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Authors

Deng, Lisa X
Sharma, Arjun
Gedallovich, Seren M
et al.

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Caregiver Burden in Adult Solid Organ Transplantation

Lisa X. Deng, MD¹, Arjun Sharma, MA¹, Seren M. Gedallovich, MD², Puneeta Tandon, MD³, Lissi Hansen, PhD, RN⁴, Jennifer C. Lai, MD, MBA¹

¹Division of Gastroenterology and Hepatology, Department of Medicine, University of California, San Francisco, San Francisco, CA.

²Division of Gastroenterology and Hepatology, Department of Medicine, Stanford University, Palo Alto, CA.

³Division of Gastroenterology, Liver Unit, University of Alberta, Edmonton, AB, Canada.

⁴School of Nursing, Oregon Health and Science University, Portland, OR.

Abstract

The informal caregiver plays a critical role in supporting patients with various end-stage diseases throughout the solid organ transplantation journey. Caregiver responsibilities include assistance with activities of daily living, medication management, implementation of highly specialized treatments, transportation to appointments and treatments, and health care coordination and navigation. The demanding nature of these tasks has profound impacts across multiple domains of the caregiver's life: physical, psychological, financial, logistical, and social. Few interventions targeting caregiver burden have been empirically evaluated, with the majority focused on education or mindfulness-based stress reduction techniques. Further research is urgently needed to develop and evaluate interventions to improve caregiver burden and outcomes for the patient–caregiver dyad.

INTRODUCTION

Solid organ transplantation can be a lifesaving, albeit care-intensive, intervention for patients with a multitude of end-stage diseases or organ failure. Much attention has been dedicated to the trials faced by the transplant patient at all stages of the transplantation journey in an effort to improve outcomes. However, relatively little attention has been given to the needs of the caregivers of transplant patients, whose well-being is crucial to that of the patients.¹ Informal caregiving encompasses support and lay medical care given to the patient by family members, partners, and friends. Caregivers play a vital role in assisting patients across all phases of transplantation and beyond.

With progression of organ failure, patients experience profound loss—the loss of work, hobbies, social support, independence, ability, and roles in their societal context.^{2–4} At

Correspondence: Jennifer C. Lai, MD, MBA, Division of Gastroenterology and Hepatology, Department of Medicine, University of California, San Francisco, 513 Parnassus Ave, Box 0538, San Francisco, CA 94143. (jennifer.lai@ucsf.edu).

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the same time, caregivers increase their roles and responsibilities as patient function declines. These tasks include assistance with basic and instrumental activities of daily living, medication management, implementation of special treatments (eg, mechanical circulatory support device maintenance, tracheotomy care), transportation to appointments and treatments (eg, hemodialysis, physical therapy), and health care coordination and navigation.^{5,6} Although similar demands exist for caregivers of patients with various chronic illnesses, in transplant medicine, there is the added pressure of being a “model caregiver” to aid in transplant eligibility and maintenance on the transplant waiting list.⁷

Caregiver responsibilities do not conclude after transplantation. There is growing recognition that organ transplantation is not a “cure” but therapy for a chronic condition that requires intensive monitoring and surveillance during the patient’s lifetime.⁸ In the early post-transplant period, patients must recover physically from transplant surgery, a process that can be hampered by poor physical reserve and sarcopenia from end-stage organ failure.⁹ They commonly experience postoperative pain and fatigue.¹⁰ During this initial period of physical debility, patients depend on caregivers for basic tasks such as transferring, bathing, and using the toilet.¹¹ Caregivers also support patients in learning new complex immunosuppressive medications that are given multiple times a day.¹⁰

In the long term, as part of transplant survivorship, caregivers continue to support patients with meticulous efforts to prevent graft rejection or loss, such as medication adherence, clinic appointments, and frequent laboratory visits.^{6,8} Some patients experience posttransplant complications that require hospitalizations or recurrent disease from the chronic disease that initially led to organ failure.¹⁰ In addition, the overall transplant experience can have long-lasting psychological tolls on both patients and caregivers.⁸

Caregiver burden is the multifaceted strain experienced by caregivers over time (Figure 1). We highlight 5 domains of caregiver burden among adult solid organ transplant patients: physical, emotional/psychological, financial, logistical, and social. In addition, we review interventions aimed at alleviating caregiver strain and supporting rewarding aspects of caregiving with the hope of optimizing the health and well-being of the patient–caregiver dyad.

Domains of Caregiver Burden

Physical—Throughout the transplant process, caregivers are responsible for extra duties and roles in the home that take a physical toll.¹² Responsibilities may fluctuate depending on the patient’s health and functional status, with higher needs during exacerbations of illness or in the immediate posttransplant period.^{13,14} Caregivers perform a multitude of labor-intensive domestic tasks, such as partial to total personal care (eg, bathing, feeding), household chores (eg, laundry, cleaning), special food preparation that adheres to dietary and fluid restrictions, medication management, highly technical disease-specific treatments (eg, peritoneal dialysis, tracheotomy maintenance), physical therapy exercises, and lifting/transportation of the patient.^{5,6}

Small studies demonstrate that physical caregiving duties may lead to poor physical health of the caregivers themselves.^{15–17} In a study of 29 dyads of lung transplant candidates and

caregivers, 15% of caregivers reported that their physical health worsened since caring for the patient and 22% reported fatigue.¹⁵ Caregivers who endorsed worsening health also reported poorer quality of life.¹⁵ In a semiquantitative study of 61 informal caregivers of liver transplant candidates, 75% of caregivers reported difficulty with concentration and 44% reported insomnia.¹⁶ Another study investigated gender differences in caregiver burden among 186 lung and heart transplant candidates and their caregivers.¹⁷ Women caring for male patients reported significantly worse health impact of caregiving as compared to other caregivers (ie, women caring for female patients, men caring for male or female patients).¹⁷ The authors suggest that these gender differences may be explained by the greater physical demands on women in providing assistance for daily activities of life for men.¹⁷ The patient's symptomatology can also affect the caregiver's physical health. Although not documented in transplant patients, a study of 132 patients with end-stage liver disease and their caregivers found that the presence of refractory ascites in patients was associated with *both* poor patient and caregiver physical quality of life.¹⁸

The physical consequences of caregiving often persist after transplantation. One study administered health-related quality-of-life surveys to caregivers of 242 lung and heart transplantation recipients at 2, 7, and 12 mo posttransplant.¹⁹ Caregivers reported worsening physical functioning and bodily pain during the first year after transplantation.¹⁹ Furthermore, negative caregiver health perceptions predicted poorer patient survival 1 y after transplant, independent of patients' own health status.¹⁹ The authors suggest that caregivers who have poor perceptions of their health may be less able to provide adequate care to their family member.¹⁹ Another study evaluated the physical health of 133 caregivers of heart transplant recipients using the Cumulative Illness Rating Scale at 2, 7, and 12 mo posttransplant. In the first year after transplantation, 29% of caregivers of heart transplant recipients experienced worsening of a general medical condition in the first year after transplantation.²⁰ An additional 8% of caregivers reported worsening health perceptions but had no objective medical decline.²⁰ Higher caregiver burden, poorer health history, and maladaptive coping styles were associated with worsening physical health.²⁰ Although caregivers often have their own medical problems, they report neglecting their own health to prioritize the patient's needs.⁶

Emotional and Psychological—Across all organ transplant populations, caregivers are at risk for emotional and psychological distress. One study administered psychometric testing to 621 caregivers of patients awaiting lung (n = 317), liver (n = 147), heart (n = 115), and kidney (n = 42) transplantation at the candidate's initial pretransplant evaluation.²¹ A total of 17% of caregivers exhibited clinically significant depressive symptoms as assessed by Beck Depression Inventory-II, and 13% reported clinically significant anxiety levels as assessed by the State Trait Anxiety Inventory.²¹ Greater caregiver burden and maladaptive coping styles were associated with high levels of depression and anxiety.²¹ A small study including 42 primary caregivers of patients listed for liver or kidney transplantation found that the prevalence of moderate to severe depression was 19% as assessed by the Epidemiologic Studies Depression Scale.²² These findings are not surprising in light of the strenuous demands of caring for patients with end-stage organ failure, which impact the caregiver's quality of life and mood. The waiting period for transplantation can be

particularly stressful. In a study of patients listed for liver transplantation (n = 47) and their caregivers (n = 24), caregivers reported elevated anxiety scores at baseline, which were surprisingly higher than patient-reported anxiety levels.²³ Caregiver-reported anxiety scores further increased during 3 to 5 mo in the transplant waiting period, which may reflect the accumulated burden of caregiving over time.²³

Furthermore, caregiver psychological distress may persist or develop *after* transplantation. One study conducted structured, standardized interviews using *Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised* criteria for 158 heart transplant recipients and their caregivers (n = 142). Among the caregivers, 18% met full or partial criteria for posttraumatic stress disorder 1 y after heart transplantation, at a similar prevalence to that of the patients (16%).²⁴ A cohort study of 190 caregivers of heart transplant recipients provided insight into the longitudinal psychological impacts of transplantation.²⁵ Cumulatively across 3 y, the onset rates of mood disorders among caregivers were as follow: posttraumatic stress disorder (23%), major depressive disorder (32%), generalized anxiety disorder (7%), and adjustment disorder (35%).²⁵ Posttraumatic stress disorder occurred predominantly during the first year after transplantation, whereas generalized anxiety disorder had a steady, linear increase in cumulative prevalence across 3 y.²⁵ Several studies, including caregivers of heart, lung, kidney, and liver transplant recipients, demonstrate that caregiver distress and burden are greatest in the early posttransplant period and improve over time.^{26–29} Improved caregiver burden within the first year of transplant is less commonly reported.³⁰ These data suggest that acute stressors surrounding the transplant surgery and difficult physical recovery period can be psychologically traumatic to caregivers. The onset of new mood disorders in caregivers beyond the early recovery period is consistent with the transplant survivorship experience, in which the chronic stressors of living with transplant (eg, long-term medical needs, financial problems) continue to impact the psychological health of caregivers.^{8,25}

Risk factors found to be associated with increased psychological distress among caregivers of solid organ transplant patients include high caregiver load, negative coping styles, poor physical health, unemployment, and lack of social support.^{21,24,26,31} Interestingly, increased patient psychological symptoms have also been associated with increased caregiver psychological distress.³² Notably, female caregivers of transplant patients are more likely to experience depressive symptoms compared with male caregivers.^{17,33} Women also report more caregiving responsibilities and less support from other family members in caregiving, which may explain some of the gender differences in psychological distress levels.^{17,33}

Beyond mood disorders, caregivers may also experience subclinical emotional distress that does not fit criteria for a mood disorder. Caregivers have reported feeling fear around the patient's deteriorating health or complications, worrying while awaiting organ donation, and feeling overwhelmed by caregiver responsibilities.^{6,34–37} Other reported emotions include guilt, anger, grief, irritability, uncertainty, loss of control, and spiritual or existential strain.^{35,36,38,39} This emotional and psychological strain of caring for patients before and after organ transplantation has been demonstrated to lead to poor quality of life for caregivers.^{12,40} In a study of caregivers of patients before and after liver

transplant, caregivers reported low mental quality of life (29 and 35%, respectively), low life satisfaction (45% and 32%), and high caregiving strain (59% and 81%).⁴⁰

Financial—Many families experience financial hardship throughout the transplantation process.^{15,41} Although transplant recipients typically have adequate health insurance, there often remain substantial out-of-pocket expenses, including insurance copayments or deductibles for hospitalizations and outpatient visits, medications, medical equipment, transportation, temporary lodging, and meals when traveling to the transplant center, parking fees, and childcare expenses.⁴¹ Adding to the stress is the threat of not being able to receive a transplant in the event of inability to pay.⁴² In a qualitative study of 11 patient–family member dyads awaiting kidney transplantation, family members expressed a broad range of financial concerns, including out-of-pocket expenses, ability to pay for immunosuppressant medications, health insurance coverage, and loss of insurance benefits after transplantation.⁴³

Financial strain may continue after transplantation, and resources that were available before transplant, such as social workers and financial coordinators, may be less available or absent in the years after transplantation.⁴⁰ A study surveyed 333 liver transplant and 318 kidney transplant recipients who were at least 1 y posttransplant about the financial impact of transplantation.⁴¹ Many patients (41%) reported that health problems related to transplantation have caused financial problems; 47% of patients had less monthly income after transplant compared with the year preceding the transplant. More than half (54%) used both personal and family savings to pay for these uncovered medical expenses.⁴¹ At the time of this study in 2007, patients reported average monthly out-of-pocket expense of \$476.60.⁴¹

Moreover, there are also indirect costs to caregiving, such as lost wages. Some caregivers must leave their formal jobs to dedicate time to the patient, which can exacerbate financial strain.³⁵ One study found that 59% of caregivers of liver transplant candidates gave up or reduced their employment because of the patient's dependence on them for day-to-day tasks as well as demands related to their medical care.¹⁶ Other caregivers must continue to work to contribute to the family income as patients are often not able to work because of medical disability.^{38,44} In a study of 50 caregivers of patients with chronic liver disease, 48% of caregivers reported working part-time or full-time, and 22% reported leaving their employment because of caregiving.⁴⁴ Some caregivers (22%) were also responsible for dependent(s) <18 y of age in their household.⁴⁴ Caregivers frequently do not receive financial assistance to care for the patient.³⁸ Thus, caregiving incurs many direct and indirect costs that can be sources of substantial stress and economic hardship both before and after transplantation.⁴¹

Logistical—The organ transplantation process is both medically and logistically complex, requiring meticulous coordination of care to guide the patient through each phase. Patients with end-stage organ failure often have decreased physical as well as cognitive functioning (eg, hepatic encephalopathy in patients with advanced liver disease) that limits their ability to navigate the transplantation process.⁴⁵ Yet, it is imperative that patients adhere to a battery of appointments and medications; if not, they may jeopardize their transplant eligibility or experience adverse outcomes such as graft rejection or loss.⁴⁶ Therefore, the caregiver often

plays a critical role in interfacing with the health care system and supporting the patient to meet transplantation requirements.

Caregivers often help patients adhere to complex medication regimens both before and after transplantation.¹⁰ Lieber et al¹⁰ conducted interviews with 20 liver transplant recipients and their caregivers on the challenges of recovery 3 to 6 mo after transplantation. Both patients and caregivers identified medication taking as a major challenge and frequently overwhelming, particularly the number and frequency of pills taken daily.¹⁰ Caregivers assist patients with the specific timing/varied schedule of medications—some of which are given multiple times a day to once every several months, need to be coordinated with diet, or dose-adjusted based on laboratory results.^{10,47} Patients and caregivers must also navigate polypharmacy, adapt to frequent medication changes, understand the indication of each medication, learn different modes of medication administration, and identify pharmacies that carry specialized drugs.^{48,49} Unfortunately, a substantial number of posttransplant patients are nonadherent to immunosuppressant therapy, which can lead to graft rejection or loss.^{50,51} Poor social support has been identified as a risk factor for medication nonadherence among solid organ transplant recipients.^{52,53}

In addition to complex medication regimens, patients with end-stage organ failure often require highly specialized treatments that necessitate caregiver assistance. These treatments include peritoneal dialysis, tracheotomy maintenance, mechanical circulatory support device (eg, left ventricular assist device, right ventricular assist device) management, sterile dressing procedures, and feeding tube maintenance.¹ As the complexity of patients' therapies increases, so too does caregiver burden. In a study of 239 heart transplant candidates and 193 caregivers, the caregivers of patients with mechanical circulatory support devices (primarily left ventricular assist devices) reported more difficulty providing care over time and higher caregiver burden compared with those caring for patients without devices.⁵⁴ Caregivers of patients with mechanical circulatory support devices must learn and use new and complex device management skills.⁵⁴ Moreover, patients with heart failure who require these devices often have greater symptom burden, which contributes to caregiver load.^{54,55}

Caregivers also experience difficulties in health care communication and navigation. Transplant centers, which require highly specialized medical and surgical expertise, are primarily concentrated in metropolitan areas, and many patients and caregivers must travel long distances to access the nearest center.^{56,57} Moreover, there are numerous logistics to coordinate, such as scheduling clinical appointments (eg, outpatient visits, laboratory testing, imaging), communicating with health insurance companies, assisting with application for disability services and benefits, and coordinating organ-specific treatments (eg, transportation to hemodialysis, cardiac or pulmonary rehabilitation).⁵⁸ Caregivers also communicate with the patient's multidisciplinary care team both during and outside of appointments and help patients to follow recommendations from their providers.⁶ In a qualitative study of 21 dyads of lung transplant recipients and their caregivers, nearly one-third (88/286) of caregivers' daily activities during the first 6 mo after transplant were related to supporting the patient's health, such as medication taking, health monitoring, appointments, and physical therapy.⁵⁸ In the inpatient setting, caregivers assist with

treatment decision-making, including critical decisions about life-sustaining treatments when patients are unable to participate because of severe illness.⁵⁹ Navigating the complex health care system can be time-consuming and overwhelming for the caregiver, and challenges are further compounded if the caregiver has low health literacy.^{60,61}

Social—Caregivers of solid organ transplant patients undergo profound changes in their personal identity, relationship with the patient, and relationship with others.^{12,16,35} The caregiver's usual roles in his or her societal context shift and become constrained when the caregiver role becomes the main purpose in life.³⁵ A loss of personal identity can occur during this process. Caregivers often give up or limit their time in roles that contribute to their individuality, such as hobbies or employment; some even relocate and experience a loss of privacy.^{16,35,38} In a small qualitative study of 3 caregivers of patients with a left ventricular assist device before heart transplantation, caregivers reported having to adapt and modify their lifestyle, family dynamics, and priorities, despite feeling ill-prepared or that they have no other choice but to do so.³⁶

The nature of the relationship between the caregiver and the patient may also change. In a cross-sectional study of 73 caregivers of lung transplant candidates, more than half (56%) reported clinically elevated caregiving strain.¹² Caregivers identified multiple contributors to caregiving strain, including feeling upset that the patient has changed so much (70%), inconvenience (80%), and feeling confined (73%).¹² Higher caregiving strain was also associated with less social intimacy between spouses and patients as assessed by Miller Social Intimacy Scale.¹² At the same time, poor patient-caregiver relationships have been associated with poor patient outcomes (eg, increased anxiety and depression and decreased self-care agency) and increased psychological distress in the caregiver after transplantation.^{26,62}

With the time-consuming demands of the transplantation process, it is not surprising that caregivers report negative effects on their social activities.^{12,35} Caregivers commonly become increasingly confined to the home or to medical settings with the patient, leading to loneliness, social isolation, and strained relationships with family and friends.^{12,35} Some caregivers felt that their family and friends were not able to relate to their experience and thus could not provide them the support that they needed.⁵ In a qualitative study of 11 caregivers of heart transplant recipients, caregivers reported feeling abandoned by family when the medical situation worsened.³⁵

Role of Coping on Caregiver Burden

How caregivers cope with the challenges of the transplantation journey has important implications on their psychological and physical health, quality of life, and ability to fulfill caregiving responsibilities. Whereas adaptive coping styles can potentially help to buffer the negative effects of caregiving, maladaptive coping strategies have been associated with greater psychological distress.^{63,64} In a study of patients awaiting lung (n = 317), liver (n = 147), heart (n = 115), and kidney (n = 42) transplantation, use of resignation and avoidance coping strategies was associated with increased depressive and anxiety symptoms.²¹ Use of avoidance coping strategies has also been associated with increased posttraumatic disorder

symptoms after transplantation among caregivers of heart transplant recipients.²⁴ Another study investigated posttraumatic growth among 218 caregivers of lung transplant recipients, which is the positive personal growth that people can experience through traumatic events.⁶⁵ Caregivers who experienced low levels of posttraumatic growth were less likely to use positive strategies like positive reframing and religion to cope with the transplantation.⁶⁵

Besides psychological health, coping styles can also affect the caregiver's physical health. Caregivers have reported increased eating as a way to cope with stressors of caregiving.²⁰ In a longitudinal study of 133 caregivers of heart transplant recipients, 14% experienced weight gain and worsening of a general medical condition in the first year after transplant.²⁰

Small studies demonstrate that coping styles impact caregiver quality of life and ability to perform caregiving duties. Myaskovsky et al⁶³ found that use of negative coping styles (eg, avoidance, self-blame) was associated with poor quality of life among caregivers of lung transplant candidates. In this study, 63% of caregivers used avoidant coping strategies and 16% used self-blame coping strategies.⁶³ In a study of 55 spouses of end-stage renal disease and transplant patients, caregivers who used fatalistic, evasive, and emotive coping were more likely to report low efficiency in handling the physical, psychological, social, and existential aspects of their partners' illness.⁶⁴

Equipping caregivers with adaptive coping strategies could potentially alleviate multiple domains of caregiver burden by improving caregiver confidence, resilience, and self-efficacy.^{21,66} No such interventions have been studied among caregivers of solid organ transplant patients to date.

Benefits of Caregiving

Caregiving can be rewarding and fulfilling, despite the many hardships involved. Caregivers have reported increased connection to the loved one they are caring for and gain satisfaction in improving the patient's well-being and quality of life.¹ Some undergo profound personal growth and find a sense of purpose and meaning.⁶⁷ In a study of 52 caregivers of liver and lung transplant candidates, caregivers identified several benefits of caregiving, including being able to help the patient (43%), spending time with the patient (28%), and personal growth (26%).⁶⁷ Other benefits reported by caregivers of patients undergoing solid organ transplantation include receiving support from others, discovering inner strength, and realizing what is important in life.^{12,40} Caregivers have also described feelings of relief, happiness, and satisfaction when the patients receive the call for transplantation.³⁶ These benefits are important for coping with the stress and burden of caregiving and should be reinforced when and where able.

Screening for Caregiver Burden

Identifying caregiver burden in routine clinical practice is important. To date, there are no screening tools for caregiver burden specific to the solid organ transplant population. However, various tools have been validated in other patient populations.⁶⁸ In particular, the Zarit Burden Interview (ZBI; originally developed to assess burden in caregivers of patients with dementia) has been examined the most throughout the literature, with strong psychometric properties and validation across multiple languages and cultures.^{68,69} The

22-item version is the most widely used version, but shorter versions of the ZBI have also been developed, including a 6-item version that has good diagnostic utility.^{69,70} The ZBI has been validated in caregivers of patients with heart failure,⁷¹ cirrhosis,⁷² and used in studies of caregivers of renal transplant recipients⁷³ and patients with interstitial lung disease.⁷⁴ Given the unique pressures faced by caregivers of transplant patients, development and validation of caregiver burden screening tools tailored to solid organ transplant populations are needed.

Interventions to Improve Caregiver Burden

Many caregivers have expressed the need for more support from the transplant team. In a study of 78 caregivers of lung transplant candidates, more than half reported needs in the following areas: expectations about the future, emotional support, financial, legal, and work issues, and who to contact for health concerns.⁷⁵ Caregivers frequently lack basic knowledge about transplantation and desire more education but report attrition of knowledge over time.^{6,10,76} Caregivers also desire emotional and psychological help but experience difficulties expressing their needs.³⁵ Interventions are urgently needed to address the multidimensional components of caregiver burden.

Caregiver Education—Several studies have investigated educational interventions for caregivers of transplant patients, although there is substantial variation in content, duration, and format.^{77–82} One survey of 351 kidney transplant recipients and their caregivers found that caregiver health knowledge was positively correlated with caregiving competency.⁸³ In nontransplant populations, low health literacy among caregivers has been associated with increased caregiver burden, poor patient self-management, and increased use of health services, highlighting the potential benefits of educational interventions.⁶¹

A pilot study of 100 liver transplant candidates and caregivers examined the effect of routine transplant education and found that posteducation, caregivers had significantly increased Rapid Estimate of Adult Literacy in Medicine-Liver scores.⁷⁷ Bailey et al⁷⁸ randomized liver transplant candidates and their caregivers to a self-management telephone intervention (eg, coping skills training, symptom management strategies; n = 56) versus routine liver disease education (n = 59). After 12 wk, there were no differences between the 2 groups in study outcomes, which included illness uncertainty, depression, anxiety, and quality of life.⁷⁸

Kayler et al⁷⁹ created educational animation videos for kidney transplant candidates and caregivers but found no differences in caregiver knowledge between the intervention (n = 78) versus standard nurse education alone (n = 66). Gerity et al⁸⁰ developed a face-to-face multimedia education intervention for lung transplant patients and caregivers that included instructional videos and practice demonstrations (eg, how to fill a pillbox of transplant medications). Although there were no differences in pre- and post-knowledge test scores between the 2 groups (n = 17 intervention group, n = 19 standard group), caregivers in the multimedia education group reported increased knowledge gains (94% versus 80%) and less anxiety about surgery (65% versus 33%) compared with those in the standard group.⁸⁰

In contrast to face-to-face education, Dew et al⁸¹ created a multicomponent internet-based intervention that provided education on a variety of topics, such as medication management and stress management for heart transplant recipients (n = 24) and their caregivers (n = 20). After 4 mo of website use, caregivers reported significantly decreased anxiety symptoms and improvement in role functioning related to emotional factors.⁸¹ Finally, Jesse et al⁸² evaluated the benefits of patient-to-patient education in a transplant group run by solid organ transplant recipients. After attending a 3-h face-to-face lifestyle education session led by a patient, the majority of caregivers reported the session was helpful (240/255; 94%) and were confident they could navigate the transplant process (211/255; 83%).⁸²

Mindfulness-based Stress Reduction—Small studies of mindfulness-based stress reduction techniques have demonstrated modest but significant benefits in caregiver stress.^{84,85} In a single-arm pilot study, 18 caregivers for heart, liver, kidney/pancreas, and stem cell candidates and recipients participated in a mindfulness-based resilience training course that incorporated mindfulness practice, yoga, and strategies for managing stress and enhancing resilience.⁸⁴ After 6 wk, caregivers reported significantly reduced stress (mean reduction in Perceived stress scale score by 3 points) but no differences in depression, anxiety, or emotional resilience scores.⁸⁴ In another single-arm pilot study, 30 caregivers of lung transplant candidates or recipients watched a DVD of mindfulness-based stress reduction techniques.⁸⁵ Caregivers who watched the entire video and practiced the techniques during 4 wk reported significantly decreased stress and anxiety.⁸⁵

Psychological Support—The role of psychological interventions on caregiver quality of life has been preliminarily explored. Rodrigue et al^{86,87} randomized patients awaiting lung transplant to supportive therapy (emotional and educational support) or quality-of-life therapy (a cognitive behavioral intervention with strategies to increase life satisfaction) during 8 to 12 wk. Interestingly, although caregivers (n = 28) did not directly participate in the interventions, caregivers of patients who received quality-of-life therapy reported significantly improved scores in quality of life (Quality-of-Life Inventory scores, $t = 2.3$), social intimacy (Miller Social Intimacy Scale, $t = 2.4$), and psychological functioning (Profile of Mood States Short Form, $t = 3.1$).^{86,87} These results support previous findings that the patient's coping and quality of life are important predictors of caregiver well-being and suggest that psychological interventions that do not involve the caregiver could still impart benefits to the patient-caregiver dyad.⁶³

Nurse-led Interventions—Some investigators have explored nurse-driven interventions to identify and improve caregiver burden. Li et al randomized patients and their caregivers to usual care (n = 36) versus a nurse-led collaborative care model (n = 37) for 3 mo after renal transplant. Nurses provided caregiver support, including assessing for psychological distress and caregiver burden and explaining the caregiver's role in the patient's rehabilitation. Caregivers in the intervention group had higher levels of health literacy compared with those in the control group (full mastery: 35% versus 28%; partial mastery: 54% versus 42%).⁸⁸ Bolden and Wicks⁸⁹ proposed applying the Stress Process Model through nurse-led interventions to support caregivers of liver transplant candidates. The Stress Process Model is a framework describing the various factors (caregiver characteristics, secondary

and primary stressors, mediators) that influence the caregiving experience.⁹⁰ Using this model, nurses can identify caregivers at risk for poor physical and mental health and provide transplant and community resources.⁹⁰ Application of the Stress Process Model to interventions for caregiver of solid organ transplant patients has not yet been empirically evaluated.

Other Interventions—Of the 10 studies on interventions targeting caregivers of transplant patients, 8 studies found positive benefits in caregiver health literacy, mood, and quality of life.^{77–82,84–88} Although the existing studies are hetero-geneous and constrained by methodologic limitations (eg, small sample sizes, lack of randomization, no comparison cohorts), caregivers in general were receptive to interventions and provided positive feedback.^{79,82} Additionally, many studies included both patients and caregivers, highlighting the potential for developing synergistic interventions that benefit the well-being of the patient–caregiver dyad.

In clinical practice, existing resources can be harnessed to support caregivers (Table 1). Clinicians should closely engage the caregiver throughout the transplantation process and prepare both patients and caregivers for the intricate management of their complex illnesses.^{1,93} The multidisciplinary transplant team should regularly screen for the various dimensions of caregiver burden both before and after transplantation. In particular, the transplant social worker plays a pivotal role in identifying needs and can connect caregivers to community mental health resources, financial counselors, and other social support.^{19,94} Incorporation of other transdisciplinary team members, such as chaplains to assess and care for existential distress or massage therapists for stress and physical strain reduction, has yet to be studied.

Clinicians can also consider referral to palliative care to provide increased psychosocial support for the patient–caregiver dyad.^{1,95,96} Palliative care is underused among solid organ transplant patients but has important potential benefits for patients and caregivers not just at the end of life but across the spectrum of the transplant experience.^{91,97} Palliative care provides support to patients and caregivers on a broad spectrum of issues, including symptom management, psychological distress, care coordination, and caregiver support.⁹¹ There is emerging evidence that palliative care for patients before and after solid organ transplant improves symptom burden, mood, quality of life, and advance care planning rates.^{98–101} Although not examined extensively in the solid organ transplant population, palliative care has been demonstrated to improve caregiver stress, depressive symptoms, and satisfaction with care in caregivers of patients with advanced cancer.^{102,103} Given the substantial needs of caregivers, the role of palliative care in addressing caregiver burden across the transplant continuum should be further investigated.

Future Research Directions

In transplant medicine, there are unexplored opportunities to optimize patient outcomes from the lens of the caregiver, particularly given their critical role in supporting the patient with end-stage organ disease and transplant. Further research is needed to characterize the impact of caregiver burden on the caregiver and on the short- and long-term outcomes of

transplant patients. Larger studies of caregivers for various solid organ transplant candidates and recipients are necessary to elucidate shared and unique attributes of the caregiving experience for patients with different types of organ failure. Creation and validation of caregiver burden assessment tools for the transplant population will enable more accurate identification of caregivers experiencing distress. Furthermore, inclusion of caregivers both before and after transplant can illuminate the evolution of caregiver needs and burden across the transplantation continuum. Qualitative studies can help to deepen understanding of the caregiving experience. Finally, interventions should be developed and evaluated that target the multiple domains of caregiver burden while simultaneously being feasible and sustainable to incorporate into the transplant clinic workflow.

CONCLUSION

The informal caregiver plays a vital role across all phases of adult solid organ transplantation but experiences significant stressors and burdens because of this demanding role. Caregiving burden spans broad domains—physical, psychological, financial, logistical, social—with the potential to disrupt every aspect of the caregiver’s life. Yet, limited knowledge exists about the experience of caregivers for transplant patients and interventions to mitigate caregiver burden. Further research is urgently needed to support a holistic approach to solid organ transplantation, one that values both patients and caregivers, with the goal to optimize well-being and outcomes for the entire family.

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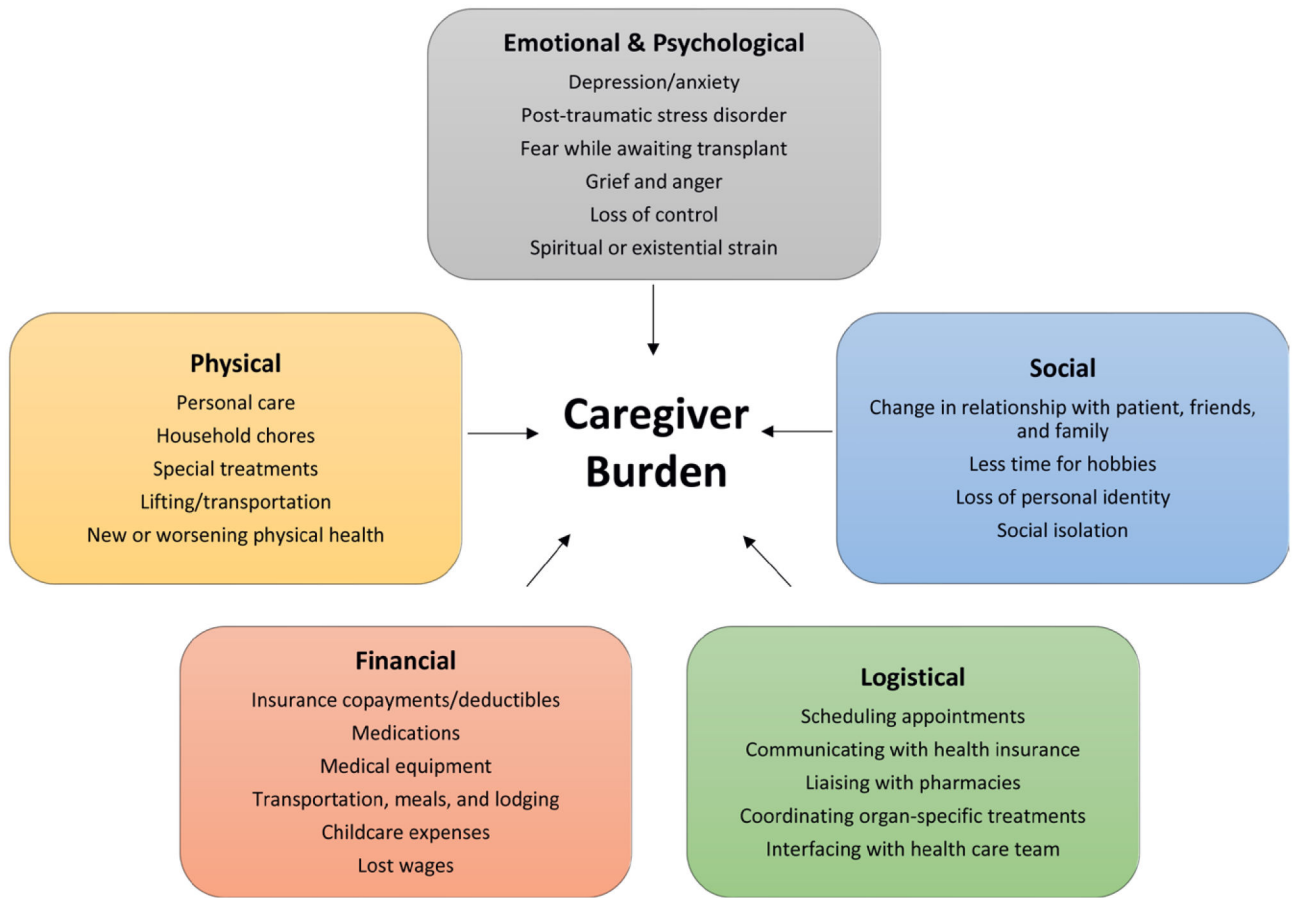


FIGURE 1.
Domains of caregiver burden.

TABLE 1.

Interventions to improve caregiver burden

Domains of burden	Examples of interventions
Physical	<ul style="list-style-type: none"> Enlist physical and occupational therapists to teach caregivers ergonomic ways of performing physical tasks, such as lifting, transferring, and bathing Advise caregivers to seek care from their primary care providers for physical health problems⁸⁸ Provide education on use of special equipment, such as peritoneal dialysis machines and ventricular assist devices
Emotional and psychological	<ul style="list-style-type: none"> Inquire about and acknowledge spectrum of emotions experienced by caregivers Screen for depression and anxiety among caregivers Refer to community mental health resources Teach adaptive coping strategies and mindfulness-based stress reduction techniques^{84,85} Consider palliative care referral to provide additional psychosocial support⁹¹
Financial	<ul style="list-style-type: none"> Refer to financial counselor Assist caregivers with short-term disability applications¹ Explore ways to reduce cost of medications, such as drug assistance programs at pharmaceutical companies Connect to local or national organizations for patients with specific diseases that negotiate with insurance to reduce insurance co-pays or provide direct co-pay assistance Encourage personal fundraising efforts, such as through online crowdfunding platforms
Logistical	<ul style="list-style-type: none"> Solicit patient navigator to help patients and caregivers navigate the health care system, including facilitating appointments, liaising with insurance, and communicating with care team Enlist transplant pharmacists for medication reconciliation, education, training, and reduction of polypharmacy⁹² Use effective communication strategies to educate patients and caregivers about their health and the transplant process¹
Social	<ul style="list-style-type: none"> Connect to support groups for caregivers of organ transplant patients¹⁹ Refer to online resources, such as forums and social media groups for caregivers Arrange for respite with backup caregiver so that the primary caregiver can rest and attend to personal needs^{2,71} Share mindfulness-based stress reduction techniques to promote self-compassion and reduce loneliness^{84,85}