ISHLT CONSENSUS STATEMENT

Engagement of Social Support Systems in Patients Being Considered for and Following Advanced Heart and Lung Surgical Therapies: An ISHLT Expert Consensus Statement

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Social support systems, particularly caregivers, play a critical role in the evaluation, treatment, and recovery of patients undergoing heart or lung transplantation or left ventricular assist device (LVAD) implantation. However, definitions, assessment practices, and expectations for social support vary considerably across programs, and evidence guiding optimal caregiver engagement remains limited. This International Society for Heart and Lung Transplantation expert consensus statement

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summarizes current evidence and provides recommendations for assessing, engaging, and supporting social support systems across adult and pediatric populations. A multidisciplinary international writing committee reviewed the literature and developed recommendations through a structured consensus process. Social support encompasses medical management, logistical, emotional, informational, psychological, and companionship assistance, with caregiver needs and responsibilities evolving across the treatment trajectory. Existing assessment approaches and interventions are heterogeneous, with limited longitudinal evidence. Consensus recommendations emphasize early caregiver identification and engagement, structured and tailored education and skills training, longitudinal assessment of caregiver needs and burden, integration of caregivers into clinical workflows, access to psychosocial and palliative care resources, and peer support. A strengths-based, individualized approach that recognizes social and structural barriers is recommended to promote equitable access and optimize patient and caregiver outcomes.

J Heart Lung Transplant

KEYWORDS:
caregiving; social support; consensus statement; advanced heart and lung therapies; mechanical circulatory support

1. INTRODUCTION

Patients undergoing candidacy evaluation, awaiting surgery or recovering from advanced heart and lung surgical therapies, such as transplantation and left ventricular assist device (LVAD) implantation, face considerable physical, psychological, and social challenges. Post-operative management is complex, with patient outcomes considerably influenced by patient self-care abilities.[1,2] Research has shown that supplemental help is needed when a patient requires medically complex care or when their physical and mental capacity may fluctuate due to their medical condition.[3,4] Given the complex nature of advanced heart and lung surgical therapies, effective and engaged social support systems are often required for patients to undergo these therapies.[5–7] The social support requirement stems from a critical need to ensure that patients have the support that is required for adherence to a complicated medical regimen and adjustment to living with a new treatment for a chronic disease. This can include rigorous medication schedules, surveillance of side effects and complications, frequent medical visits, and lifestyle changes after transplantation or LVAD implantation. A key component of a patient's social support system is a capable caregiver, most often a family member or partner. This role is typically unpaid, carried out by family, friends, neighbors, or other community members who assist with self-monitoring, self-management, and medical management tasks. Beyond these responsibilities, caregivers often provide emotional and practical support and, in some cases, financial assistance—frequently while also managing household and family tasks previously handled by the patient.

The process of effectively engaging these support networks remains difficult, requiring tailored strategies to address varying patient and caregiver needs, the fluctuating capacities of patients, and the dynamic nature of support relationships. The goals of this consensus statement are to 1) summarize the current state of evidence and practice regarding social support systems, including caregiver roles, for adult and pediatric individuals undergoing evaluation, treatment, and recovery from advanced heart and lung surgical therapies, and 2) provide consensus-based recommendations to guide programs in effectively assessing, engaging, and supporting patients and their caregivers in order to optimize adherence, recovery, and long-term outcomes following cardiothoracic transplantation or LVAD implantation. Notably, the context surrounding a patient's social support system varies by nation and region, in part due to differences in public support for services such as healthcare costs, medication costs, and transportation. Programs should interpret this document within their own region's sociopolitical and geographic context accordingly.

2. METHODOLOGY

This consensus document was developed in accordance with policies of the International Society for Heart and Lung Transplantation (ISHLT) Standards and Guidelines Committee. Members of the consensus committee were selected and approved by the ISHLT Standards and Guidelines Committee to reflect the multidisciplinary scope

and diversity of the Society. Six project leaders were appointed to oversee document development. The broader writing committee was assembled to ensure expertise across heart transplantation, lung transplantation, left ventricular assist devices (LVAD), and pediatric populations. In addition to subject-matter expertise, committee members were selected to promote diversity in geography, gender, and career stage, and included a range of professional perspectives, including physicians, advanced practice providers, nurses, nurse researchers, and psychologists.

The writing committee was organized into six working groups, each assigned responsibility for a specific subsection of the document and led by one or two project leaders. Each working group included representation from heart transplantation, lung transplantation, LVAD, and pediatric disciplines to ensure comprehensive perspectives. Targeted literature searches were conducted for each subsection using databases such as PubMed and Embase to identify relevant peer-reviewed publications, with a primary focus on studies published between 2000 and July 2025. Earlier foundational studies were included when deemed important by consensus of the writing group. Given the limited evidence base, a broad range of study designs was considered, including observational studies, case reports, and single- and multicenter retrospective and prospective studies. A more focused and systematic literature search was conducted to identify interventions aimed at enhancing social support for patients undergoing advanced heart and lung surgical therapies, as described in detail below. A centralized reference library was maintained and updated throughout the drafting and revision process.

A modified consensus development process was used to generate and refine recommendations. Working groups developed initial draft statements based on available evidence and expert interpretation. Where evidence was particularly limited, the writing group prioritized development of principle-based consensus recommendations intended to promote consistency while allowing flexibility across diverse practice settings. These statements were iteratively reviewed by the full writing committee through structured virtual meetings held between September 2024 and May 2025. Feedback was incorporated across multiple rounds of revision. Consensus was defined a priori as agreement by ≥80% of participating members. In cases of initial disagreement, statements were revised based on group discussion and re-circulated until consensus was achieved or the statement was reframed to reflect areas of uncertainty.

Project leaders integrated contributions from each working group into a unified document, ensuring consistency in terminology, scope, and framing of recommendations. In keeping with ISHLT Standards and Guidelines Committee requirements for consensus documents, recommendations were not formally graded by level of evidence. Instead, they reflect expert consensus informed by the best available data and clinical experience. The draft manuscript underwent external peer review, and feedback was incorporated through additional rounds of revision. Final approval of the consensus statement was obtained from all members of the writing committee.

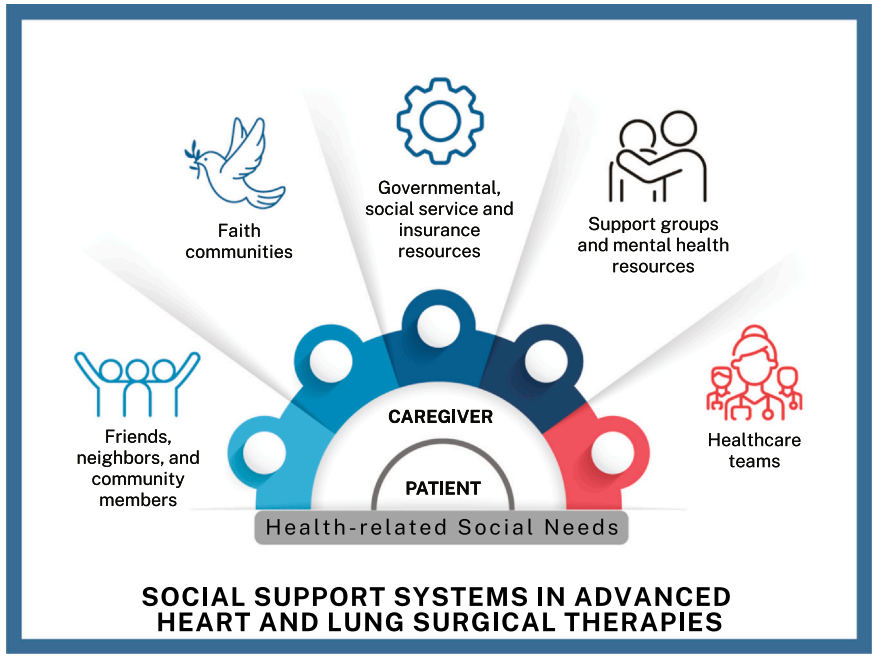
3. DEFINITION OF SOCIAL SUPPORT SYSTEMS OF PATIENTS UNDERGOING ADVANCED HEART AND LUNG SURGICAL THERAPIES

3.1. Defining social support systems for patients undergoing advanced heart and lung surgical therapies

In the literature, social support systems are broadly defined as the network of relationships or resources perceived or received by individuals and encompasses emotional, informational, instrumental, and companionship assistance.[8,9] Supplemental support is highly correlated with patient outcomes in cardiothoracic transplant and LVAD care across the lifespan.[10–13] However, the evidence linking specific caregiver support is mixed.[14] Most cardiothoracic transplantation and LVAD programs, along with the healthcare systems they operate within, define social support narrowly, often equating it with the presence of a capable caregiver alone. The identification and expected engagement of caregivers varies by healthcare system and program, occurring when a patient names a caregiver or when one is visibly involved in medical interactions. Although greater emphasis is placed on caregiver involvement during the transplant or LVAD evaluation and post-surgical phase, many caregivers have already been fulfilling this role before advanced heart and lung surgical therapies are considered.

It is important to acknowledge that the role of social support differs within the pediatric context. Caregivers are adult legal guardians, most often parents, who ultimately are the primary decision makers and consenting

Figure 1 Social Support Systems in Advanced Heart and Lung Surgical Therapies.



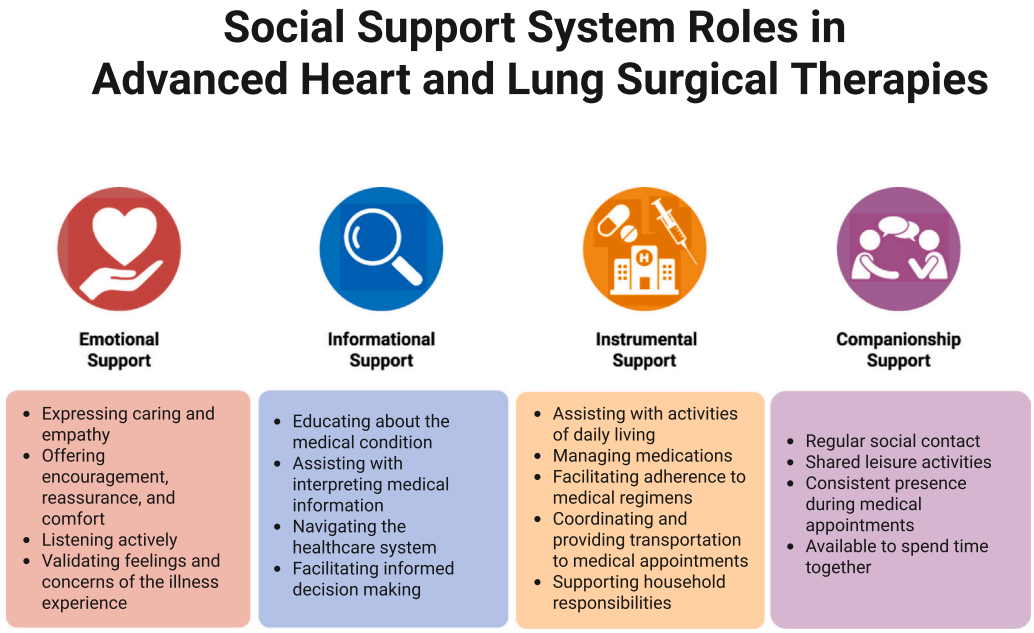
individuals regarding advanced therapies. Adult caregivers of children are responsible for management of treatment, logistics (e.g. transportation), insurance and financial demands, and the overall well-being of the child requiring advanced heart or lung therapies. As such, caregivers are not typically 'identified' or 'required' in the same context as adult social support systems. Rather, both adult caregivers and pediatric patients are viewed as a unit being cared for within a family-systems approach.

Based on current evidence, we propose the following definition of social support systems for patients undergoing advanced heart and lung surgical therapies **(**Figure 1**)**. *Social support systems for patients considering cardiothoracic transplantation or LVAD implantation refer to the network of individuals and resources that provide medical management, logistical, emotional, and psychological assistance throughout the treatment journey*. These systems typically include family members, partners, friends, and community or spiritual support persons, as well as formal resources such as support groups, social workers, and healthcare teams. Effective social support systems ensure that patients have reliable caregivers to assist with complex medical regimens, logistical support, symptom monitoring, and medical management, while also promoting emotional resilience and adherence. It is important to note that some aspects of social support that are necessary in some countries are provided by government programs or societal infrastructure, such as universal healthcare systems and financial assistance programs. The context of the patient and caregiver's place of residence as well as the geographic location of the transplant center are both important in assessing adequacy of support systems (e.g. relocating to be in closer proximity of transplant or LVAD centers).[15] The stability, availability, and capacity of these supports are factors that influence candidacy, recovery, health-related quality of life (HRQoL), and long-term outcomes after advanced heart and lung surgical therapies.

3.2. The role of the social support system in advanced heart and lung surgical therapies

The role of the social support system in advanced heart and lung surgical therapies has evolved over time. In addition to influencing medical outcomes, research has shown that providing support to patients following heart or lung transplant or durable LVAD implantation may also mitigate the impact of psychosocial risk factors such as cognitive impairments, intellectual disability or mental health challenges on post-transplant or post-implant outcomes.[5,6,16] Overall, the role of providing support involves addressing patient needs that include: 1) emotional, 2) informational, 3) instrumental, and 4) companionship needs (Figure 2). Although all members of the healthcare team play an important role in addressing those needs, caregivers often assume such responsibilities once the patient is discharged. Lack of a caregiver is one of

Figure 2 Social Support Systems Roles in Advanced Heart and Lung Surgical Therapies.



the most common psychosocial contraindication to pursuing advanced heart and lung surgical therapies.[17] However, the definition of what constitutes an adequate caregiver is variable and understudied. For most programs, an important component of the evaluation process for advanced heart and lung surgical therapies includes assessment of a patient's social support system regarding availability, knowledge, and understanding of the patient's condition. Conveying treatment options and care requirements to both the patient and caregivers prior to the surgical intervention, as well as expectations following a transplant or durable LVAD implant is equally as important.[6,18] Additionally, these needs change over time; depending on the phase of care or complications experienced by the patient, the amount of time and support required can fluctuate.

3.2.1. Emotional support

Caregivers are commonly expected or presumed to provide emotional support during all phases of the surgical period, including evaluation, the waiting period, and post-operatively. This is provided through physical presence, encouragement, and emotional caring.[19,20] Emotional support is particularly important given the significant psychological and emotional stress associated with complex medical conditions and treatments faced by patients being evaluated for and undergoing advanced heart and lung surgical therapies.

3.2.2. Informational support

Informational support involves helping patients understand their medical condition, interpret clinical information, and make informed decisions. Caregivers often assist in organizing, collecting and communicating information between the patient and health care providers.[20] Integrating medical care to include partnership with the caregiver and other members of the patients' support system such as parents, siblings, and friends can increase the likelihood of accurate, timely, and effective transfer of information.[21] This type of support also encompasses involvement in decision making, such as pursuing aggressive interventions and assisting with the transition to end-of-life care.[22]

3.2.3. Instrumental support

Instrumental support involves concrete, practical assistance provided by caregivers. Specifically, it encompasses direct help with essential tasks and logistical aspects of managing complex medical conditions, such as assistance with activities of daily living, medication management, coordinating and providing transportation to appointments, facilitating adherence to treatment regimens and supporting household responsibilities as well as managing financial issues.[6] This

type of support is especially intense in the post-transplant and post-LVAD population. Caregivers often serve as an extension of the medical team to manage complex care tasks including adherence to complex medical regimens, management of complications including device-related issues and dressing changes for patients with LVADs.

3.2.4. Companionship support

Companionship refers specifically to the support derived from meaningful interpersonal interactions and a sense of belonging and connectedness. This type of support involves regular, enjoyable social interactions that provide patients with feelings of companionship, friendship, inclusion, and emotional closeness. Such interactions can mitigate feelings of isolation and loneliness, which are commonly experienced in patients facing prolonged illness, complex medical routines, or extended recovery periods.[23]

3.3. Dynamic nature of needs and caregiving intensity

Social support systems play a pivotal role in shaping the illness and recovery trajectories for patients undergoing heart or lung transplantation or receiving an LVAD. The dynamic nature of illness and recovery in advanced heart and lung disease means that social support needs to evolve over time, from intensive caregiving in the perioperative period to long-term assistance with self-management, transportation, and emotional adjustment.

Following heart or lung transplantation or implantation of a durable LVAD, the patient's health condition is expected to improve. It is anticipated that the patient's ability to assume personal responsibility for their activities of daily living and adherence to the prescribed plan of care increases over time, thereby reducing dependence on the caregiver to support those activities. However, recovery from such procedures is influenced by the patient's degree of disability prior to surgery and condition at discharge as recovery times can vary widely. Further, the patient may have been dependent on others even before the surgery, limiting the degree of independence that can be expected after returning home. A caregiver's experience can be significantly impacted when a patient experiences unexpected complications or recovery is delayed.

While caregiving demands may lessen over time, they can also intensify in cases of complications or end-of-life circumstances. Many caregivers may struggle to discuss end-of-life concerns, such as in the context of transplant re-listing or LVAD deactivation.[24,25] The role of the caregiver often persists until the end of life for patients with a heart or lung transplant or LVAD implant. The caregiver may participate in advance care planning discussions and in some cases will take on the role of surrogate decision maker at the end of life. Particularly in the LVAD population, device deactivation is described as a period of confusion, characterized by caregivers seeking to understand the legal and ethically-permissible care of patients with an LVAD approaching death.[24]

4. CURRENT INTERNATIONAL GUIDELINE AND CONSENSUS RECOMMENDATIONS FOR SOCIAL SUPPORT SYSTEMS OF PATIENTS UNDERGOING ADVANCED HEART AND LUNG SURGICAL THERAPIES

International guidelines addressing social support recommendations for patients undergoing advanced heart and lung surgical therapies are primarily those provided by the ISHLT (Table 1). It is widely recognized that insufficient or inadequate social support can negatively affect patient outcomes across patient populations receiving these advanced therapies. However, it is important to highlight that although many programs require the identification of a dedicated and capable caregiver or caregivers prior to cardiothoracic transplantation or LVAD implantation, not all programs across the globe endorse this criterion. The current guidelines described below also do not provide specific recommendations endorsing this requirement. *Ultimately, assessment of social support should focus on a strengths-based approach and aim to facilitate rather than deny transplantation or LVAD implantation.*[26]

4.1. Heart transplantation recommendations

The ISHLT Guidelines for the Evaluation and Care of Cardiac Transplant Candidates strongly endorse the importance of social support for patients being considered for heart transplantation.[27] According to these

Table 1 Summary of Guideline and Consensus Recommendations

Guideline	Domain	Guideline and Consensuses Recommendations Related to Social Support Systems in Patient Undergoing Advanced Heart and Lung Surgical Therapies	Limitations
International Society for Heart and Lung Transplantation Guidelines for the Evaluation and Care of Cardiac Transplant Candidates—2024Peled et al. (2024)	HeartPeds	• In heart transplant candidates, confirmation of social support is recommended, including caregivers who: 1) understand the severity of patient's illness and their role as caregiver toward a potential transplant recipient; 2) can support both the patient's emotional and physical needs; 3) are dedicated to providing dependable care. *[COR 1; LOE B-NR]* • The unique and central challenge of the pediatric heart transplant candidate psychosocial assessment is that children are not responsible for, nor do they have control over, their environment or family functioning. Specifically in pediatric heart transplant candidates, the focus of the psychosocial assessment should be on identifying strengths and opportunities for optimization rather than reasons to deny transplant. *[No Recommendation]*	• Does not define 'adequate social support' • Does not provide recommendations on how to evaluate social support
Consensus Document for the Selection of Lung Transplant Candidates: An Update from the International Society for Heart and Lung TransplantationLeard et al. (2021)	Lung	• Adequate support and caregiving in both the pre- and post-operative period are critical for success with lung transplant, and lack of support may increase risk of non-adherence and post-transplant mortality. Transplant centers are encouraged to consider socioeconomic status within the broader context of the patient's support system and psychological resources in order to identify patients requiring enhanced surveillance and support. However, socioeconomic factors should not warrant exclusion from candidacy. *[Consensus Recommendation]*	• Does not recommend strategies to assess socioeconomic status • Lack of definition on levels of socioeconomic status that warrant concern
The 2018 ISHLT/APM/AST/ ICCAC/STSW Recommendations for the Psychosocial Evaluation of Adult Cardiothoracic Transplant Candidates and Candidates for Long-Term Mechanical Circulatory SupportDew et al. (2018)	LVADHeart	• The psychosocial evaluation should evaluate *[Consensus Recommendation]*: o Availability, stability, and capacity of family and other sources to provide support o Understanding and knowledge among family and other supports of Treatment options and current care needs. o Expectations of family and other supports about care needs after intervention (i.e., transplant, mechanical circulatory support)	• Does not recommend specific strategies to evaluate these domains
The 2023 International Society for Heart and Lung Transplantation Guidelines for Mechanical Circulatory Support: A 10-Year UpdateSaeed et al. (2023)	LVAD	• The psychosocial evaluation should screen for factors specific to patients' personal, social, and environmental resources and circumstances, including: a.) Coping with illness b.) Social support c). Social history [COR 1; LOE B] • In patients with a history of non-adherent behavior, lack of sufficient social support and limited coping skills are relative contraindications to DMCS. [COR IIb; LOE C] • Caregiver burden should be assessed before DMCS implantation to assure that support will be available. Agreement on behalf of the patient is not sufficient. [COR 1; LOE C] • Significant caregiver burden or lack of any caregiver is a relative contraindication to patient's DMCS implantation. [COR IIb; LOE C]	• Lack of guidance around assessment tools for caregiver burden
International Society of Heart and Lung Transplantation Consensus Statement for the Selection and Management of Pediatric and Congenital Heart Disease Patients on Ventricular Assist DevicesLorts et al. (2021)	PedsLVAD	• The goal of the psychosocial assessment is to identify patient and family strengths, weaknesses and intervention needs, particularly as they relate to VAD care demands. [Consensus Recommendation] • Similar to pediatric pre-heart transplant listing, primary domains of the pre-VAD psychosocial evaluation should minimally include: patient and family treatment adherence, barriers to medical management, disease and VAD-related knowledge, cognitive and/or neurodevelopmental functioning, current and historic mental health, substance use, social support, family functioning, and abuse and legal history. [Consensus Recommendation]	• Does not recommend specific strategies to evaluate these domains • Lack of definition on 'family functioning'

Continued

Table 1 Summary of Guideline and Consensus Recommendations

Guideline	Domain	Guideline and Consensuses Recommendations Related to Social Support Systems in Patient Undergoing Advanced Heart and Lung Surgical Therapies	Limitations
A Consensus-Based Framework for the Psychosocial Evaluation of Candidates for Cardiothoracic Transplant and Ventricular Assist DevicesLefkowitz et al. (2025)	Peds	• The psychosocial evaluation should *[Consensus Recommendation]*: o Assess patient and family social support history including family dynamics, conflict and support systems o Encourage family involvement in development of a plan of care for managing patient medical needs o Assess social and physical environment conditions (e.g. housing, exposure to substances), trauma and mental illness histories, insurance coverage, and access to resources and transportation	• Does not recommend specific strategies to evaluate these domains

APM=Academy of Psychosomatic Medicine; AST=American Society of Transplantation; COR=Class (Strength) of Recommendation; DMCS=Durable Mechanical Circulatory Support; ICCAC=International Consortium of Circulatory Assist Clinicians; ISHLT=International Society of Heart and Lung Transplantation; LOE=Level (Quality) of Evidence

LVAD=Left Ventricular Assist Device; NR=Nonrandomized; Peds=Pediatrics; STSW=Society for Transplant Social Workers; VAD=Ventricular Assist Device

guidelines, caregivers are expected to understand the seriousness of the patient's condition, assume caregiving responsibilities, and provide consistent emotional and physical support. Importantly, the guidelines also stress the need for the psychosocial evaluation (which includes social support) to be dynamic over time. Notably, these are the only guidelines that assign a specific level of evidence for a recommendation related to heart transplant recipients' social support. However, despite this recognition, the guidelines do not define adequate social support or recommend how to evaluate social support. This lack of specificity may lead to significant variability in how social support is assessed across transplant centers, potentially impacting equitable access to transplantation.

The 2018 ISHLT Recommendations for the Psychosocial Evaluation of Adult Cardiothoracic Transplant Candidates and Candidates for Long-Term Mechanical Support similarly highlight social support as an important domain for evaluation.[6] The document is comprehensive and asserts that psychosocial support should be considered when evaluating patients for heart transplant or LVAD. Specifically, the statement recommends considering the availability, stability and capacity of the social support system as well as the understanding of those in the social support system about the transplant process and expectations of care needs in the post-transplant phase. Similar to the ISHLT Guidelines for the Evaluation and Care of Cardiac Transplant Candidates, they do not provide specific recommendations on how to evaluate this support.

4.2. Lung transplantation recommendations

The ISHLT Consensus Document for the Selection of Lung Transplant Candidates is the only document that includes recommendations related to social support in the lung transplant population. It highlights that unreliable social support systems or caregiving plans are among the factors with high or substantially increased risk of a negative outcome for the patient.[5] This consensus statement recommends that social support is adequately assessed and supported as part of the candidate's evaluation process. It also recommends that transplant centers explore socioeconomic factors alongside psychological and social support systems to identify patients who need additional monitoring and assistance. However, socioeconomic challenges alone should not exclude patients from transplant candidacy. Notably, the consensus document does not include recommendations for specific strategies to assess socioeconomic status and lacks a definition on levels of socioeconomic status that warrant concern.

4.3. LVAD recommendations

There are several guidelines and consensus statements that include recommendations for patients considered for LVAD therapy. The 2023 ISHLT Guidelines for Mechanical Circulatory Support recommend psychosocial evaluation of LVAD candidates and suggest all patients should be screened for the presence and adequacy of social support.[28] Significant caregiver burden or lack of sufficient social support is a contraindication to LVAD implantation. As stated above in the heart transplantation recommendations, 2018 ISHLT Recommendations for the Psychosocial Evaluation of Adult

Cardiothoracic Transplant Candidates and Candidates for Long-Term Mechanical Support recommends considering the availability, stability and capacity of the social support system, the understanding of those in the social support system about the LVAD implantation process and expectations of care needs in the post-implant phase.[6] Despite these recommendations, none of the documents offer guidance regarding what should comprise the social support system for an individual patient or specific assessment tools for this population.

4.4. Pediatric recommendations

Pediatric social support recommendations are encompassed in several guidelines and consensus documents for patients considering heart transplantation or LVAD implantation. The ISHLT Consensus Statement for the Selection and Management of Pediatric and Congenital Heart Disease Patients on Ventricular Assist Devices states that the psychosocial assessment should aim to identify strengths, challenges, and support needs for patients and families undergoing VAD implantation. Key evaluation areas include adherence, medical management barriers, disease and device-related knowledge, cognitive functioning, mental health history, substance use, social and family support, and abuse or legal history.[29] The Consensus-Based Framework for the Psychosocial Evaluation of Candidates for Cardiothoracic Transplant and Ventricular Assist Devices similarly states that the psychosocial evaluation should examine the patient and family's social support history, including family dynamics and conflicts, promote family involvement in care planning, and assess environmental and psychosocial factors such as housing, trauma, mental illness, insurance status, and access to transportation and other resources.[30]

A vital difference in the evaluation of all pediatric transplant candidates is that patients are largely—if not completely—dependent on caregivers for all aspects of care, including social support. Furthermore, pediatric candidates do not have agency to choose their caregivers or ensure adequate care outside of the wishes of their social support network. Fortunately, in most societies, additional social support systems exist for children in governmental, charitable, and educational settings, adding to the social support from primary caregivers. Mitigating these risks and utilizing these resources is a landscape navigated by pediatric transplant programs on an individual level, but no guidelines exist to harmonize or maximize the social support potentially available in pediatric transplantation.

5. ASSESSMENT TOOLS FOR SOCIAL SUPPORT SYSTEMS

Social support systems are routinely assessed during evaluations for advanced heart and lung surgical candidacy as part of a comprehensive psychosocial evaluation. These assessments are designed to identify patient and caregiver strengths, potential barriers, and unmet needs that may influence clinical outcomes. The 2018 ISHLT Consensus Document on the Psychosocial Evaluation of Adult Cardiothoracic Transplant Candidates and Candidates for LVAD, authored by Dew et al., provides a foundational framework and identifies ten core psychosocial domains that should be systematically evaluated:[6]

1. Treatment adherence and health behaviors
2. Mental health history
3. Substance use history
4. Cognitive status and capacity to give informed consent
5. Knowledge and understanding of current illness
6. Knowledge and understanding of current treatment options
7. Coping with illness
8. Social support
9. Social history
10. Knowledge about and capacity to operate LVAD (specific to patients being considered for LVAD implant)

Several of the Dew et al. domains, such as social support, coping with illness, treatment adherence, and knowledge of illness and treatment, rely on caregiver involvement and capacity. To facilitate this assessment, many adult advanced heart and lung surgical therapy programs use a standardized psychosocial assessment checklist or tool such as the Psychosocial Assessment of Candidates for Transplantation (PACT)[31], Transplant Evaluation Rating Scale (TERS)[32], Psychosocial Levels System (PLS)[33], Millon Behavioral Health Inventory (MBHI)[34], or the Standard Integrated Psychosocial Assessment for Transplant (SIPAT)[35]. Each of these tools

includes a standardized but subjective assessment of the patient's social support system by a psychosocial professional team member. Tools vary greatly in the social support system characteristics assessed and their level of detail (i.e., availability, stability, capacity, understanding). Few of these tools focus on the caregiver, such as assessment of caregiver burden. Most programs rely on informal assessments conducted by the social work team to assess caregiver burden and rarely follow caregivers longitudinally.[36]

Despite conflicting guideline recommendations, many programs still include the lack of an identified and capable caregiver as a contraindication to transplantation or LVAD implantation. Existing psychosocial evaluation tools provide a broad overview of social support system availability—such as caregivers—but do not specify assessment of the practical aspects of availability which may include verification of time off from work for the caregiver, caregiver health, competing caregiver obligations, or the ability of the caregiver to relocate. "Availability of the caregiver" can mean a verbalized commitment to be a caregiver or a contract with the caregiver. Furthermore, existing assessment tools do not comprehensively assess functionality of the social support system or capacity to fulfill this critical role. According to theoretical models, caregiver self-efficacy, health literacy, mental health, cognitive function, support from others, and burden are important factors that impact caregiver contributions to patient care.[4] These elements are not routinely assessed before or after transplant or LVAD implant. Incorporating more thorough and longitudinal caregiver assessments may provide a better understanding of caregivers' capacity to serve as a primary support person for patients with these advanced treatment options and may also help clinicians identify gaps in the patient's support system that could be mitigated through supportive interventions. While evidence is lacking to support an endorsement for any specific standardized assessment tools, Table 2 provides an overview of commonly used psychosocial evaluation assessment tools.

5.1. Pediatric considerations

While the social support research literature is less robust in the pediatric population, it is known that social support, and specifically, parental and family support, is critical for optimizing outcomes post-transplant or LVAD implant. Across the solid organ transplant literature, stressors within the family support system, including single-parent household, family conflict, low family cohesion, and poor family communication have been found to be associated with post-transplant adherence challenges.[37] Assessment of caregiver and social support within pediatrics emphasizes caregiver willingness and ability to manage the therapy regimen. A recent Consensus Document on the Psychosocial Evaluation of Pediatric Candidates for Cardiothoracic Transplant and LVAD, emphasized domains for assessment similar to the adult recommendations.[30] Caregiver mental health, health literacy, access to transportation, housing and related resources, adherence to child's treatment requirements, and available caregiver social support (i.e., grandparents, extended family) are also critical to the effectiveness of this role. Often adult caregivers or parents have primary caregiver responsibilities for other children as well. Standardized social support assessment tools are not commonly used in pediatrics. Assessment and intervention are tailored to the unique needs of the child and caregiver unit. Notably, when a caregiver or social support system is not identified for a child with critical illness, typically government or state authorities are engaged rather than using the lack of social support as an absolute contraindication to transplant or LVAD therapy.

6. CAREGIVER AND PATIENT OUTCOMES ACROSS THE TRAJECTORY OF THE ADVANCED THERAPY JOURNEY

The experience of the caregiver supporting individuals prior to and after advanced heart and lung surgical therapies can be labor-intensive.[38–40] Post-transplant and LVAD care involves high-intensity medical regimens, complex decision-making, and frequent interactions with the medical team. As such, caregivers often describe the role as equivalent to a full-time job. Common caregiver experiences are further described in Table 3. Based on the trajectory of the patient's clinical course, caregiving demands may intensify, further compromising caregivers' health and emotional stability.[41,42] Many describe the experience as a "roller coaster" marked by unpredictability and with their own social or professional lives being put on hold.[43] Reported caregiver outcomes across these populations include multidimensional burden, impact on psychological health,[44–46] impaired physical health, and overall HRQoL [47–49] and feelings of satisfaction and reward (Figure 3).

Table 2 Psychosocial Caregiver Evaluation Measures

Psychosocial Evaluation Measure	Psychosocial Domains assessed	Social Support Subscale	Method of Administration	Scoring and Cut-offs	Psychometrics
Stanford Integrated Psychosocial Assessment for Transplant (SIPAT)	1. Patient's Readiness Level and Illness Management 2. **Social support System Level of Readiness** 3. Psychological Stability and Psychopathology 4. Lifestyle and Effect of Substance Abuse	1. Availability of Social Support System 2. Functionality of Social Support System 3. Appropriateness of physical living space & environment (Poor- excellent	Clinician Interview	Total Score range 0–129 ● 0–6 Excellent candidate ● 7–20 Good candidate ● 21–39 Minimally acceptance candidate ● 40–68 High risk candidate ● >69 Poor candidate	Inter-rater reliability 0.847–0.853
The Psychosocial Assessment of Candidates for Transplantation (PACT) scale	1. Social support 2. Psychological health 3. Lifestyle factors 4. Understanding of transplant and follow-up	1. Family/Support System Stability 2. Family/Support System Availability	Clinician interview	Final score 0–4 ● 0=poor candidate ● 1=borderline candidate ● 2=acceptable candidate ● 3= good candidate ● 4=excellent candidate	Inter-rater reliability (intraclass correlation= 0.85)
Transplant Evaluation Rating Scale (TERS)	1. Prior psychiatric history with axis 1 disorders 2. Prior psychiatric history with axis 2 disorders 3. Substance use/abuse 4. Compliance 5. Health behaviors 6. **Quality of family and social supports** 7. Prior history of coping 8. Coping with disease and treatment 9. Quality of affect 10. Mental status (past and present)	Quality of family and social supports assessed based on support availability, willingness to support patient (Good-excellent, fair-good, fair-poor)	Clinician interview	The sum of the weighted scores for each domain produces a total score range 26.5–79.5. Higher scores represent greater impairment in the levels of psychosocial functioning.Quality of family/social support weight 2.5 (1.0–4.0 scale)	Inter-rater reliability 0.8–0.9
Psychosocial Levels System (PLS)	1. Past psychiatric history 2. Quality of family/social support 3. Prior coping history 4. Coping with disease and treatment 5. Quality of affect 6. Proneness to anticipatory problems 7. Mental status	Quality of family and social supports assessed based on support availability, willingness to support patient (Good-excellent, fair-good, fair-poor)	Clinician interview	Based on information gathered, the clinician assigns a level that represents the patient's overall psychosocial functioning. ● Level 1=mild/minimal ● Level 2=moderate ● Level 3=severe **Scoring differs based on which version is administered*	Not well documented
Millon Behavioral Health Inventory	1. Personality style 2. **Psychogenic attitude** 3. Psychosomatic correlate 4. Prognostic index	Psychogenic attitude domains include a scale called Social Alienation that relates to a person's level of social support	Self-report	Base Rate Scores are used for interpretation. Scores >75 indicate problematic traits and a score of >85 indicate a personality disorder	Not well documented

Bolded = specific domains that address caregiver support and suitability

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Table 3 Caregiver Experiences Across the Care Trajectory

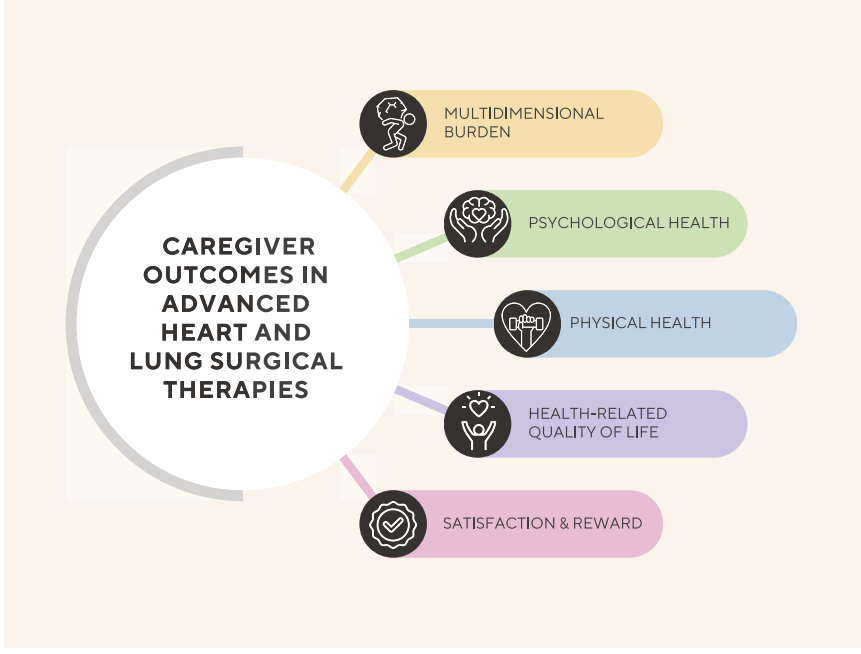
Caregiver Experiences	Illustrative Examples from Published Literature	Citations
Anxiety, fear, nervousness, frustration and uncertainty about the future	Not knowing when the transplantation will happen	Yagelniski et al., 2020; Anthony et al. 2014
	Patient's condition worsens and they are afraid their loved one might die before an organ becomes available	Kurz et al., 2001; Glaze et al., 2021; Ivarsson et al. 2014 Jesse et al., 2021
	Living through the experience that the transplant was canceled last minute	Glaze et al., 2021
	Mixed feelings when receiving a call that an organ was available; described as devastating and stressful, but also happy and relieved as this flags the start of something new and vital for themselves and the patient	Glaze et al., 2021; Ivarsson et al., 2014
	Persistence of feelings post-transplant because they are aware of what might be ahead of them, including the risk of cancer, medication side effects, acute or chronic rejection and premature death	Ivarsson et al., 2014; Goetzmann et al., 2012
	Constant worry about the patient's condition and future, each day can have unexpected ups and downs	Ivarsson et al. 2014; Jesse et al., 2021DeGroot et al., 2021
Feeling overwhelmed, burdened, and fatigued	Onset of caregiving when a patient needs a transplant or LVAD described as a forced choice and having no other option between life and death, also referred to as a Hobson's choice	Magid et al., 2016; Magasi et al., 2019
	Amount of information received when patients are waitlisted, which was often perceived as complex, too difficult or frightening	Glaze et al., 2021; Ivarsson et al., 2014
	Multitude of roles and responsibilities they are requested to take on a daily basis during the transplant process	Kurz et al., 2001; Glaze et al., 2021; Crowe et al., 2020; Petruik et al., 2017; DiFusco et al., 2020
	Feeling overwhelmed by the demands of caregiving for a patient with an LVAD and recognizing the profound impact of caregiving on caregiver health-related quality of life, including physical and emotional health	Magasi et al., 2019
	Fatigue and having difficulties sleeping	Rodrigue et al., 2007; Xu et al., 2012; Casida et al., 2015; Jesse et al., 2021
Setting aside own needs or competing time demands	Assisting the patient physically, mentally and socially is such a time-consuming and demanding job, caregivers tend to disregard their own needs, hobbies and friends	Ivarsson et al., 2014; Jesse et al., 2021
	Caregivers with young children are particularly strained, and prioritize their children's well-being and supportive needs over their own needs for support	Ivarsson et al., 2014
	Mobilization of networks of support provides caregivers of LVAD patients with time to step out of their caregiver role to pursue other roles and responsibilities	Magasi et al., 2019
Loneliness and social isolation	The request to relocate closer to the transplant center while waiting and during the immediate recovery phase means that they sometimes need to leave their homes unattended and are far away from their regular support networks and other relatives	Yagelniski et al., 2020; Crowe et al., 2020
	In some regions, the patient and primary caregiver needs to relocate closer to the transplant center while waiting for a transplant or during the immediate post-transplant recovery phase	Yagelniski et al., 2020
	Engaging less in social activities or meetings with friends or family, sometimes described as feeling confined, to make sure their loved one receives optimum care	Glaze et al., 2021; Ivarsson et al., 2014 Crowe et al., 2020; Petruik et al., 2017; DiFusco et al., 2020
	A sense of role loss and abandoning social and leisure activities to meet caregiving demands intensified caregiver burden, especially when an individual was the only caregiver of an LVAD patient	Magasi et al., 2019

Continued

Table 3 Caregiver Experiences Across the Care Trajectory

Caregiver Experiences	Illustrative Examples from Published Literature	Citations
Change in the relationship with the patient	Especially in couples, changes in the relationship with the patient can lead to conflict, problems with intimacy or interpersonal distancing	Rodrigue et al., 2007
	Patients sometimes withheld information from them to spare them	Ivarsson et al., 2014
	Family or friends have difficulties to relate to their experiences of waiting or receiving a transplant and some even feel betrayed by their environment	Yagelniski et al., 2020; Ivarsson et al., 2014
	Relationship strain has been reported by both LVAD patients and their caregivers, including misaligned expectations between patient and caregiver resulted in relationship strain	Magasi et al., 2019
Financial concerns and social and professional sacrifices	Reducing or giving up employment in order to be able to take up their caregiver duties, which might cause financial difficulties	Yagelniski et al., 2020; Jesse et al., 2021; Glaze et al., 2021
	Insurance companies not providing a financial compensation for taking time off work to take care of their loved one	Yagelniski et al., 2020; Ivarsson et al., 2014
Positive aspects of caregiving	Enjoying everyday moments and independence	DeGroot et al., 2021
	Feeling grateful for having more time together with their loved one	Magasi et al., 2019

Figure 3 Caregiver Outcomes in Advanced Heart and Lung Surgical Therapies.



Most research has focused on spousal or partner caregivers, leaving the experiences of parents, children, siblings, and other relatives underexplored. The trajectory of caregiver burden over time also remains unclear, as most studies examine only the pre- or immediate post-transplant or implant period. While the pre-transplant or implant phases are consistently reported as the most stressful, some caregivers find post-transplant adjustment more challenging than anticipated.[50] Early recovery often requires attention to complex medical regimens,

frequent clinic visits, close monitoring, and management of complications. During this phase, caregivers can provide a substantial amount of support. Ongoing availability of the caregiver is often assumed by patients and providers even past the early recovery phase despite evidence that some caregivers cannot sustain this role.[51] When patients experience complications, such as chronic rejection or device-related adverse events, caregiving demands intensify, often triggering increased burden and stress.

6.1. Multidimensional burden

Burden refers to the physical, emotional, social, and financial strain experienced by those providing support to patients before and after advanced heart and lung surgical therapies. Burden arises from both objective demands (e.g., managing household tasks, assisting with self-care activities, financial impact) and subjective strain, which can negatively affect caregivers' physical, psychological, financial, social, and spiritual well-being.[12,43] Despite their central role, caregivers often feel overwhelmed by the sudden, extensive responsibilities that are expected of them.[41,52] In a sample of caregivers of lung transplantation candidates, most reported the need for more support related to financial, legal, and work issues, caregivers' feelings and worries, who to call with healthcare concerns, and what to expect in the future.[53]

Burden has been characterized across the different advanced heart and lung surgical therapies populations. A large study reported higher burden in caregivers of older patients awaiting heart transplantation with an LVAD than for candidates without an LVAD, although burden overall was low to moderate.[39] Importantly, caregiver burden is often dynamic—highest in the pre-transplant or pre-implant phase, but often persisting or recurring after surgery, especially in the context of complications (e.g. chronic rejection, or device-related issues).[54] This notion of the dynamism of caregiver burden is supported by a multi-site study that identified predictors of caregiver burden one year after heart transplantation or LVAD implantation in older patients, which included baseline caregiver burden, patient baseline HRQoL, and improvement in patient HRQoL across time.[42] However, in the lung transplantation population, a review found persistent caregiver strain across the pre- and post-transplant course.[38]

6.2. Psychological health

Caregivers of patients undergoing advanced heart and lung surgical therapies report anxiety and depression from evaluation through recovery, with distress often persisting after the index surgery.[44,45] In a multi-center cohort of 621 caregivers at initial transplant evaluation, 17% of caregivers screened positive for depression and 13% for anxiety; higher burden and maladaptive coping were associated with worse emotional symptoms.[52] A prospective study of 190 heart transplant caregivers followed for three years found that caregivers experienced major depressive disorder, adjustment disorders, transplant-related post-traumatic stress disorder, and generalized anxiety disorder; risk increased with heavier caregiving demands, prior psychiatric history, poorer patient–caregiver relationship, younger caregiver age, and avoidance coping.[55] In lung transplantation, a recent review reported that caregivers experienced heightened anxiety and depression both before and after transplant, underscoring longitudinal psychological vulnerability.[38] Caregivers of patients with LVADs report moderate levels of depression and anxiety, even after several years of caregiving.[56] In another study of LVAD caregivers, it was found that higher perceived stress and lower preparedness are linked to greater depressive symptoms.[40]

6.3. Physical health and health-related quality of life

Recent studies show that caregiver HRQoL in advanced heart and lung surgical therapies populations is dynamic. HRQoL is often acceptable at baseline and during the first post-transplant year, especially in the emotional and social domains. However, heterogeneity exists across cohorts and physical functioning can be a major domain that worsens over time.[57] In a longitudinal cohort of 242 caregivers of patients with a heart or lung transplant, HRQoL was generally high throughout year one, yet physical functioning declined; notably, poorer caregiver general health at 12 months predicted worse recipient survival over the subsequent seven years.[57] Among caregivers of older advanced heart failure patients awaiting heart transplantation or LVAD implantation, baseline overall HRQoL was high but anxiety was higher in the long-term LVAD group, and caregiver

comorbidities and anxiety were linked to worse caregiver HRQoL.[44] By 6 months after heart transplantation or long-term LVAD implantation, these same researchers reported that caregiver overall HRQoL continued to be high.[47] In lung transplantation, diary studies show caregivers report lower overall daily mood than recipients despite frequent positive emotions.[58] A recent review of lung transplant caregiving similarly concludes that caregiver HRQoL is often high in year one but is adversely affected by complications and symptom burden.[38]

6.4. Satisfaction and reward

Beyond the negative effects of caregiving, several studies report that caregivers of patients receiving advanced heart and lung surgical therapies express satisfaction and reward from the role. Caregivers describe closer connection with the patient, pride in improving their loved one's well-being, personal growth, and meaning.[52] For caregivers of patients with an LVAD, qualitative syntheses revealed that caregivers expressed gratitude for more time with their loved one and a dialectical tension between gratitude and burden.[22,43,59]

6.5. Dyadic outcomes of patients and caregivers

Caregivers and patient outcomes are closely interrelated, especially in the advanced heart and lung surgical therapies population, in which a caregiver is often required in order to proceed with surgery. Poor caregiver health and well-being predict worse patient survival, adherence, and psychosocial outcomes.[57,60] Caregivers anxiety and depression influence patient HRQoL, while relationship quality predicts patient self-care and treatment adherence.[57,61] Patients perceiving higher social support pre- and post-transplant demonstrate better adherence and outcomes.[6,11,62] In the LVAD population, patients with higher psychosocial risk factors, including limited social support, were at increased risk for device-related infections, gastrointestinal bleeding, pump thrombosis, and hospital readmission.[63] Additionally, preparedness, mutuality, and availability of supportive networks both positively and negatively influence HRQoL of LVAD patients and their caregivers.[59] Gender differences may also exist, with male patients benefiting more from female spousal support, while female recipients with male caregivers report less benefit after transplantation.[61] Additionally, patients following lung transplantation with spousal caregivers demonstrated better survival compared to those supported by adult children or siblings.[51]

Caregivers' immersion in caregiving responsibilities can lead them to neglect their own physical health, a pattern documented among family caregivers of heart transplant recipients, whose physical health measurably declined over the course of caregiving.[64] Similarly, LVAD caregivers followed for a year after patient discharge reported ongoing self-neglect, including poor eating habits and skipped medical checks, suggesting this pattern of self-carelessness may persist well beyond the immediate post-implant period and could, over time, compromise caregivers' capacity to sustain their caregiving role.[56]

6.6. Pediatric caregiver outcomes

Caregivers of pediatric cardiothoracic transplant or LVAD recipients experience similar outcomes as the adult population. One qualitative study described the experience of caring for a child with a heart transplant as "feeling constantly responsible, constantly worried, and constantly blessed".[65] A systematic review of pediatric patients supported with an LVAD reported decreased caregiver psychological well-being, high stress, and difficulty adjusting to new responsibilities.[66] In pediatric solid organ transplantation, a recent review noted that caregiver stress, anxiety, and depression are prevalent and can impair a parent's ability to consistently support complex adherence tasks.[67] Data from pediatric solid organ transplant also showed families have greater anxiety and global stress than healthy controls.[68] Caregivers of children with durable LVADs face additional challenges, including implanting LVADs that are sometimes only used in the hospital, resulting in prolonged hospital stays and increased strain on family responsibilities.

In addition, parents are often forced to take periods of leave from employment to care for their critically ill child. Time away from work, additional costs related to appointments, hospitalizations, and treatment needs contribute to financial stressors. Among children with critical congenital heart disease, which make up approximately 50% of the pediatric heart transplant population, lifetime family financial burden of disease is estimated to be 2.1 million USD.[69] Among pediatric patients supported on mechanical circulatory support, parents reported that family financial stress increased with length

of time on the device.[70] It is also well-acknowledged that caring for a critically ill child contributes to increased healthcare utilization and mortality risks for caregivers themselves.[71]

7. INTERVENTIONS TO ENHANCE SOCIAL SUPPORT SYSTEMS OF PATIENTS UNDERGOING ADVANCED HEART AND LUNG SURGICAL THERAPIES

A comprehensive search of English language, peer-reviewed articles was performed on PubMed, Embase, PsycINFO, Cochrane Central register of Controlled Trials (Central), CINAHL, and Scopus, to identify quantitative and qualitative publications describing interventions to enhance social support systems of patients undergoing advanced heart and lung surgical therapies. The search strategy was developed collaboratively among the writing group and involved a combination of the following keywords: thoracic transplantation, lung transplantation, heart transplantation, mechanical circulatory support, ventricular assist device, solid organ transplantation, pulmonary, caregiver(s), spouse, partner, parent(s), family, informal caregiver, intervention, psychosocial, psychological support, social support, social network, emotional support, informational support, instrumental support, transition, patient care team, quality of life, support groups, mental health, health behavior, language, pediatric, infant, child, teen, adolescent, transition, caregiver burden, coping, education, therapy, health literacy, navigator, and psychoeducation.

Articles were included if the study: 1) was in the English language and peer-reviewed; 2) was a primary study (i.e., mixed-methods, qualitative, randomized controlled trials, cohort, retrospective, prospective, cross-sectional, longitudinal, observational, and case studies); 3) included caregivers of pediatric or adult heart or lung transplant candidates or recipients or LVAD patients; and 4) described interventions to enhance social support systems of pediatric or adult patients undergoing advanced heart and lung surgical therapies.

A total of 14 articles were identified and addressed studies conducted within heart transplantation (n=2), lung transplantation (n=1), MCS (n=6), and pediatrics (n=5). Of the included articles, the publication year ranged from 2004 to 2024, with most studies conducted in the United States (n=10), followed by Canada (n=3), and a single study published in Germany. Table 4 further describes these intervention studies.

7.1. Heart transplant interventions

Two studies were identified in this population with both being single site, prospective, and enrolling small sample sizes. One focused on a web-based intervention versus historical control designed to improve mental health, HRQoL, and medical compliance in a cohort of heart transplant recipients and caregivers.[72] The other study included a mindfulness-based resilience training without a control group to improve stress-related outcomes in a cohort of solid organ transplant recipients and their caregivers.[73] Participants in the web-based intervention group demonstrated improvement in mental health and HRQoL outcomes, but not medical adherence compared to the historical control group. Participants in the resilience training study did not demonstrate significant improvement in outcomes after training.

7.2. Lung transplant interventions

One study within the lung transplantation population was identified; this prospective study was conducted at a single center, was prospective, and had a small sample size with limited generalizability.[74] Positive outcomes were observed in quality of life, mood, and social intimacy for both patients and caregivers when patients awaiting lung transplantation received psychological interventions (e.g. telephone-based supportive or quality of life therapy), demonstrating interconnected benefits.

7.3. LVAD interventions

Six intervention studies were identified in the LVAD population. Several studies in this population focused on the pre-implant experience of caregivers. One multi-center randomized trial was aimed at improving knowledge and decision making for caregivers of patients being considered for an LVAD.[18] One randomized pilot included simulation-based

Table 4 Interventions to Support Caregivers of Patients Being Considered for or Following Advanced Heart and Lung Surgical Therapies

Author, Year Country	Design	Sample Characteristics	Intervention	Summary of Caregiver Findings	Limitations
Heart Transplant					
Dew2004USA	• Single center • Prospective	• Intervention=24 patients and 40 family caregivers • Control=40 patients and 40 family caregivers	• 4-month web-based intervention with stress and medical regimen management workshops • Monitored discussion groups • Access to electronic communication with the transplant team • Information on transplant-related health issues	• Decreased anxiety and hostility • No differences in caregiver compliance • Improved QOL in caregiver social functioning over time • Caregivers were willing and able to use the intervention website • Greater website use was significantly correlated with greater improvement in role functioning and was related to emotional factors	• Small sample size • Internet access required
Stonnington2016USA	• Single center pilot • Exploratory, prospective	• Intervention=31 patients (17 with HTx) and 18 caregivers	• 6-week mindfulness-based stress reduction class • 6 sessions in a group setting with 20 individuals per group	• Non-significant improvement in perceived stress, anxiety, and mindfulness scores • Improved well-being • Satisfied with the number and length of sessions	• Mixed sample of transplant types • Unclear how much of the effect was driven by the group versus individuals incorporating the training into their daily lives
Lung Transplant					
Rodrigue 2006USA	• Secondary analysis of a randomized trial of a patient intervention • Single center	• Supportive Therapy =18 patients • QOL therapy=19 patients • 28 caregivers	• 3-month weekly telephone-based psychological interventions for patients • Randomized to either supportive therapy or QOL therapy • Caregivers did not participate directly in the interventions	• Improved QOL, mood, and social intimacy when patients received QOL therapy • Patients' gains predicted caregivers' outcomes	• Small sample size • Limited to indirect caregiver benefits from patient-focused interventions
LVAD					
Heilmann2011Germany	• Single center	• Intervention=31 patients (LVAD=24) and 33 family members (12=LVAD)	• Supportive psychotherapy provided by psychologist	• No difference in time spent by the psychologist between groups	• Small sample size • Not a primary caregiver intervention or study
Nakagawa2017USA	• Single center • Prospective	• Intervention=112 patients	• Pre-LVAD palliative care consultation	• Family awareness of patients' wishes significant increased after intervention	• Not a primary caregiver intervention or study
McIlvennan2018USA	• Multi-center randomized stepped wedge • Prospective	• Intervention=71 caregivers • Control=111 caregivers	• 8-page pamphlet and 26-minute video decision aid for patients and caregivers considering DT LVAD • Control consisted of existing educational materials	• Improved knowledge in control and intervention groups, larger absolute improvement with study intervention. • Improved decision quality assessed by values-choice concordance	• Study population weighted to white female spouses as caregivers • Variation in educational materials between sites

Continued

Table 4 Interventions to Support Caregivers of Patients Being Considered for or Following Advanced Heart and Lung Surgical Therapies

Author, Year Country	Design	Sample Characteristics	Intervention	Summary of Caregiver Findings	Limitations
Woodburn2018USA	• Single center • Quality improvement	• Intervention=41 patients and 28 caregivers	• Structured programmatic approach to the end-of-life in patients with DT LVAD	• Caregiver family experience was improved pre versus post intervention	• Small sample size • Not designed to be powered for statistical significance
Barsuk2019USA	• Single center pilot • Randomized	• Intervention=20 dyads • Control=20 dyads	• Simulation based mastery learning versus usual care	• Improved LVAD self-care skills learning outcomes versus usual care	• Unclear which element influenced the results; giving better structure, allocating time, or the intervention
Pfahl2023USA	• Dissemination and implementation	• Intervention=187 clinicians	• Asynchronous online training program for clinicians to support caregivers	• A quarter of the clinicians completed the training and of those, one third used the training with caregivers	• Did not assess direct caregiver outcomes
Pediatrics					
Lawrence2011USA	• Single center • Descriptive	• Intervention=20 HTx patients and their caregivers	• Family-centered educational program	• Improved knowledge about transplant and management of the treatment regimen	• Small sample size • Non-reliable outcome measure
Nicholas2016Canada	• Convergent parallel mixed methods • Exploratory	• Intervention=49 individuals (19 parents of HTx patients)	• Residential 3-day camp designed to offer support and education	• Improved knowledge, social support, and coping • Caregivers were satisfied with the camp	• Time commitment and cost would be a barrier to wide-spread adoption
AntonUSA2019	• Single center study • Retrospective chart review	• Intervention=12 HTx patients and their caregivers	• 2-year structured transition program with 7 educational sessions	• No changes in caregivers' perception of child readiness or confidence in child's ability to transition	• Small sample size • No clear benefit for caregivers
Wijesekera2023USA	• Single center pilot • Prospective	• Intervention=9 HTx patients and their families • Control=9 HTx patients and their families	• Resilience training program delivered using a video telehealth platform	• Six completed the intervention • Program was feasible and acceptable • Reduction in parent depression and PTSD	• Small sample size • Limited family availability to participate
Anthony2024Canada	• Pilot hybrid • Convergent parallel mixed methods	• Intervention=16 mothers of HTx patients	• 2-day mindfulness-based retreat	• Intervention was feasible, adoptable, acceptable and appropriate • Increased mindfulness, perceived social support, and family integration	• Small sample size • Accessibility for broader populations

HTx=heart transplant; LVAD=left ventricular assist device; PTSD=post-traumatic stress disorder; QOL=quality of life

training versus usual care to improve self-care skills for patients and caregivers.[75] There were several other single-center descriptive or retrospective studies, including a focus on palliative care and end-of-life processes.

7.4. Pediatric interventions

Five interventions with caregivers of pediatric heart transplantation patients were identified. Interventions included a three day residential camp designed to offer support and education to patients, siblings and families through the delivery of recreational and educational sessions;[76] a two-day mindfulness based retreat involving a structured schedule of mindfulness and compassion-based sessions for mothers only;[77] a pilot randomized trial of telehealth sessions to deliver evidence-informed resilience training to parents and their children;[78] a structured transition program;[79] and a family-centered educational program which involved parents and children being given education packs.[80] A range of outcomes were assessed including coping, depression, anxiety, post-traumatic stress, distress tolerance, family adjustment, family impact, social support and knowledge. Two studies also included interviews, focus groups or observation. The pilot randomized trial was the only study that included a control group.[78] Overall findings suggested interventions were feasible and acceptable for most parents with positive effects on mental health, coping or knowledge.

Overall, the interventions for caregivers focused on education, mental health, social support and quality of life outcomes, with overall findings indicating positive change following the interventions. The findings are limited by methodological heterogeneity, single-center studies, small sample sizes, few randomized designs, and lack of generalizability and diversity (e.g. non-English speaking participants excluded). There is a notable lack of caregiver-specific interventions, lack of data concerning the impact of the caregiver interventions on patients, and longitudinal data to assess evolving needs over time, as well as limiting conclusions that can be drawn about sustainability of the positive impact of interventions.

8. IMPLICATIONS OF CAREGIVING ON EQUITY AND ACCESS TO ADVANCED HEART AND LUNG THERAPIES

8.1. Social determinants of health

Social determinants of health (SDOH), such as race, gender, education, income, and insurance status, have been used as a proxy for exploring associations between outcomes such as waitlist mortality, survival, delisting, and readmission.[15] Patients from historically disenfranchised groups, such as those of minority racial or ethnic groups (varies by country of the transplant center), those of lower socioeconomic status, and women, may be less likely to be considered for transplantation, which in turn may be influenced by caregiving needs. There are significant physical, financial, logistical, and social burdens placed on the caregivers throughout the care process.[52] These burdens may fluctuate over the course of care due to the episodic nature of the disease and treatment trajectory. The multilevel nature of the interplay between these variables makes consideration of uniform recommendations to address these inequities challenging. However, early identification of caregiver needs may promote equitable access to care; thus, an individualized, tailored approach to care is recommended. A single-center study demonstrated equitable outcomes post-heart transplant by race and socioeconomic status by offering more comprehensive care, tailored to the patient's individual needs.[81] Yet, these approaches are not standardized across centers.

8.2. Equity and access to advanced heart and lung surgical therapies

Despite well-documented research on inequitable access to care, limited improvements have been made in reducing barriers to equitable access to advanced heart and lung surgical therapies.[82,83] Variability exists in the eligibility requirements for caregivers of heart and lung surgical candidates across programs. This variability is related to lack of clarity and limited data on what type of caregiver is indicated for good short and long-term outcomes.[12] There is evidence that ideal caregivers should have education on illness severity, have a plan for meeting the patient's household needs and identify secondary support to help when the primary person is not available.[13] Networks of support have been further identified as a crucial resource for caregivers.[59] A single-

center study revealed that caregivers, who are spouses, were associated with better survival post lung transplant than other types of caregivers.[51] However, there is a need for more studies to identify modifiable characteristics of caregivers that can contribute to improved caregiver and patient outcomes, irrespective of social standing.

Current subjective recommendations for caregivers and social support may contribute to inequitable allocation of advanced heart and lung surgical therapies. A single-center study revealed that spouses were less likely to be identified as a caregiver when the candidate for heart transplant was a woman or Black race compared to a man or White race, respectively. Identifying other family or friends as the primary caregiver over a spouse was associated with lower likelihood of allocation to heart transplantation, but this variable only reached statistical significance for men.[84] In addition, a spouse was considered adequate as the caregiver for men, but not for women in a national U.S. mixed-methods study of healthcare professionals randomized to identical patient vignettes, varying only by patient race and patient gender, Black woman, White woman, Black man, or White man.[85] The presence of non-adult children also supported a negative recommendation for the eligibility of women for heart transplantation, particularly Black women; whereas, the converse was true for men. In another study, healthcare professionals were significantly less likely to recommend heart transplantation based upon a patient's Black race, when the professional was 40 years of age or older in a larger mixed-methods study of healthcare professionals randomized to identical vignettes varying only by race, Black men or White men.[86] Reasons for the greatest influence on the allocation of heart transplantation and bridge to heart transplantation were perceived levels of social support and adherence, assessed subjectively. Ideally, this evaluation of social support would occur at the initial referral for advanced heart and lung surgical therapies. However, implicit beliefs about access to care may influence the assessment process, thus reinforcing the need for a standardized screening and evaluation processes.[83,86]

8.3. Pediatric considerations

It is important to acknowledge and consider the inherent biases specific to SDOH when evaluating pediatric patients and their caregivers for advanced heart and lung surgical therapies. While single parent home and lower socioeconomic status have been identified as risk factors for pre- and post- transplant outcomes in pediatric patients,[37,87,88] decision-making that is reliant on such caregiver risk factors can contribute to inequitable access to advanced heart and lung surgical therapies for children. It is recommended that factors specific to the environments in which pediatric patients live, work and learn, including housing, financial, insurance, and transportation stressors, are identified, with resources and support provided by healthcare teams to mitigate risks on child health and quality of life outcomes.[30] Advocacy at institutional and governmental levels are needed to bolster the availability of resources for caregivers of critically ill children to lessen the cascading effects on family environments and outcomes. Further, it is important to appreciate the ways in which caring for a child requiring advanced heart and lung surgical therapies may further exacerbate adverse SDOH for children and families.

9. CONSENSUS RECOMMENDATIONS FOR ENGAGEMENT AND SUPPORT OF THE SOCIAL SUPPORT SYSTEM

Caregivers are an integral part of the healthcare team managing patients before and after heart or lung transplantation and LVAD implantation. Although the literature provides mixed evidence regarding whether a dedicated caregiver should be an absolute requirement for advanced heart and lung surgical therapies, there is broad agreement that patients benefit from engaged and prepared social support systems. For those individuals who comprise the social support systems, particularly caregivers, structured strategies and interventions are essential to facilitate engagement, promote preparedness, and mitigate caregiver burden. Based on the available literature and expert consensus, Table 5 outlines key recommendations and strategies to support caregivers across the continuum of evaluation, treatment, and long-term follow-up.

First, caregivers should be identified and engaged early in the evaluation process**.** Early involvement allows transplant and LVAD programs to understand the patient's social support structure and clarify expectations for the caregiving role. Structured and objective assessments of social support can help teams identify a primary caregiver as well as additional individuals who may assist with responsibilities such as transportation, medication management, and home monitoring. Engaging caregivers in shared decision making, including the use of

Table 5 Expert Consensus Recommendations for Social Support Systems in Advanced Heart and Lung Surgical Therapies

Consensus Recommendations	Strategies to Consider
Identify and engage caregivers early in the evaluation process	• Use structured and objective assessments of social support • Identify a primary caregiver along with additional people that can assist with tasks and responsibilities • Engage caregivers in the decision-making process, including using decision support tools and exercises in values clarification • Educate caregivers on expectations, including written role descriptions, time demands, and home monitoring
Deliver targeted education and hands-on skills training	• Provide a standard curriculum to caregivers incorporating program-specific requirements and protocols • Assess learning needs and health literacy as appropriate • Ensure caregivers know when and how to contact the medical team • Use simulation-based skills training, especially for tasks such as home spirometry, blood pressure monitoring, dressing changes, left ventricular assist device equipment and other home devices, and consider using knowledge and skills testing, as appropriate • Offer refresher sessions as needed
Systematically assess caregiver needs and context of care	• Assess and attempt to understand the geopolitical, cultural, familial, and social context of the patient and caregiver • Screen at evaluation, established intervals, and during high-stress periods (e.g. hospitalization) using a validated tool • Modalities used for assessment can include in-person, virtual, or hybrid—tailored to patient and caregiver needs, clinical context, and available resources • Refer caregivers to available local or national resources • Encourage caregivers to engage in mental health evaluations and treatment as appropriate
Integrate caregivers into clinical workflows	• Document caregiver needs within the patient's medical record, including contact information, learning needs, burden risk scores • With patient consent, ensure caregivers have the ability to communicate with the medical team and view the patient electronic medical record • Consider billing for caregiver training services as appropriate
Embed palliative care and psychosocial resources	• Offer to involve palliative care early in the evaluation process to assist with communication and advance care planning • Link to caregiving resources in the community that offer caregiver support across multiple conditions
Build peer connection	• Facilitate caregiver support groups or other forms of peer mentoring • Refer to online platforms that offer caregiver peer support

decision support tools and values clarification exercises, can improve understanding of treatment options and align expectations. Clear education regarding anticipated responsibilities, time commitments, and monitoring requirements is particularly important to ensure caregivers are adequately prepared for the intensity of care required, especially in the early postoperative period.

Second, targeted education and hands-on skills training are important to ensure caregiver preparedness. Caregivers should receive a standardized curriculum that incorporates program-specific protocols and practical skills necessary for post-operative and long-term management. Educational strategies should be tailored to caregiver learning needs and health literacy levels. In addition to didactic education, hands-on and simulation-based training may improve caregiver confidence and competence in tasks such as home spirometry, blood pressure monitoring, wound care or dressing changes, and device management for LVAD systems. Programs may also consider incorporating knowledge or skills assessments and offering refresher sessions to reinforce training and address evolving caregiver needs over time.

Third, programs should systematically assess caregiver needs and context of care. It is important to assess and attempt to understand the geopolitical, cultural, familial, and social context of the patient in caregiver to provide values-concordant care. In addition, caregiving responsibilities can impose significant emotional, physical, and financial strain. Screening caregivers at key time points, such as during evaluation, at regular intervals after implantation or transplantation, and during high-stress periods such as hospitalizations, can help identify individuals at risk for burnout or distress. Assessments may be conducted through in-person, virtual, or hybrid approaches depending on clinical context

and available resources. When caregiver strain or psychosocial concerns are identified, referral to mental health services, counseling, or community resources should be considered.

Fourth, integrating caregivers into clinical workflows can facilitate communication and improve coordination of care. This integration may include documenting caregiver contact information, learning needs, and risk for caregiver burden within the patient's medical record. With patient consent, caregivers should have appropriate access to communicate with the healthcare team and may benefit from the ability to view portions of the electronic health record. Formal caregiver training services may also be incorporated into clinical workflows, and when appropriate, programs may explore billing mechanisms for caregiver education and training services.

Fifth, transplant and LVAD programs should consider embedding palliative care and psychosocial resources within the care continuum. Early involvement of palliative care specialists can assist with complex communication, goal-setting, and advance care planning, particularly during the evaluation phase and periods of clinical uncertainty. In addition, linking caregivers to community-based organizations that provide support across chronic illness populations may help address practical needs and reduce caregiver isolation.

Finally, programs should facilitate peer connections among caregivers. Opportunities for peer mentoring and caregiver support groups can help normalize the caregiving experience, provide practical insights from individuals with lived experience, and foster emotional resilience. In addition to in-person groups, online communities and digital platforms may offer accessible and scalable avenues for peer support.

10. FUTURE DIRECTIONS

While there is literature to support improved outcomes in patients with heart or lung transplantation or LVAD implantation who have a caregiver, the strength and rigor of the data are limited. Additionally, there is limited research exploring the relationships between dyads and social networks and how they impact patient and caregiver outcomes. There are many opportunities and areas to investigate further in this population.

First, investigating the relationships between patient recovery, caregiver experiences and caregiver and patient outcomes should be a priority, as such evidence can inform clinical care and shed light on where interventions are needed the most.

Second, developing and testing these interventions to engage and support caregivers are needed in this population. Drawing upon literature regarding other forms of caregiving is important, considering mobile, telehealth, and artificial intelligence strategies.

Third, the definition of 'adequate social support' is vague within the advanced heart and lung surgical therapies community. This definition is often left to programs to determine; however, establishing a more structured recommendation linked to outcomes would be beneficial to maintain equity.

Fourth, prospective longitudinal studies, contrary to the mostly cross-sectional, small sample size single site studies, could help to inform the trajectories of caregiving from evaluation through surgical recovery and the impact on caregiver and patient outcomes over time.

Fifth, strategies to empower available caregivers with the skills to be successful regardless of their race, gender, and socioeconomic status should be evaluated. In addition, implementation science methods for equity should be considered to expand knowledge.[89] Specifically, addressing bias and subjectivity in the assessment of social support may also increase equity in allocation of therapies.[90]

Lastly, future research should explore caregiver experiences and outcomes in subgroups of caregivers, given that most evidence now stems from spouses or partners, most frequently women, or in the case of pediatric patients, mothers. Furthermore, in the pediatric cardiothoracic transplant literature, little is reported on the impact of caregiving on someone who is not the biological parent.

11. CONCLUSION

Caregivers are an integral part of the healthcare team managing patients being considered for and following advanced heart and lung surgical therapies. Data are limited in describing the caregiver role, responsibilities, and outcomes, especially longitudinally. In this consensus statement, we reviewed the evidence to date and have put forth expert consensus recommendations on engaging and supporting this population. Future research is needed

to better understand the caregiver role, its impact on caregiver and patient outcomes, and interventions to support them.

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