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#### Recommended Citation

Jesse MT, Hansen B, Bruschwein H, Chen G, Nonterah C, Peipert JD, Dew MA, Thomas C, Ortega AD, Balliet W, Ladin K, Lerret S, Yaldo A, Coco T, and Mallea J. Findings and recommendations from the organ transplant caregiver initiative: Moving clinical care and research forward. Am J Transplant 2021; 21(3):950-957.

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# Findings and recommendations from the organ transplant caregiver initiative: Moving clinical care and research forward

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## Funding information

Novartis; American Society of Transplantation; NATCO The Organization for Transplant Professionals; Society for Transplant Social Workers; Henry Ford Health System; International Society for Heart and Lung Transplant; National Kidney Foundation

Lay-caregivers are essential to the continuum of care in adult organ transplantation. However, we have a limited understanding of the experiences, exigencies, and outcomes associated with lay-caregiving for organ transplant patients. While much discussion and debate has focused on caregiver requirements in relation to transplant candidate selection, little focus has been given to understanding the needs of caregivers themselves. In response to this, the Organ Transplant Caregiver Initiative was created, and a meeting was held during October 6–7, 2019. Transplant healthcare professionals, researchers, and lay-caregivers discussed the experiences, educational needs, existing research, and research recommendations to improve the experience of lay-caregivers for adult organ transplant patients. In this report, we summarize the

**Abbreviations:** AST, American Society of Transplantation; CMS, Centers for Medicare & Medicaid; FMLA, Family Medical Leave Act; MELD, Model for End Stage Liver Disease; OCTI, Organ Transplant Caregiver Initiative; PSECOP, Psychosocial and Ethics Community of Practice.

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Organ Transplant Caregiver Initiative and meeting findings, providing a preliminary action plan to improve education, research, and advocacy for organ transplant caregivers.

#### KEYWORDS

ethics and public policy, editorial/personal viewpoint, education, social sciences, patient education, mental health

## 1 | INTRODUCTION

Organ transplantation is a life-sustaining, care-intensive intervention for patients with end-stage organ disease. Lay-caregivers (also referred to as informal or family caregivers, henceforth caregivers) provide an essential role across the stages of transplantation and living donation, including referral, evaluation, maintaining listing status, surgery, short- and long-term recovery. Caregivers are members of the patient's family, friends, or community who provide any of multiple types of social support, including instrumental, informational, and emotional support for the patient. Caregivers typically do not have financial or contractual obligations to provide support, but often sacrifice income due to caregiving demands.<sup>1</sup> Caregiving for transplant patients can entail providing assistance with complex medication regimens, transportation, activities of daily living, emotional support, fundraising, and coordination of other support members.<sup>2-5</sup>

Verification of social support is a requirement to be waitlisted in most organ transplant programs.<sup>6</sup> Caregivers fulfill this role and provide vital contributions throughout the transplant process. Despite this, gaps remain in understanding the experience and impact of caregiving in organ transplantation. Caregivers report both significant levels of burden and benefit from their role.<sup>2-5</sup> Specific burdens and benefits derived from caregiving vary and change over time, depending on patient and other contextual factors. However, limited data are available on the physical, emotional, and economic impact of caregiving on the transplant caregiver, or caregivers' impact on transplant patient outcomes. For example, there are virtually no data on whether or what aspects of caregivers impact patient survival or other outcomes. Financial and economic costs have been closely examined in other chronic illness populations indicating variability across specific illnesses and countries.<sup>7</sup> However, financial impact of caregiving has not been closely examined for organ transplant populations despite caregivers reporting significant financial burdens.<sup>5</sup> As a result of the dearth of data and complexity of the circumstances, prioritizing caregivers as relevant stakeholders in organ transplantation is vital to further understanding of the organ transplant caregiving experience and impact.

In response to calls for a greater focus on organ transplant caregivers, the Organ Transplant Caregiver Initiative (OTCI) was started in 2018 and a consensus meeting was held during October 6-7, 2019 in Dallas, Texas. The purpose was to bring together relevant stakeholders (including caregivers) to (a) determine the specific burdens and potential benefits of caregiving, and identify existing resources

and resource needs reported in the empirical literature, (b) identify and develop comprehensive educational resources for organ transplant caregivers, and (c) define research goals to help address the needs of caregivers for organ transplant populations. In this report, we summarize the OTCI and meeting findings and provide a preliminary action plan to improve education and research for organ transplant caregivers.

## 2 | METHODS

The American Society of Transplantation (AST) Psychosocial and Ethics Community of Practice (PSECOP) established the OTCI in early 2018 in response to a call from the AST Patient Summit (occurred October 23, 2017). During a breakout session, organ transplant recipients and caregivers voiced the need for more resources for caregivers including comprehensive educational resources, supportive resources including mental health related, and research funding. In response, an invitation was sent to the membership of the PSECOP for participation and monthly conference calls were scheduled to discuss the OTCI's objectives. During each call (occurring monthly beginning in February 2018), OTCI members developed objectives including improvements in educational resources and development of caregiver-specific research priorities. A decision was made to focus on caregivers in adult transplantation as a starting point, given that adults constitute the greatest pool of patients in organ transplantation and because caregiver issues in pediatric care are distinct and would require separate consideration. From the calls, preliminary review of the empirical literature published in peer-reviewed scientific journals (eg, searched via PubMed), and review of publicly accessible education resources, several overarching themes or content domains were identified. Domains were categorized as generalizable across all organ transplant populations (ie, transplant caregiver role and responsibilities, legal and financial considerations, caregiver quality-of-life and self-care, and special considerations) and organ specific (lung, liver, kidney, heart). From these domains, eight workgroups were established to address both the education and research within the respective content areas. Each workgroup identified and reviewed existing resources (eg, publicly available resources, empirical literature) to outline all possible topics. Emphasis was placed on identifying gaps in existing knowledge. As there were often significant gaps in the organ transplant specific literature, workgroups were encouraged to review other pertinent chronic illness literature or resources if relevant. However, given

the unique demands associated with caregiving in organ transplant, literature from other populations focused on content thought to be generalizable to broader caregiving experience (eg, basic strategies for caregiver self-care) with the objective of complementing the organ transplant literature. Each workgroup created two presentations for the meeting: educational presentations summarizing recommended content and research presentations summarizing the existing literature, research gaps, and initial recommendations for needed research.

The OTCI meeting occurred during October 6–7, 2019 in Dallas, Texas, with the financial support of Novartis and AST. Additional sponsors included the Henry Ford Transplant Institute, NATCO-The Organization for Transplant Professionals, National Kidney Foundation, Society of Transplant Social Workers, and the International Society for Heart and Lung Transplantation. Twenty-four individuals from across the United States attended the meeting including clinical psychologists, epidemiologists, social workers, physicians, clinical researchers, and caregivers of organ transplant recipients (representing the four organs). The objectives were to: (a) summarize the current empirical evidence on organ transplant caregiver burdens, benefits, and interventions; (b) develop a comprehensive educational toolkit for caregivers of adult organ transplant populations; and (c) develop a consensus-based, prioritized list of specific research goals on caregiving in adult organ transplant populations, with clear reasoning behind each priority. Over the course of 2 days, presentations followed by group discussions occurred on the educational needs and research priorities on caregivers of adult organ transplant patient populations. Following each education presentation, discussion questions included whether additional information within that content area should be included, whether anything was not helpful or should be excluded, and any other resources to be reviewed. Following each research presentation, discussions included review of main themes of the research to date, what research was needed, what research should be prioritized, and any other information helpful in developing research priorities. All sessions were recorded for accurate documentation of proceedings. During and following the conference, detailed notes were taken to ensure all thematic content was recorded. Thematic content from research discussions was condensed to reflect central themes. In January 2020, OTCI participants and sponsors were sent online surveys requesting they rank research themes from highest to lowest priority (described further below).

### 3 | SUMMARY OF BURDEN, BENEFITS, AND INTERVENTIONS

The literature reviews and discussions revealed significant limitations in our current knowledge of burdens, benefits, and interventions for caregivers of adult organ transplantation populations. Caregiver burden is a broad term, encompassing both objective elements (eg, specific tasks) and subjective elements (eg, caregiver perception of strain) that can adversely impact caregivers' physical,

**TABLE 1** Summary of organ transplant caregiver perceived burdens and benefits

#### Caregiver burdens reported across organs

##### Lifestyle

- Required lifestyle changes
- Financial concerns/sacrifices
- Less personal time/time constraints/competing time demands
- Work-related adjustments

##### Patient well-being and care needs

- Rapid disease progression
- Worry about candidate/recipient's health
- Patient suffering
- Patient behavior, keeping patient's mood positive

##### Impact of caregiving

- Uncertainty/unpredictable future
- Feeling unprepared
- Disturbed sleep
- Emotional adjustments
- Physical strains
- Neglecting own needs

#### Examples of organ-specific factors related to greater caregiver burden(s)

##### Kidney

- Patient on either hemodialysis or peritoneal dialysis (vs transplant)

##### Liver

- Alcoholic etiology
- Higher Model for End-Stage Liver Disease (MELD) score
- Previous hepatic encephalopathy and cognitive dysfunction
- Need to care for recipient and donor

##### Lung

- Cleaning and care of tracheotomy

##### MCS/heart

- Biopsies posttransplant
- Higher resting heart rate
- Difficulty managing infections and driveline
- Worry about pump performance

#### Commonly identified caregiver benefits

##### Patient-related

- Spending more time with the patient
- Providing physical, financial, and emotional support to the patient
- The gift of transplant and a second chance at life/patient survival
- Improved patient well-being and quality of life

##### Personal growth

- Realizing/recognizing what is important in life
- Discovering one's own inner strength
- Gaining a new life perspective

(Continues)

TABLE 1 (Continued)

Feeling wanted or needed  
 Hope for life renewed  
 Greater faith

Note: References for table provided in Table S2B.

financial, psychological, social, and spiritual functioning.<sup>8</sup> The current literature suggests that over half of organ transplant caregivers report high levels of burden, based upon scale-specific clinical cut-offs, both prior and after transplantation.<sup>9,10</sup> Commonly identified burdens among organ transplant caregivers are outlined in Table 1 (references provided in Table S2B). However, changes in organ transplant caregiver burden over time remain unclear and some findings suggest that burden is context specific. For example, burden levels can differ depending on the type of organ transplantation (eg, heart vs lung), the etiology of disease for a given organ (eg, alcoholic liver disease vs other liver etiologies), the phases of transplant (eg, evaluation for listing vs living with transplant), and specific aspects of medical care (eg, maintaining a tracheotomy, sterile dressing changes), amongst others.<sup>2,4,9-13</sup>

Understanding burden in organ transplant caregivers is critical given the empirical literature has shown associations between greater caregiving burden and more depressive symptoms, anxiety, mood disturbances, sleep disturbances, decreased health-related quality of life, and lower life satisfaction among organ transplant caregivers.<sup>2,9,13-15</sup> While there is evidence that caregiver health-related quality of life (HrQOL) predicts patient mortality,<sup>16</sup> whether caregiver burden impacts transplant recipients' clinical outcomes is largely unknown. Although not yet examined in transplantation, the general chronic disease literature has shown that greater caregiver burden, even when accounting for sociodemographic and physical health factors, is associated with a significantly greater risk of caregiver mortality.<sup>17</sup>

While there are numerous burdens, organ transplant caregivers also report a variety of benefits, or benefit finding, from their role as caregiver. Benefit finding is defined as the gaining of positive coping or adjustment from a significant life stress or trauma.<sup>18</sup> Commonly reported transplant caregiver benefits are outlined in Table 1. While greater caregiver benefit has been associated with greater caregiver life satisfaction,<sup>9</sup> it is unknown to what extent caregivers experience benefit, whether perceived benefit changes over time, whether context impacts benefit finding (eg, type of organ, phase of the transplant process), or what processes are involved in organ transplant caregivers reporting greater benefits from caregiving. Lastly, there are no data on whether organ transplant caregiver perceived benefits impact either caregiver or patient outcomes.

Ultimately, there is a shortage of high-quality research on interventions for caregivers of adult organ transplant patients. The majority of interventional research involving caregivers of organ transplant patient populations has focused on the development, implementation, and provision of educational resources.<sup>19,20</sup> Therapeutic interventions suggest that self-management interventions may not

improve self-efficacy compared to standard education,<sup>21</sup> whereas mindfulness may be beneficial for reducing stress or distress.<sup>22,23</sup> However, many of these studies were with small samples from single institutions and therefore may not generalize across varied contexts.

#### 4 | EDUCATION: DEVELOPMENT OF THE ORGAN TRANSPLANT CAREGIVER TOOLKIT

Within patient-centered care frameworks, educational efforts should target the patient and their support network, engaging all relevant stakeholders (eg, patients, caregivers, healthcare providers) in both design and implementation. Education should also be culturally tailored (eg, linguistically appropriate), ongoing, multidirectional in communication or feedback, empowering, contribute to shared decision-making, and foster trust across stakeholders.<sup>24,25</sup> Within the broader chronic disease framework, educational content has focused on information sharing, shared decision-making, activities of care related to managing lifestyle factors, self-care practices, adaptive coping strategies, and behavioral self-management.<sup>26</sup>

Before the meeting, the workgroup agreed that there was a need to develop a dynamic and comprehensive toolkit for caregivers of organ transplant populations, with the intention of modeling the toolkit after the AST Live Donor Toolkit<sup>27</sup> and other established caregiver resource guides (eg, American Cancer Society<sup>®28</sup>). Prior to the meeting, stakeholders compiled and reviewed existing educational resources, discussed areas of educational content, and outlined factors to be addressed in the development of educational resources (eg, health literacy, cultural sensitivity). Over the course of preparing for discussions during, and post-meeting efforts, the generalizable educational content domains evolved to encompass the themes in Table 2.

From the meeting in Dallas, the group also discussed the need to utilize multiple formats (eg, video, written). This requires the engagement of additional stakeholders (eg, web development) as the goal is to provide a comprehensive, accessible, and routinely updated educational resource. This also requires the infrastructure to maintain and update the resource. Also apparent from the meeting was the unmeasurable value of having caregivers engaged throughout the entire process. At this time of this writing, the Organ Transplant Caregiver Toolkit is under development.

#### 5 | RESEARCH PRIORITIES

Clearly apparent was the relative dearth of empirical literature on the experience of organ transplant caregivers. During meeting presentations and discussions, numerous topics and themes emerged. Across the themes, two core themes emerged; the specific research focus or content (eg, improved understanding of caregiver mental and physical health, cultural/spiritual/religious factors, types of interventions) and research methods/design (eg, dyadic studies, prospective longitudinal studies). Full summary of themes provided in

Table S1A. Research themes were entered into an online survey (Qualtrics) and sent to all members of the initiative members, regardless of attendance at the meeting. Nineteen, of 27 invited, responded, and provided rankings of themes from lowest (1) to highest (10) priority. The final rankings of high research priorities are presented in Table 3. While specific areas of research focus were identified (eg, caregiver mental health), the most pervasive theme across discussions and subsequent ranking was the need for prospective research studies examining the caregiver-patient dyad on both patient and caregiver outcomes. Also, of very high priority was the need for research to identify the most efficacious content, format, timing, and frequency of educational efforts on both caregiver and patient outcomes.

## 6 | ADDITIONAL DISCUSSION: ADVOCACY

An additional discussion topic of advocacy for federal policies to provide greater protections for organ transplant caregivers emerged during the meeting. Although there have been considerable improvements in federal and state policies establishing protections for organ transplant populations, organ transplantation still incurs considerable financial expense.<sup>29</sup> Federal policies, such as the Family Medical Leave Act (FMLA), are designed to protect eligible employees from job loss when necessary to take time off work to care for an immediate family member with a serious health condition. However, FMLA only provides job protection without required pay stipulation. The limits on the amount of unpaid job-protected leave may not address the unique needs in end-stage organ disease and transplantation. Certain states and cities have paid leave programs, although such programs remain few and limited.<sup>30</sup> Unpaid leave can create notable financial burden to caregivers, most of whom may not have assessed their economic status prior and do not receive financial assistance for the care they provide. Further discussion on potential advocacy for protections and resources for organ transplant caregivers, at both the state and federal level, is necessary to offset financial burdens.

## 7 | DISCUSSION

The findings of this initiative and report provide a preliminary plan for improving education, research, and advocacy for organ transplant caregivers. First, there is a dire need for comprehensive, freely accessible educational resources for caregivers of organ transplant populations. This will require resources and ongoing support from existing infrastructures (eg, national organizations) to maintain and update educational content. Secondly, focused research funding is needed to improve our understanding of the impact of caregiving in organ transplant patient populations and develop, test, and refine interventions aimed at improving outcomes for both patients and caregivers. For those interested or

**TABLE 2** Transplant caregiver toolkit generalizable domains

Educational content
<b>Themes and general content</b>
Transplant caregiver role and responsibilities
Identifying caregivers (eg, who and how, confirming and changing caregivers)
Transplant evaluation
Transplant hospitalization
Posttransplant discharge and recovery
Effective communication with the transplant team (eg, patient advocacy, styles of communication)
<b>Legal and financial considerations for caregivers</b>
Legal Issues and considerations (eg, Family Medical Leave Act [FMLA], power of attorney for health care, family responsibilities discrimination, guardianship)
Financial issues and considerations (ie, paid leave programs, power of attorney for finances, managing social security/veterans' benefits, short-term disability for caregivers, tax breaks, caregiver expenses)
<b>Caregiver quality of life and self-care</b>
Caregiver self-care
Caregiver stress
Relationship stress during caregiving
Caregiver rewards
Caregiver burden
Support groups
When to ask for help/who to ask
<b>Special considerations with caregiving</b>
Cultural, spiritual, and religious considerations with caregiving
End-of-life and palliative care
Privacy and relationship issues
Participating in clinical research
Emergency preparedness planning (ie, flu season, natural disasters, public health crises, power outages)

involved in transplant research, collaborative relationships across centers should be developed and young investigators should be mentored to explore this topic of research. Third, there is a need to develop collaborative relationships between healthcare systems and organizations (eg, National Kidney Foundation, American Society of Transplantation) to advocate, locally and nationally, for legal protections and additional resources for these caregivers. Fourth, it is vital to engage caregivers in all processes to contribute their unique perspectives and experiences.

Caregivers provide invaluable patient support outside the formal hospital system, but also act as care navigators (eg, attend doctor's appointments) within the medical setting. Caregivers engage in vital communication and provide information with the multidisciplinary clinical team and are a source of social and emotional support for patients. Clinicians often expect caregivers to dedicate time and resources with an undefined end date while

**TABLE 3** Recommended research priorities and reasoning from the organ transplant caregiver meeting

Mean ranking score <sup>a</sup>	Highest research priorities
	<b>Research focus or content</b>
9.06	Impact of caregiving on the caregiver Currently, we have a limited understanding of the impact of caregiving on caregivers. To develop and test interventions we must first have a significantly better understanding of the impact of caregiving on the caregiver
9.00	Development and refinement of educational and other resources for caregivers including optimal timing and frequency of provision Consistent theme across discussions on both education and research was the absence but dire need for comprehensive educational resources. However, the question remains on the most efficacious content, format, timing, accessibility, frequency, and other characteristics of education
8.72	<b>Research methods/design</b> Prospective work on pre- to posttransplant predictors of outcomes for caregivers and patients Limited data examining the long-term impact on caregiving
	<b>High priorities</b>
	<b>Research focus or content</b>
8.41	Caregiver impact on patient
8.22	Impact of therapeutic interventions with the caregiver
8.11	Impact of interventions engaging additional supports and/or resources for the care of the patient
8.00	Impact of financial assistance program or planning tools
7.82	Caregiver mental health
	<b>Research methods/design</b>
7.76	Improved assessment and measurement of caregivers, including identification of caregivers at risk for negative outcomes
7.72	Multi-site studies
7.67	Mix-methods data collection
7.18	Adequate sample sizes/sampling
6.44	Dyadic data collections

<sup>a</sup>Potential range was 1 (lowest priority) to 10 (highest priority).

staying abreast of numerous aspects of the patient's care. Amid their role as a support system for the transplant recipient, caregivers also must manage their own emotional and personal adjustments, including significant lifestyle changes. As clinical providers require individuals to assume this role, we have the ethical obligation, under both beneficence and non-maleficence, to assist and support caregivers throughout this process. Furthermore, providers have an ethical duty, based upon the principle of autonomy, to provide education on medical services offered to facilitate patients' ability to make informed decisions. However, organ transplantation is a complicated, dynamic, and interpersonal process involving multidisciplinary teams interacting with diverse social support networks and the broader community over prolonged periods of time. How individuals, departments, healthcare systems, and other organizations provide education on organ transplantation to patients and caregivers has the potential to directly impact access and outcomes. A consensus from this initiative was the dire need for comprehensive educational resources for organ transplant caregivers.

We, as healthcare providers, scientists, and the greater organ transplant community, have the shared knowledge to develop, test, and refine resources and interventions for organ transplant caregivers. The OTCI identified needed areas of research focus, content, and methodology. The highest identified priority for interventional research was to determine the most efficacious timing, frequency, duration, and content of education to impact both patient and caregiver outcomes. Other high priority interventional research included therapeutic interventions, interventions aimed at mobilizing additional social supports, and the impact of financial assistance programs. Ultimately, fully powered, multi-institutional, randomized controlled trials are necessary to clearly determine the effects of caregiver interventions. While the current literature on caregivers is an essential starting point for our understanding of caregiver-related educational needs, well-designed interventional research is desperately needed. To accomplish this, more research funding initiatives at the federal level should be provided for caregiver-based research and caregiver-focused requests for applications.



This initiative is an important first step in improving the experience of our caregivers. We, the members of the OTCI, hold that the findings from this meeting will stimulate further discussion and advocacy for efforts to improve education, resources, research, and policy to assist caregivers of adult organ transplant patient populations.

## ACKNOWLEDGMENTS

The following societies, organizations, and companies provided financial support for the Consensus Conference: Novartis, American Society of Transplantation, NATCO The Organization for Transplant Professionals, Society for Transplant Social Workers, Henry Ford Health System, International Society for Heart and Lung Transplant, and the National Kidney Foundation. We would also like to thank James R. Rodrigue, PhD, for his ongoing support and mentorship. This manuscript is a work product of the American Society of Transplantation's Psychosocial and Ethics Community of Practice, Organ Transplant Caregiver Initiative.

## DISCLOSURE

The authors of this manuscript have no conflicts of interest to disclose as described by the *American Journal of Transplantation*.

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#### SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

**How to cite this article:** Jesse MT, Hansen B, Bruschein H, et al. Findings and recommendations from the organ transplant caregiver initiative: Moving clinical care and research forward. *Am. J. Transplant*. 2021;21:950–957. <https://doi.org/10.1111/ajt.16315>