The transplant process is confusing, tiring, and anxiety-inducing, with new medical information, varied procedures, and worry over the patient's well-being. Pre-transplant, there is a sense of urgency; post-transplant, there is a sense of unease, and it's not unusual for caregivers of transplant patients to experience PTSD. Transplant team services and supports are designed primarily for the transplant recipient. However, because the caregiver is integral to the transplant patient's health, they deserve to be supported by the transplant team. This can be done with a designated caregiver coordinator.

<sup>89</sup>Mullen, J. (2022, November 29). How our organ transplant system fails people of color. Association of American Medical Colleges. <https://www.aamc.org/news/how-our-organ-transplant-system-fails-people-color>.

<sup>90</sup>Health Resources and Services Administration. (2022, December). Organ Donation and Transplantation. [https:// data.hrsa.gov/ topics/health-systems/organ-donation](https://data.hrsa.gov/topics/health-systems/organ-donation).

With a designated caregiver coordinator in place, the caregiver would have a team member dedicated to them for questions, information, as well as connections to resources or support. The caregiver coordinator would guide caregivers through the full spectrum of the transplant process, making themselves available for any questions or concerns, even several years post-transplant. In addition, a designated caregiver coordinator would support a caregiver's well-being.

Our work illustrated that the transplant team as it currently stands does not have the capacity to evaluate a caregiver's mental, emotional, or physical health until the situation is extreme—when it may be too late to intervene. Across transplant centers, ensuring the presence and continuity of a caregiver throughout the process is implausible. However, a caregiver's absence inadvertently jeopardizes the success of the transplant patient. The presence of a caregiver coordinator throughout the process assisting caregivers with their health needs and ensuring individualized support would not only reduce caregiver absences but would also prompt earlier intervention.

Further, the Centers for Medicare and Medicaid Services (CMS) should develop new reimbursement pathways to incentivize healthcare providers (including nurses and social workers) to train and support family caregivers in providing the complex medical tasks associated with transplant care. In 2023, CMS issued a 2024 Medicare Physician Fee Schedule Proposed Rule to reimburse healthcare practitioners to provide caregiver training services.<sup>91</sup> This rule should be adopted and leveraged across transplant centers to support training and support services targeting family caregivers.



**The presence of a caregiver coordinator throughout the process assisting caregivers with their health needs and ensuring individualized support would not only reduce caregiver absences but would also prompt earlier intervention.**



**Recommendation 4: Implementation of Routine Family Caregiver Screenings and Delivery of Support Services to Respond to Unmet Needs at Critical Points Along the Transplant Journey**

One of the most important aspects of being a family caregiver is having the knowledge, support, and resources needed to fulfill the caregiving role and maintain the health of the transplant patient. Yet, many of the caregivers we interviewed shared that they were unprepared for their role as a transplant caregiver, mostly due to either a lack of or inadequate information about their role and what would be required of them during the transplant process. Some also did not understand the magnitude of the caregiving they were taking on, including the tasks associated or the significant time and financial commitment. With screening in place, caregivers could be provided with information and education as soon as they were identified, preparing them for their role from the outset.

The delivery of support services can include standardized information packets, referrals, and connections within the transplant ecosystem and social support in general. Developed in 2018, the Organ Transplant Caregiver Initiative provides a preliminary action plan to improve education for organ transplant caregivers. This includes the development of a comprehensive, accessible, and routinely updated organ transplant caregiver toolkit modeled after established caregiver resource guides.<sup>92</sup> A recent study on hematopoietic cell transplantation (HCT) caregivers also recommends screening for family caregivers' ability, comfort level, mental health status, resources, and social determinants of health. These assessments can then guide family caregiver education, support, and training to ensure supportive resources match individuals' needs, particularly for those new to the family caregiving role.<sup>93</sup>

<sup>91</sup>U.S. Department for Health and Human Services. (2023, November 2). CMS finalizes physician payment rule that advances health equity. <https://www.hhs.gov/about/news/2023/11/02/cms-finalizes-physician-payment-rule-advances-health-equity.html>

<sup>92</sup>Jesse, M. T., Hansen, B., Bruschwein, 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). <https://doi.org/10.1111/ajt.16315>.

<sup>93</sup>Applebaum, 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). <https://doi.org/10.1016/J.JTCT.2022.12.014>.



### **Recommendation 5: Policies that Provide Financial Assistance and Workplace Protection and Appropriate Medical Coverage for Transplant Caregivers**

Our findings revealed the economic impact of transplant caregivers and the financial burden of the transplantation process. Implementing financial assistance for transplant caregivers and ensuring adequate medical coverage would allow them to care for the transplant recipient without jeopardizing their current or future financial situation.

Federal policies, such as the Family Medical Leave Act (FMLA), help protect the jobs of employees who take time off work to care for an immediate family member. However, FMLA only provides job protection and does not ensure individuals continue to earn much-needed income during their leave. These limits on the amount of unpaid job-protected leave may not address the unique needs in end-stage organ disease and transplantation. Establishing a national paid family and medical leave program can provide the paid time family caregivers need to navigate the often-complex care associated with transplantation. Other federal policies to support caregivers, including transplant caregivers, can include tax credits and better coverage for transplantation through Medicaid and Medicare.

Strengthening state programs like Medicaid also play a role in alleviating transplant caregivers' financial burden. A recent study of medical coverage for hematopoietic cell transplantation (HCT) among Medicaid beneficiaries found inequities in support for patients and their caregivers resulting in significant financial burden.<sup>94</sup> The study revealed variations and gaps in coverage for caregiver expenses and payments/reimbursements for out-of-pocket expenses despite transportation, meals, and lodging expenses are covered by Medicaid in most states. For example, some states restrict coverage for expenses only when the Medicaid beneficiary is a child and/or only when admitted as an inpatient.

A caregiver should not have to lose sleep over the possibility of losing their job because they need to take time off to help care for their transplant recipient.

**They should not have to worry that maintaining their transplant recipients' health and life will bankrupt them.**

**Establishing a national paid family and medical leave program can provide the paid time family caregivers need to navigate the often-complex care associated with transplantation.**



<sup>94</sup>Auletta, J. J., Khera, N., DeMartino, P., Kelkar, A. H., Yusuf, R. A., Davies, S. M., Knutson, J., Beaver, E., Maloney, A., & Majhail, N. S. (2023). Assessing Medicaid coverage for hematopoietic cell transplantation and chimeric antigen receptor t cell therapy: A project from the American society for transplantation and cellular therapy and the national marrow donor program ACCESS initiative. *Transplantation and Cellular Therapy*, 29(11), 713–20. Doi: 0.1016/j.jtct.2023.08.007.

# Appendix A:

## References Analyzed in Literature Review

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# Appendix B: Literature Review Methodology

A literature review was conducted to gain a preliminary understanding of the experiences of transplant caregivers, with two main questions in mind: “What are the challenges faced by transplant caregivers, especially posttransplant?” and “What is the experience of the transplant caregiver, from pretransplant to posttransplant?” The review was done using DeepDyve, a database that searches PubMed, Google Scholar, and the database’s own holdings. Studies were limited to the United States and the search terms used were “transplant caregivers,” “transplant care,” “caregiving transplant,” and any combination of those three terms with the addition of the word “lung,” “liver,” “kidney,” “heart,” or “stem cell.” Several studies were identified by going through the bibliographies of other relevant studies. To further contextualize the transplant landscape including current research surrounding transplant caregivers, experiences they face as caregivers, and any interventions that have been tested, a meta-summary was used to identify cross-cutting themes.

A total of 81 articles were identified across all transplant types (i.e., solid organs to stem cell transplants). A significant majority included a variation of randomized controlled trials, retrospective/prospective cohort studies, and longitudinal studies. The remaining studies included seven qualitative studies, seven literature reviews, and one measurement validation. Although studies spanned the past ten years, more than half were published within the last five years and predominantly focused on stem-cell transplantation. The major themes from this review included Transplant Experiences, Interdependent Relationships, Growth and Positive Experiences, Mental Health and Well-Being, and Equity, highlighting the transplant caregiver landscape in relation to experiences, challenges, and interventions.

The theme of Transplant Experiences surrounded caregiver experiences across solid organ and stem cell transplantation, as well as throughout the transplant process, specifically pre- and post-transplant. The theme of Interdependent Relationships highlighted the symbiotic relationship of the patient-caregiver dyad, growth, and positive experiences. The theme of Mental Health and Well-Being reflected both negative and positive psychosocial consequences of transplant caregiving on patient and caregiver. The theme of Equity reflected systemic influences inequitably impacting the transplant caregiving trajectory.

We concluded our literature review with a description of the existing interventions that have been developed and tested to support transplant caregivers.

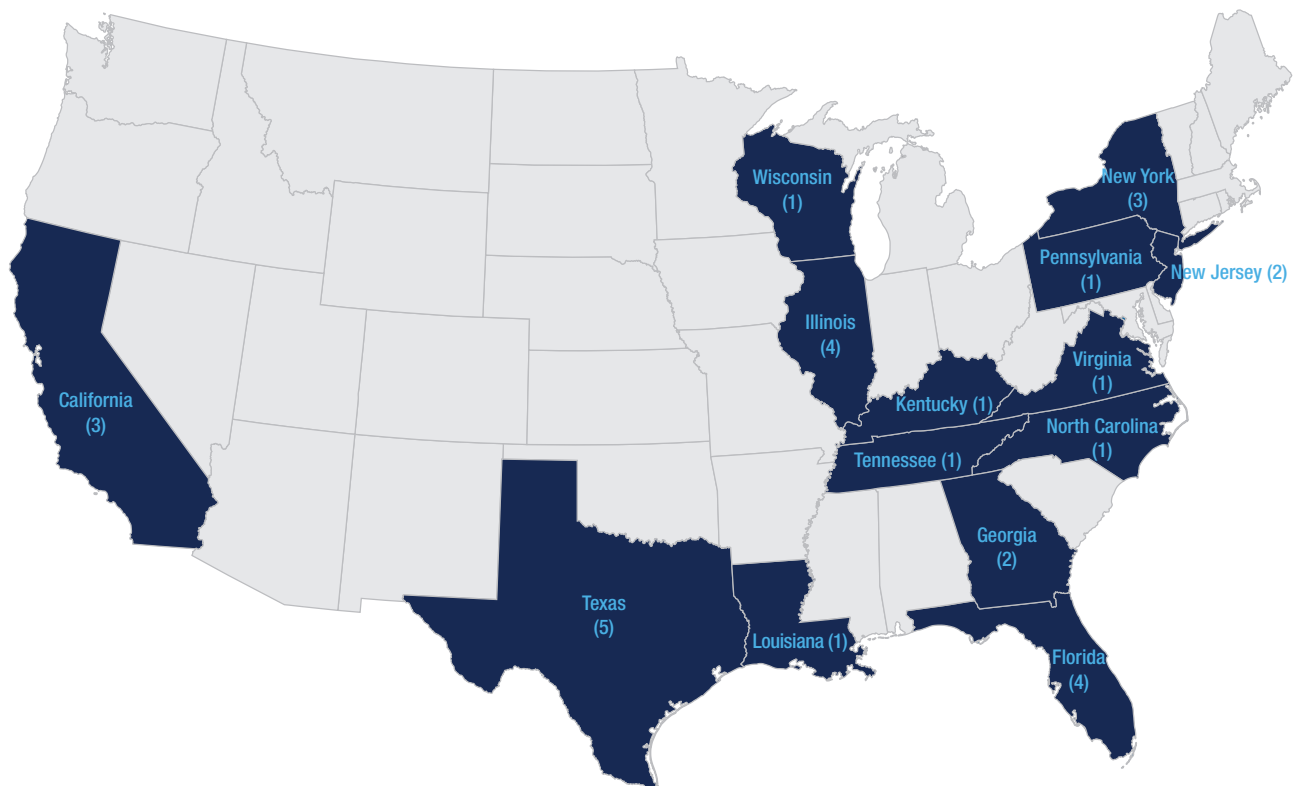
# Appendix C: Caregiver Focus Group Methodology

To facilitate these focus groups, the National Alliance for Caregiving partnered with Schlesinger Group. Schlesinger Group is a leading data collection company that offers both qualitative and quantitative means of gathering data, along with providing high-quality recruitment and research services.

In September 2022, Schlesinger Group hosted five, two-hour focus groups on behalf of NAC. These focus groups consisted of 30 participants across age, race, income status, geographic location, sexual orientation, gender identity, stage of transplant process, and relationship to the transplant recipient. While four of the focus groups were mixed, one group was exclusive to the LGBTQ+ community, and if an LGBTQ+ identifying participant preferred, they were placed in that group.

## Demographics

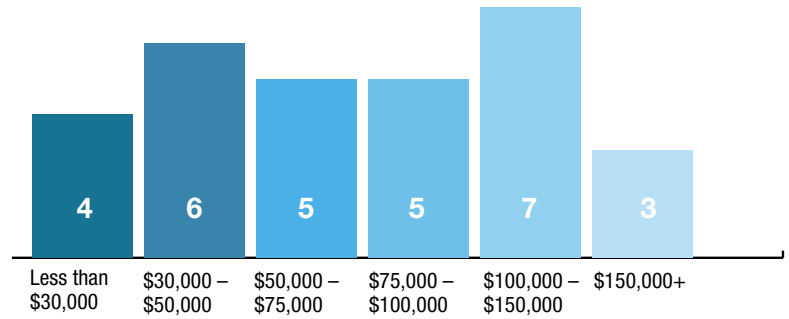
### Geography of Caregiver



### Transplant Stage of Caregiver's Recipient

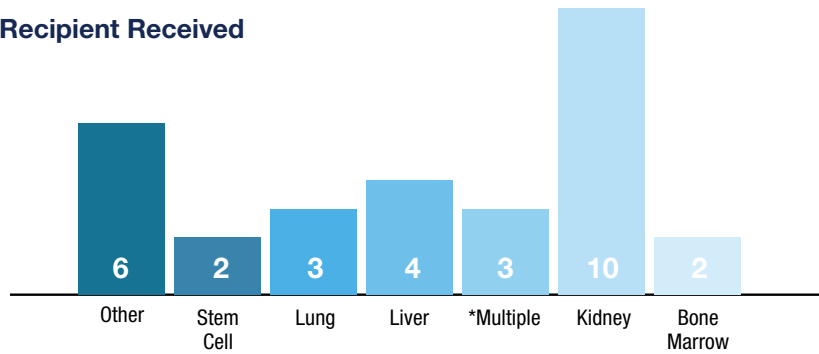
**53%** Post-transplant  
**47%** Waiting for transplant

### Income of Caregiver



### Type of Transplant Caregiver's Recipient Received

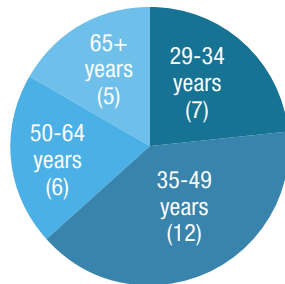
*\*\*Multiple\* included: stem cell and others; kidney, heart, and stem cell; kidney and pancreas. For "other" no follow up questions were asked.*



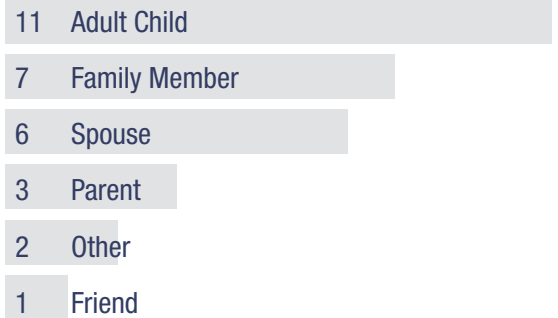
### Gender of Caregiver

**27%** Male  
**73%** Female

### Age of Caregiver



### Relationship of Caregiver to Care Recipient



### Sexual Orientation of Caregiver

- 18 Heterosexual
- 5 Gay
- 5 Bisexual
- 1 Other
- 1 Prefer Not to Say

### Race/Ethnicity of Caregiver

- 14 White
- 6 Black or African American
- 4 Latino/Hispanic
- 2 American Indian or Alaska Native
- 2 Asian
- 2 Multiracial

# Appendix D: Portraits of Caregiving: Oral Histories

## Albert

*Albert cares for his partner, who has received a kidney transplant and was undergoing dialysis when he and Albert started dating. Albert knew going into the relationship that he would be a part of his partner's care team one day. Albert's partner was able to remain healthy and eased into needing a new kidney, so Albert was able to ease into the care partner role as well, attending relevant groups and dialysis alongside him.*

*As a teenager, Albert had been in a caregiving role, so he had some experience when it became time to help care for his partner. From his earlier experience as a caregiver, Albert knows the importance of self-care and remaining healthy so he can help keep his partner healthy. He also knows the importance of boundaries. He can be anxious about ensuring that his partner gets everything he needs, but he understands the importance of giving space when his partner wants independence.*

*The healthcare team did not provide Albert with any information on being a transplant caregiver. He gathered information on his own from the patient groups his partner was engaging with, along with listening carefully and asking questions at his partner's doctor's appointments. He was not provided information on caregiver support groups, and although he feels he could have asked for it, he didn't want to take the focus from his partner. He has been able to speak with his own doctor about being a care partner.*

*Albert expects that his partner will need another kidney transplant in the future. He thinks he himself will need more support through the second transplant, and that he will be more involved in the screening and pre-transplant process. His own personal challenge is taking care of himself and curbing the anxiety he feels over being sure he can help his partner.*

*Post-transplant, Albert has been involved with support groups and patient advocacy groups because he wants to give back and provide help to the transplant community. He is a retired teacher, and he loves teaching, so he is often called on to provide others with information. However, Albert thinks it is incredibly important that caregivers know that they do not have to engage with the transplant community or support groups to get the information and resources they need. No caregiver should feel guilty into participating in exchange for resources.*

*Albert explains the most helpful information he received was in plain language from someone to whom he could speak directly and ask questions. He thinks support groups can be very helpful to caregivers, especially when they're comprised of people from different backgrounds who can provide varied perspectives and understandings on transplants. These support groups are a convenient place for caregivers to get advice and can help them feel like they're not alone.*

## Brian

*Brian was the caregiver for his wife, who needed a kidney transplant a few years ago. While they were engaged, Brian's wife went into septic shock due to kidney failure, and that, combined with her pre-existing Type 1 Diabetes, led to high blood pressure and ultimately, kidney failure.*

*Brian and his wife went through extreme challenges to get her a kidney. They were on a waitlist in Minnesota and were called almost immediately, but the kidney wasn't viable. Because they had received the first call so soon they assumed another kidney would quickly be found, so they left their lives in Connecticut to live in Minnesota. They eventually moved back to Connecticut when no kidney was found. In Minnesota, they experienced about 10–15 calls for non-viable kidneys, which severely affected their mentality.*

*Brian and his wife faced constant setbacks while waiting for a kidney transplant call. His wife experienced medical complications like falls or mini strokes that would cause her to be removed from the waitlist. Brian would nurse her back to an acceptable health to be re-listed for a kidney. This was also frustrating because they had to depend on the system to put them back on the waitlist when they were ready, and it caused even more anxiety and a feeling of urgency around finding a kidney in time.*

*Brian did not receive any help from the transplant medical team. He feels the team at their Connecticut hospital became apathetic to his wife's condition, as it was being "handled," and stopped really advocating for her once she was on the transplant waitlist. Becoming his wife's caregiver and care coordinator became Brian's full-time job, and he ended up taking a layoff from work. He learned a lot about caregiving "on the fly" and through 9-1-1 calls.*

*After Brian left his job, he and his wife temporarily moved to Florida to escape the Connecticut winters and to give his wife a better chance of regaining her strength. There, they met a doctor who became a strong advocate for Brian's wife. He got them listed for a kidney in several hospitals by continuing to make calls, which is how Brian learned that he needed to continuously contact anyone he could to get something from the healthcare system. Being listed at several hospitals got Brian's wife her kidney, but it also meant Brian was financially and logistically planning travel, meals, and hotel stays wherever the kidney could possibly be located. He would chart transplants at their waitlisted centers to determine the likelihood of receiving a kidney from a given center.*

*Post-transplant, Brian's wife took over a lot of her own care, and Brian was able to start looking for work. However, a setback occurred when Brian's wife was diagnosed with post-transplant Cytomegalovirus (CMV). His wife had to go back to the hospital, and Brian had to start caring for her again. Reflecting on his journey, Brian thinks this setback may ultimately be what caused him and his wife to separate. They both needed to continue on with their lives, and he didn't feel he could continue caring for her.*

*Due to his experience, Brian believes there needs to be some coordination among transplant centers. As someone who had to take care of all his wife's paperwork moving through multiple centers and waiting for a kidney, he thinks there could have been better communication that would have reduced his workload. He also believes caregivers need financial support, especially when it comes to travel, and workplace protection. Ultimately, someone should be providing caregivers with a roadmap so they know what to expect and where they can go to for support.*

## Cody

*Cody is a caregiver for his young daughter, who was born eight weeks early with biliary atresia, a rare liver disease. Doctors told Cody and his family that she would eventually need a liver transplant, and in the meantime performed a surgery that was able to delay the need for a new liver.*

*While on the waitlist for the liver, Cody did his best to keep his daughter as healthy as possible, because they didn't want her to remain in the hospital for a long time after the transplant. They experienced three dry runs where they practiced what would happen if a liver became available, and the transplant team prepared them for what they could expect and the emotions they might experience if a liver turned out not to be viable. Cody's daughter was able to get a liver within a year and a few months.*

*The transplant team also provided Cody and his family with a comprehensive binder of information and resources. It included information on mental health resources, methods of spiritual support, and social workers they could contact. Each section of the binder was explained by someone on the team who was familiar with it. The coordinator sat down and explained the medications their daughter would be taking and why, and a social worker spoke to them about the financial aspect, such as assistance with hotels and meals.*

*Cody's family are members of the Chickasaw Nation, and they felt the healthcare team was very respectful of their culture and did their best to learn about it. When his daughter went onto the transplant list, Cody knew there might not be many American Indian organs available because many elders believe the body must remain fully intact to pass on.*

*Post-transplant, Cody has run into some barriers as a caregiver. His daughter needs to have lab work done occasionally, and the closest lab is far from their home. Having to travel to get lab work done disrupts their whole day. They wanted their local tribal hospital to start drawing the labs, but the hospital did not feel equipped to do so on an infant. There was also a period where Cody struggled to get the hospital and his insurance through Indian Health Services on the same page.*

*Cody's daughter is now a year and a few months post-transplant, and Cody feels the healthcare team is still there for him as a resource. He has become involved with Transplant Recipients International Organization (TRIO) and is able to mentor those waiting for a transplant. He appreciates the opportunity to speak with those experiencing the same thing he went through, because not everyone can understand what going through a transplant is like.*

*As a caregiver, Cody hopes more resources can be created on how to reach out to a donor family. He knows a lot of transplant recipients and caregivers who want to connect and speak with their donor families. He is also aware of the current push to get more American Indians and Alaska Natives involved in donating organs. To do so, he believes Indian Health Services needs to be heavily involved with the campaign and that American Indians and Alaska Natives need to be identified on official health forms, instead of being categorized as "other."*

## Georgette

*A few years ago, Georgette's sister started experiencing medical complications. While Georgette lived in New York City, her sister and her family lived in Atlanta, where her husband worked. It was decided that the medical complications were serious enough that Georgette's sister should travel to New York for treatment so Georgette could be there to help her. Neither Georgette nor her sister realized that the magnitude of the treatment needed would end up being both a heart and kidney transplant.*

*The unexpected shock of her sister needing not one, but two organ transplants, set the tone for Georgette's caregiving experience. Luckily, she felt well-supported by the medical team. They prepared her for what to expect of a transplant and what was involved, and the social worker at the hospital provided her with information. They also introduced her and her sister to a support group of other transplant recipients and caregivers for them to connect with.*

*Georgette's sister was only on the waitlist for her transplant for about a month, meaning the entire family had to adjust and process the situation very quickly. Her sister was in the hospital for three months following her transplant, and that was the most stressful time of Georgette's caregiving experience. Nothing could have prepared her for the shock of seeing her sister for the first time after her surgery.*

*During the three-month hospital stay, Georgette had to run back and forth from the hospital to check on and spend time with her sister while also juggling her work schedule. Luckily, her job was flexible with her work location, so she did not have to travel far. Georgette also took over caring for her niece while her sister was in the hospital, and she was responsible for her school schedule.*

*Although Georgette felt supported by the healthcare team and they provided a huge amount of support in navigating the financial aspects of receiving a transplant, Georgette did not feel they were necessarily there for her, especially after her sister was discharged. Although they spent some time with her niece as the daughter of the transplant patient, she thinks it would have been helpful if they had checked in on how she was doing mentally, and she feels she would have needed this if her sister's recovery had been longer.*

*When her sister was ready to go home, the healthcare team provided her and Georgette with information on her medications, and this was an aspect that Georgette's sister was able to handle on her own. Throughout the transplant experience, Georgette and her sister had the support of their family, and once discharged, they purchased a house together so Georgette could continue to help care for her sister. Georgette's husband was also able to start acting as another caregiver, providing Georgette with an additional level of support.*

*To better prepare and support caregivers for their role, Georgette believes they should be provided with a high-level amount of information, but not be overwhelmed or scared by what they're being told. She thinks educational videos could be provided so the caregiver can watch them at their leisure and follow-up with any questions. She also really enjoyed the support groups she was a part of and thinks it would be beneficial to have caregiver-only support groups where caregivers can speak more freely. Finally, she believes it's important to support caregivers financially in the areas that may not be considered, such as providing transportation or parking reimbursement and childcare support.*

## Hailey

*When Hailey's daughter was born, Hailey instantly became a caregiver. Upon her daughter's birth, doctors had to remove about 98 percent of her intestines, and only gave her a few weeks to live. They did not explore any options on how to help her. Hailey and her husband refused to give up, and an internet search revealed a hospital close by that would be able to perform an intestine transplant. Over a period of four months, they transitioned her to the new hospital to see if this was an option that could save their daughter.*

*Hailey and her family lived in New York, and the hospital that was ultimately able to get their daughter a transplant was in Pittsburgh. Hailey quite her job and moved to Pittsburgh to get her daughter treatment while her husband stayed behind, continuing to work in New York. Hailey felt that the transplant became her entire life. She felt extremely isolated, had no one to talk to, and did not feel supported by the healthcare team.*

*To be able to care for her daughter, Hailey took meticulous notes on everything the healthcare team told her. She essentially had to become a nurse herself, learning medical jargon and keeping a binder full of information she had gathered. She was not told how to deal with a stoma bag— instead, she learned tips and tricks from other moms on the floor. At the time, intestinal transplant was still new, and Hailey's daughter was on multiple medications that were too much to handle. Hailey very carefully learned which ones were essential and which ones she could wean her daughter from.*

*Post-transplant, Hailey was able to bring her daughter back home. She realizes their family was extremely lucky to be able to afford to leave and live in another city for a short amount of time, and that a lot of people who need a transplant would not be able to financially support themselves through that necessity. Hailey's family was able to fund another family's relocation to get the transplant they needed, and she believes there should be funding in place so the need to move isn't a roadblock to anyone who needs a transplant.*

*Hailey faced several barriers of her own post-transplant. Once after a hospital stay, her daughter, who was still a baby, developed a hole in her head. The hospital would not treat her, and Hailey had to learn how to care for and treat her daughter in this instance by herself. When her daughter grew older, Hailey had to fight and even hire an attorney to get her the accommodations she needed in school.*

*Hailey was never connected to a social worker even though she had asked. Although Hailey and her husband remain in touch with their daughter's healthcare team, it is Hailey doing the reaching out if she needs it. Hailey's daughter is very involved in the transplant space and is friends with those who are on her team.*

*To support transplant caregivers, there needs to be better education on what transplant options are and what financial support can be provided. If Hailey and her husband hadn't discovered transplant was a possibility, their daughter would have died. It would also be useful to have an open forum where caregivers could share the tricks, tips, and information they've learned, or a universal app that automatically updates with transplant information from hospitals and doctors. Social workers at transplant centers should be available as a point person for caregivers to connect with the hospital and to get medical information.*

## Ira

*When Ira met his wife, Glenda, she had manageable Type 1 diabetes. Their relationship began as a care partnership, where Ira would attend his wife's doctor's appointments and would help her manage her chronic disease. Increasing complications with her diabetes necessitated that Glenda would need a kidney transplant, and to ensure the diabetes did not return, a pancreas transplant as well.*

*Ira and Glenda did a lot of research and gathered a lot of information on how to get the transplant as quickly as possible. They were listed for organs in both New York and in the Midwest, and they were looking into a living donor, since Glenda's brother was a kidney match. A living donor would mean Glenda would have to wait on the national recipient list for a pancreas, but they were willing to go this route due to how fast her kidney was declining.*

*Luckily at the time, the UNOS list favored patients looking for more than one organ, and Glenda was able to receive both a kidney and pancreas. The coordination of doctors and medications that Ira and Glenda had already been dealing with due to her chronic*

disease carried over into managing her transplant. Ira was not provided education on becoming a caregiver by the transplant medical team, although they would answer questions if asked. Instead, he and Glenda joined a lot of support groups and did research on every phase of the transplant process to become as knowledgeable as possible.

Ira and Glenda did face a barrier at one point with their insurance and in getting the medication she needed, although they were lucky to know a Medicare insurance broker from one of their support groups who was able to help them. Ira and Glenda continue to get a lot of support from groups and the transplant community rather than the healthcare system, and have been attempting to give back as much as possible by getting involved in political and legislative activities.

Post-transplant, Glenda has preferred to continue seeing the doctors who were involved in her transplant, and they have continued to be active in her care even 20 years later. Ira and Glenda see a transplant as a long-term commitment and want to keep in contact with their transplant center. However, they are disappointed Glenda hasn't been used more as an ambassador of a successful transplant. They are concerned that other than being a data point of a successful transplant a few years down the road, centers are uninterested in Glenda's story.

After seeing how COVID-19 affected transplant centers, Ira believes there needs to be better protocol in place for emergency situations. He does not think the pandemic was handled well by centers, or that transplant patients and caregivers were provided the information they needed at the time. He believes those on the transplant list and their caregivers should get organ- and disease-specific training and education, that centers should be more supportive of patient support groups, and that courses should be provided on how to take notes during a doctor's appointment. Additionally, he believes there needs to be post-transplant education for caregivers as well, and that centers should be able to connect patients for support and to be reassured by hearing successful transplant stories.

## Jeanne

Jeanne has been caring for her daughter since she was very young. As a child, a viral infection attacked her daughter's heart, causing her to need a heart transplant; in 2020 as a young adult, Jeanne's daughter needed a kidney transplant as well. Jeanne has been her daughter's caregiver since the heart transplant, and she was the living donor for her daughter's kidney transplant.

Much of the time Jeanne felt like she was flying by the seat of her pants. She did not get much education from the healthcare team, except on the medication her daughter would need after her 9-month stay in the hospital post heart transplant. When doctors told Jeanne her daughter was ready to go home, she was terrified about her ability to continue to heal without medical machines and professionals. Jeanne feels this fear is only heightened when the transplant recipient is one's child, and the caregiver hears stories of other children's experiences. She does not feel the medical team reassured her or gave her information on what could happen and how she could handle it.

Jeanne's daughter was able to remain with her pediatric transplant team for her kidney transplant despite being over age 18 at the time of transplant, for which Jeanne was grateful. Her daughter has a very good relationship with the team and can reach out any time she needs. However, Jeanne didn't feel that she was a priority to the team as a caregiver, and once her daughter turned 18 they stopped looking to her for input. She feels that there should be a system in place that allows the team to check in with the caregiver and be sure that they're comfortable in their evolving role.

While pre-transplant seems like a blur now, post-transplant was the hardest time for Jeanne as a caregiver. It took her a year or two post-transplant to address and realize what she had gone through while her daughter was in the hospital. Jeanne had to resign from her job to fully care for her daughter, a huge financial hit for her family. She was not offered financial support services from the hospital and the assigned social worker did not communicate with her about options. She believes the hospital may not have thought they looked like a family who needed help, and that the door was shut on her when they left the hospital. The caregiving experience also caused cracks already in the foundation of her marriage to deepen, and she and her husband divorced.

Jeanne has an extremely close relationship with her daughter and has never stopped caring for her. She has not found any caregiver-specific supports anywhere, but she and her daughter have become involved with an advocacy group working on legislation for transplants.



*Jeanne feels the medical team could have done more to support her. She recommends that transplant centers have a separate department just for caregivers to ensure they know there is information and support available to them. This department could provide relationships, financial and workplace support, and information.*

*While in the midst of the transplant journey, it's important to give caregivers the support they need when they need it, without overwhelming them. Jeanne looks back on her experience and knows it has made her and her daughter very close, and that her daughter is just now beginning to understand everything Jeanne did for her.*

## Jesus

*Jesus is a care partner for his younger sister, who, after visits to several doctors was diagnosed with kidney disease. She was told that she would need a kidney transplant. Jesus' mom is older and was already dealing with some health complications of her own. That experience, coupled with Jesus' background working in the healthcare field, made him feel more comfortable speaking with doctors.*

*As the big brother, Jesus holds an important role as his sister's sounding board. She will call him when she needs an opinion on a medical issue or with questions on what she should do next, and Jesus will give her his thoughts. When his sister was sick and waiting for the transplant, Jesus would take her out once a week so they could spend time together. Now, post-transplant, they make a day out of her follow-up doctor's appointments. As a supervisor at his place of work, Jesus feels lucky to have the flexibility to be able to help his sister in this way.*

*Jesus' family is very close and are used to taking care of one another, so he doesn't feel that their dynamic changed much with the transplant. Although the hospital did not give him much education or information on transplants, nor resources he could access, he felt comfortable enough with having his family for a support system. Jesus' wife is also a nurse, and he often goes to her with any medical questions he has.*

*At one point, Jesus was in an emergency situation in which he had to advocate for his sister. She was in pain and it was taking a long time for a doctor to see her. Jesus had to remind the hospital of the patient's bill of rights and push for his sister to get timely treatment.*

*Post-transplant can be a very anxious time. When the hospital told Jesus his sister was ready to be discharged after transplant, he couldn't believe how fast it seemed. He remembers driving her home very slowly and trying not to go over any bumps because he was afraid of jostling her. Everything that happens post-transplant is scary and unknown—even an illness like a cold is cause for concern. Jesus said he was very on edge, waiting to see what was going to happen and how things would turn out, but as a care partner, he wasn't really able to express this stress because he needed to be there for his sister.*

*Jesus did attend some support groups with his sister, and he found it helpful to speak with others going through the same experience as him. His sister is still in touch with her healthcare team, although Jesus would not feel comfortable reaching out to them for anything he needed, because he sees them as being a resource solely for his sister. He thinks it would have been helpful if the hospital ensured he had support group resources and knew where to find information he needed and what he could expect as a care partner.*

## Lorraine

*Lorraine became the caregiver for her adult niece when she was diagnosed with liver cancer and then hepatic encephalopathy. Her niece's daughter and ex-husband lived in different states, but Lorraine was only a few hundred miles away, so she traveled to be with her niece while she waited for a liver transplant.*

*Lorraine and her niece experienced a false alarm when they were called in for a transplant only to find out that the liver was not viable. Although they were prepared for this outcome, they were blindsided by the grief they felt. Pre-transplant was a difficult time for Lorraine—her niece was on steroids, which caused a lot of mood swings, and Lorraine was anxious about being on the waitlist and when her niece would get a transplant.*

*There was no formal education provided by the healthcare team on how to be a transplant caregiver, or what to expect. They did meet with social services to declare Lorraine as her niece's support, and her niece attends AA meetings, but otherwise all the information Lorraine gathered was on her own. She had previous life experience caring for her grandparents as a teenager, so she was used to having to ask for the information she needed and taking notes at doctor's appointments. Even when asking for information, Lorraine felt a lot of what she was told was "spoon-fed" to her, as if the medical professionals she spoke to were worried she wouldn't be able to handle the reality of her situation, and she did not experience great communication.*

*Post-transplant, Lorraine feels she can still reach out to the medical team with questions, but that it's not as helpful as it could be. The hospital held patient/caregiver support groups, but they were not well-attended. She ran into some financial trouble in her ability to pay for her niece's medication and had to find a solution on her own. Lorraine is very vocal about taking care of her health and her own needs and found support in her friends and family members.*

*To help transplant caregivers, Lorraine feels healthcare teams need to be more open in their communication and the information they provide to caregivers before the caregivers must ask for it. They also need to provide caregivers with a better understanding of HIPAA and financial assistance. Lorraine's niece is currently involved with Transplant Recipients International Organization (TRIO), which provides caregiver peer-to-peer meetings, and Lorraine believes programs like this can also help caregivers feel less alone.*

## Nancy

*Nancy began caring for her husband about eight years ago when a routine blood test diagnosed him with early-stage blood cancer. The doctor informed Nancy's husband that his best hope for longevity was a stem cell transplant, so he went on the waitlist. There was a lot of anxiety for Nancy while they were waiting for the transplant because there was some uncertainty with her husband's genetic markers, but she feels they had the ability to handle this anxiety with resources and space to process the information they were given.*

*Nancy was provided education by the healthcare team through a pre-transplant training session. She got to meet everyone on her husband's team and was informed about their various roles.. She was also provided literature to read, which was helpful but could also be very scary, because the literature states everything that could happen, creating the potential for additional anxiety.*

*The most difficult part of being a caregiver for Nancy was immediately post-transplant. Nancy had to essentially be a nurse technician and provide her husband with the proper amount of medication through a port, which was incredibly nerve-wracking for her. Outside the bubble of the hospital with ready information and help, Nancy didn't feel as confident, but it had to be done—the only other option was to have her husband remain in-patient. Regardless, they still had to visit the doctor and see a visiting nurse every week.*

*Nancy found support in the form of her friends and family, who would visit with her for some respite time. She also felt her husband's healthcare team would check on her as the caregiver. During her time as a caregiver, Nancy recognized the importance of taking time to care for herself and started seeing a therapist. Nancy had very good health insurance and did not struggle financially during this time. However, knowing costs and how much money went into just accommodating her husband's new diet, Nancy can't imagine how caregivers and patients can go through this process without good insurance.*

*There was no support or information provided on anticipatory grief, and Nancy thinks it would have been helpful if the center had prepared her a little in case things went wrong. Nancy did ask to meet with a palliative care team herself, although they never needed to be utilized. However, she thinks focusing too much on negative what-ifs may scare caregivers, so there needs to be a balance.*

*Nancy realizes that she and her husband were in the best possible position regarding education, familiarity with the healthcare system, and financial stability. She knows others don't have these resources, and she sees ways further help can be provided to caregivers.*

*Nancy is now involved in a peer-to-peer telephone line for stem cell transplant caregivers to help others like her. She believes there should be an available line for all transplant caregivers to call and speak to a real person to get actual information and support. She also thinks there should be more outreach to determine what each individual caregiver needs, and more local services. In her time*

on the peer-to-peer line, Nancy has also realized caregivers are concerned about the state of their home. Since transplant recipients are immunocompromised, the homes they are returning to need to be clean and well-kept. She thinks home visits to let caregivers know how to make the space safer for their care recipient could help ease some anxiety.

## Omar

Omar has been through a rough experience caring for his wife, who received a heart and kidney transplant. He has supported her through everything and helps her with whatever she needs. This has been especially challenging because Omar worked in Georgia during the transplant process and his wife lived in New York City. He was not able to move to New York to be with her until four months after her transplant.

Since Omar needed to be in Georgia to work, his wife's sister Georgette lived with her in New York to manage the day-to-day aspects of care. Georgette was the one who got in touch with and learned information from the doctors, and she would relay this information back to Omar. Omar's wife will also tell him things he needs to know about her care, and Omar has sought out others who have also been through the transplant experience to speak with them.

Omar feels he has made huge sacrifices in his work life and his financial stability to care for his wife. He would try to visit his wife every one or two weeks but had to travel back to Georgia to make money. Sometimes, he was not able to find enough money for the flight. He used to work as a barber, so his work hours were as flexible as he needed them to be, but if he wasn't working, he wasn't making money.

Financial assistance is something Omar wishes he had been offered, because he does not have time to look for it. He can only concentrate on his wife's care and working enough to keep up with their bills. He has not investigated financial support from the government because he does not trust that they will actually provide him with any help. However, if someone at the hospital had made him aware of this kind of financial support and helped him to apply for it, he would have done so.

Omar feels like the healthcare team has been supportive of his wife, but he has never interacted with them. His work hours mean he is not able to call them if need be. Omar wishes there was a way that someone could sit down and talk to him about the transplant caregiver experience so he could ask questions. He has never been through something like this before and he would prefer the support of someone who knows what they're talking about.

Spirituality and faith have been a large part of Omar's support system, but he does not feel he has gotten support from the healthcare team in the way that he needed it. To better support transplant caregivers, he believes there should be a fund made available to transplant recipients to help with financial costs. He also would have liked to have someone like a social worker visit their home and speak with him and his family so they could determine exactly what they needed and provide them with the appropriate help.

## Yang

Yang has been caring for her son who was diagnosed with chronic heart failure at a young age. After several surgeries as a child, her son received a heart transplant in 2018 at the age of 15. Yang believes that caring for his chronic heart condition prepared her somewhat for being a transplant caregiver, although not completely. Even though the heart transplant was successful, Yang will be a caregiver for her son for life.

The time Yang's son spent on the transplant waitlist was very short—just two weeks. Yang and her family were thoroughly screened by the healthcare team to ensure that her mental health, family stability, and financial situation would provide her son with the proper care. Since this pre-transplant period was so short, Yang does not feel like she fully understood what it would be like to be a transplant caregiver. She was not emotionally prepared and could have used much more support, especially as a caregiver and an advocate in this very specialized area of transplant.

To become a transplant caregiver, Yang had to quit her job. Providing care for her son is full-time work, and it was impossible for her to be spending hours a week away. Yang is an immigrant and does not have any close family in the United States, so she does not

*have built-in family support. One difficulty Yang talks about is caring for her daughter as well as her son. Because her son has been so ill, most of Yang's attention has had to be on caring for him, and as a result her daughter has become very independent.*

*While her son was in recovery post-transplant, Yang stayed at the Ronald McDonald House. This allowed her to go back and forth between the hospital whenever needed. They also had on-site physical therapy for her son, and a psychiatrist. Because the other people staying in the House were going through the same experience, Yang felt supported in that they could all speak with one another and ask each other questions about what they were going through.*

*Once they left the Ronald McDonald House, Yang felt an acute support drop-off. She did not know medical terms, and it was a time of great uncertainty for both her and her son. She felt like they were expected to go from beginner mode to expert mode immediately. When her son switched from pediatric to adult care, the support from the healthcare team became even more scarce. Yang was not provided any information or support on this transition and was completely overwhelmed by the system and what she should be doing.*

*This transplant came at a difficult time for her son, who was already in a transition period of his life as a teenager. Yang explains that teenagers do not have much concept of death and their own mortality, and her son was forced to face these subjects. He was able to go to college in New York, across the country from Yang, but the first time he had to go to the ER was very hard on them both. He moved back home to finish his education. Yang says her mental health has taken a hit, and it became very important for her to realize when she needed to ask for help, including seeing a therapist herself.*

*Yang is grateful for the opportunity to care for her son, and for how close the experience has brought them. She has joined Transplant Recipients International Organization (TRIO) in the hopes that she can help guide transplant caregivers through some of the challenges she has faced. As for the support she believes should be given to transplant caregivers, she states that there needs to be more casual support, not necessarily with medical advice but professionals reaching out and asking caregivers how they are doing. She also understands the importance of self-care through her own experience and hopes to see more respite and retreat options for transplant caregivers.*

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