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A consensus-based framework for the psychosocial evaluation of pediatric candidates for cardiothoracic transplant and ventricular assist devices

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The psychosocial evaluation plays an essential role in the multidisciplinary assessment of pediatric patients for thoracic organ transplantation or ventricular assist device (VAD) placement. However, there is considerable practice variation with regard to the content and process of the evaluation, with no known recent published guidelines. Furthermore, the pediatric evaluation necessarily differs from the adult evaluation in a number of substantive ways, including caregiver roles and decision-making. A writing committee of 25 multidisciplinary experts in pediatric cardiothoracic transplantation/VAD was established, who conducted a comprehensive literature review which resulted in the development of this consensus-based framework. This framework, which is a collaborative effort of the International Society for Heart and Lung Transplantation (ISHLT), the International Pediatric Transplant Association (IPTA), the Pediatric Heart Transplant Society (PHTS), the Advancing Cardiac Therapies Improving Outcomes Network (ACTION), and Transplant Families, represents the first known framework specific to both the content and process of the psychosocial evaluation for pediatric cardiothoracic transplantation/VAD. Attention was paid to relevant ethical, cultural and health equity considerations inherent in the pediatric evaluation process. Rather than provide a proscriptive evaluation process, the goal was to create a flexible framework to encourage consistency across centers,

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while also acknowledging the complexities inherent in evaluating children and their families for cardiothoracic transplant and VAD.

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1. Introduction

In both pediatric and adult settings, the psychosocial evaluation is a critical component of the multidisciplinary evaluation for heart and/or lung (thoracic organ) transplantation and ventricular assist device (VAD) placement. In pediatrics, this evaluation typically serves multiple purposes: (1) to collect psychosocial information about the patient and family relevant to post-transplant/VAD functioning; (2) to provide recommendations to the patient, family and medical team with regard to interventions to support optimal functioning post-transplant/VAD; and (3) to establish an early relationship with patients and families to provide decision-making support and psychoeducation around expectations for the various stages of VAD placement and/or transplant (e.g., listing, surgery, recovery, post-transplant care requirements) as they relate to one's readiness or willingness to pursue transplant.[1]

In 2018, a consensus paper describing best practices for the adult psychosocial evaluation for thoracic transplant and VAD was published in the Journal of Heart and Lung Transplantation.[2] With the aim of creating consistency across programs, these guidelines embodied expert opinion across an international group representing multiple transplant and VAD-related organizations. The consensus paper provided a summary of the current evidence base for adult psychosocial evaluations as well as expert-reviewed recommendations for both the content and the process of the psychosocial evaluation. It represented the first known published document of its kind.

The pediatric transplant literature and practice in thoracic transplant and VAD evaluation have lagged behind their adult counterparts. As such, many of the early attempts to develop standardized instruments and assessment practices have involved the adaptation of adult evaluation materials[3] and the utilization of a risk-identification approach. In adult settings, psychosocial evaluation findings often contribute heavily to the team's decision-making regarding patient suitability for transplant. Given that high-quality data demonstrating the predictive value of the pediatric transplant psychosocial evaluation is lacking,[1] pediatric patients are less likely than are adults to be declined for transplantation due to psychosocial reasons. Insight yielded from pediatric psychosocial evaluations should in most cases be used to identify areas for intervention and support for patients and families, rather than to determine transplant suitability. From a psychosocial perspective, the question in pediatric thoracic transplantation is most often regarding when, not if, a child will proceed to transplant/VAD.

Furthermore, the evaluation of the pediatric patient differs from that of the adult patient in a number of important ways. First, the evaluation of children must include an understanding of the context in which the child exists, including the family and community[1,4]; second, in pediatrics there is a reliance on caregiver report for most of the information about child functioning[1]; third, decision-making and treatment responsibility typically rests in the hands of caregivers; and fourth, there are ethical considerations in transplantation and VAD implantation that are unique to pediatric patients.[4]

Given these marked differences in the pediatric vs adult thoracic transplant/VAD assessment as well as the challenges in developing a pediatric assessment process that parallels the adult process, we are proposing shifting the lens of the pediatric thoracic transplant/VAD assessment from a primarily deficit-oriented approach (which focuses on risks and vulnerabilities) to a framework that also includes consideration of patient and family strengths and resilience, developmental factors that influence functioning, and the dynamic, interactive impact of the contexts in which children and families live. Likewise, we consider the impact of cultural factors and health disparities on child health and well-being, in the interest of promoting equitable care.

As a result of the absence of standardized practices for conducting the pediatric pre-thoracic organ transplant/VAD evaluation, there is considerable practice variation across centers with regard to who conducts the evaluation, content areas and level of depth of each area, methods of assessment (i.e. clinical interview vs standardized measures), how findings are reported both in writing and in communication with the transplant team, and how recommendations are utilized. Similar to the Dew et al adult consensus report,[2] the lack of standardization across pediatric centers has the potential to result in inequities in decision-making and care provided.

A paper published in 2014[4] described best practices in the pediatric solid organ transplant psychosocial evaluation, based on the extant literature at that time. This current consensus statement differs from that paper in that it includes a large international group of experts representing a number of different professions and organizations; it incorporates advances in knowledge and practice over the past 10 years; and it reflects an increased focus on issues of culture, diversity, and health disparities. Furthermore, this statement focuses on issues specific to thoracic transplantation and VAD implantation.

2. Guidelines for the use of this document

Similar to the Dew[2] paper, this document represents a consensus of expert opinion in pediatric heart and/or lung transplantation and VAD and would not meet criteria for "systematic review" as defined by Cochrane (www.cochranelibrary.com) or other similar organizations. While the many areas in which there is strong empirical evidence are highlighted, the general

dearth of large sample, multi-center psychosocial research in pediatric thoracic transplantation and VAD necessitates the addition of expert clinical input. Furthermore, there are numerous factors involved in the evaluation of children and their families for thoracic organ transplant and VAD, encompassing varied domains of functioning and well-being, including individual attributes of the patient, the family, and the multiple larger systems in which they exist. As such, the range of literature reviewed for these guidelines is quite wide. Finally, we purposefully developed this framework in the form of domains to include and processes to consider – as the actual evaluation itself requires flexibility as each patient undergoing evaluation represents a unique combination of these many factors. A prescriptive evaluation process would not sufficiently account for all that is encountered. Instead, the ultimate goal is to provide a framework to encourage consistency in how pediatric transplant centers and VAD programs approach the evaluation.

3. Methods

The original idea and plan for this document came out of a meeting of psychologists in May, 2021 representing a number of different organizations related to pediatric transplant and VAD, including the Cardiology and Transplant Special Interest Groups (SIGs) of the Society for Pediatric Psychology (SPP), the International Pediatric Transplant Association (IPTA), and the International Society for Heart and Lung Transplantation (ISHLT) with the identified goal of developing a version of the publication by Dew et al[2] that was appropriate for use with pediatric thoracic populations. A Writing Committee was developed which consisted of transplant professionals in these organizations as well as those representing the Advancing Cardiac Therapies Improving Outcomes Network (ACTION), Pediatric Heart Transplant Society (PHTS), the Society for Transplant Social Workers (STSW) and Transplant Families. The goal was to develop as diverse a group of professionals as possible, representing multiple disciplines involved in pediatric transplant and VAD (psychology, social work, cardiology, nursing, advanced practice nursing) and varied geographic location (with members from 18 programs across 5 countries and 2 continents).

The Writing Committee was organized into a leadership group, which consisted of the Chair, Associate Chair, and then multiple subgroups, including (1) Recommendations for the content of the psychosocial evaluation; (2) Recommendations for the process of conducting the psychosocial evaluation; (3) Recommendations specific to evaluation of pediatric candidates for VAD; and (4) Special considerations, which included review of the evidence and recommendations in the areas of recognizing (a) ethical considerations, (b) developmental factors, and (c) sociocultural considerations. Any members of the Writing Committee not assigned to one of the four paper subsections were involved either in writing the introduction, methods, and conclusions, and/or reviewing drafts of the manuscript.

The main strategy for the literature searches for each section focused on identifying empirical papers and review articles (see Table 1) regarding (1) psychosocial risk and protective factors for adverse medical and psychosocial post-thoracic transplant or post-VAD implantation outcomes in pediatric populations, (2) developmental factors influencing the evaluation process and post-thoracic transplant or post-VAD implantation outcomes, and (3) impact of sociocultural factors and health disparities on pediatric thoracic transplant/VAD outcomes; and (4) ethical issues in the pediatric transplant evaluation. The forthcoming recommendations come from this iterative process which included review of the available literature as well as expert

Table 1 Inclusion Criteria and Search Strategy for Empirical Evidence Supporting Consensus Recommendations

Inclusion Criteria:

1. Peer-reviewed articles
2. Articles published in English
3. Articles focused on children under the age of 18, and/or parents of children
4. Publication dates between 2000 and mid–2023, inclusive

Search term strategy combination of:

1. Terms to identify the relevant patient population [pediatric heart transplant* or pediatric lung transplant* or pediatric heart/lung transplant* or pediatric ventricular assist* or pediatric transplant*] and parents/caregivers
2. Terms to identify content area [evaluation* or psychosocial* or developmental* or sociocultural* or health disparities*]
3. Terms to identify relevant post-transplant/post-implantation clinical and behavioral outcomes that could be affected by psychosocial factors ([title words: survival or morbidity or mortality or rejection or adheren* or complian* or medicat* or self-manage* or health-manage* or substance*] OR [key words: health or survival or morbidity or mortality or rejection, or patient compliance or medication adherence or coping or parent coping]). And (c) Additional terms iteratively identified by Writing Committee members charged with examining the literature on specific psychosocial domains (e.g., medical adherence history, mental health history, substance use/abuse history, social support).
4. Articles that did not include the key search terms but were important in documenting the impact of other factors (e.g. child developmental stage, health disparities, racism) on child health outcomes more generally.
5. Additional articles either found in the bibliographies of identified publications or authored by or known to Committee members. Included (especially when little to no literature was identified in pediatric cardiothoracic transplantation or in VAD) were seminal empirical articles from other areas of pediatric organ transplantation and from literature on advanced pediatric heart and/or lung disease populations.

opinion/experience on current and evolving clinical applications of the available literature.

4. Recommendations for the content of pre-transplant psychosocial evaluation

The following domains include recommended content areas of assessment as part of a comprehensive psychosocial evaluation and are also summarized in Table 2.

4.1. Assessment of risk factors for poor post-transplant outcomes

4.1.1. Treatment adherence and health behaviors

4.1.1.1. Background

One of the most profound and controllable factors that may prevent negative outcomes after thoracic organ transplant is adherence to immunosuppression medications,[5–9] as non-adherence is associated with allograft rejection and other poor medical outcomes.[5–9] Nonadherence is common among pediatric post-transplant patients, with estimates ranging from 22–97% per systematic review of the literature.[10] In addition to adhering to their medication regimen, patients must regularly attend clinic visits and procedures and maintain healthy physical activity, sleep, and diet to promote both psychological and physical wellness.[11] Missing medical appointments, limited physical activity, poor sleep or dietary patterns may affect patient health and outcomes pre- and post-transplant.[9] Engagement in such health behaviors are strongly influenced by patients' and caregivers' self-management abilities, which are dynamic across development and include abilities to modulate emotions, cognitions, and behaviors towards health-related goals.[12,13] Many of the domains of the psychosocial evaluation discussed below impact adherence, and it is essential to assess adherence directly.

4.1.1.2. Evaluation recommendations

Pre-transplant evaluations should assess current ability to engage in medical treatments and regimens prior to transplant, as it is predictive of future behavior.[14] It is recommended that multiple modalities be used to assess how a child and caregiver are following their medical regimen, including child/adolescent and caregiver interviews, medical records review, and clinical and laboratory tests[9] as available. Barriers to engaging in adaptive health behaviors, including giving or taking medications, should be assessed early and re-assessed on an ongoing basis. Patient barriers to adherence may include pill swallowing difficulties, forgetting, unpleasant side effects, issues of body image, or wanting to avoid negative peer perceptions in adolescence; caregiver barriers may include disorganization secondary to skills deficits or mental health concerns, management of multiple concurrent stressors, or poor communication between multiple caregivers in the same home or between caregivers of different homes in which the child resides. Assessment of executive functioning, cognitive ability, and self-regulation of emotions and behaviors may also be warranted as they relate to patient and family ability to understand and follow their medical regimen. Patients with limited cognitive and executive functioning capacities may need additional support and supervision from a caregiver, particularly with medication and health management. Caregivers with limited skills in these areas may need additional assistance from other family members, community resources, or the healthcare team.

4.1.2. Mental health history

4.1.2.1. Background

Assessment of patient and caregiver mental health histories, including current and past psychological functioning, is an important domain that should be assessed in pre-transplant psychosocial evaluations. Psychiatric disorders are relatively common in pediatric heart transplant patients, as one study estimated prevalence rates of depressive or anxiety disorders as high as 14.1% during the heart transplant admission, and up to 39.8% in patients ≥8 years of age requiring VAD.[15] Similarly, approximately 17% and 13% of caregivers of pediatric patients awaiting transplant have also reported clinically elevated symptoms of depression and anxiety, respectively.[16]

The transplant process is a stressful experience for the patient, caregivers, and family system.[17] While some degree of distress is expected, mental health difficulties have been shown to negatively impact post-transplant outcomes. In a large sample (N=1192) of children undergoing heart transplant, depression during or preceding admission for transplant was independently associated with higher rates of readmission and inferior graft survival post-transplant, whereas anxiety was associated with higher readmission rates.[18] Lower behavioral functioning and higher distress are also associated with more challenges following medication regimens post-transplant in pediatric patients.[9] Medical traumatic stress or symptoms of posttraumatic stress disorder (PTSD) related to other factors may be present as well, and may be associated with medication nonadherence.[19] Less is known about the impact of caregiver mental health on patient outcomes post-thoracic organ transplant specifically; however, research across solid organ transplant populations suggests that caregiver stress and coping difficulties are associated with medication non-adherence.[20] Help-seeking behavior (e.g., past engagement in therapy), insight into areas of challenge, and openness to mental health treatment may be viewed as areas of strength in the face of mental health symptoms. It is important to note that assessment of mental health information should not be used as means for disqualification of pediatric transplant/VAD candidates; rather, it is to develop anticipatory support structures for particularly vulnerable children and families.

4.1.2.2. Evaluation recommendations

Current mental health symptoms and past mental health history should be assessed via multiple sources (e.g., patient self-report, caregiver proxy, and caregiver self-report), as

Table 2 Content Domains for Pre-transplant Evaluation

Content Domain	Background	Evaluation Recommendations and Possible Measures
1. Treatment adherence and health behaviors	• Adherence to medications, appointments, and procedures is critical to preventing negative outcomes post-transplant	• Assess current ability to engage in medical treatments and regimens prior to surgery via multiple modalities including patient and caregiver interviews, medical records review, and clinical and laboratory tests • Assess barriers to health behaviors and medication taking prior to transplant
2. Mental health symptoms and history	• Although some degree of distress is expected in the context of transplant, psychosocial functioning can impact patients' and caregivers' adherence to medical regimen and, in turn, other post-transplant outcomes.	• Patients' and caregiver's past and current mental health histories should be assessed via multiple sources, such as clinical interviews with patients and caregivers, and patient self-report and caregiver questionnaires. o Patient-self report: GAD–7, PHQ–9, PROMIS measures, C-SSRS o Caregiver proxy-report: CBCL, PSC o Caregiver self-report: HADS, PSI-SF
3. Substance use	• Substance use among potential transplant recipients represents both ethical and medical challenges. • Substance use among patients and caregivers has been shown to relate to medication non-adherence.	• Some transplant programs include toxicology screenings as part of pre-transplant evaluation. • Patient and caregiver substance use history can be assessed via clinical interview.
4. Cognitive status and educational functioning	• Children with complex CHD, heart/lung disease associated with some genetic syndromes, and/or other neurological insult (e.g., stroke) are at heightened risk for neurodevelopmental delay or disorder. • This is *not* a contraindication to transplant, as long as there is solid social support and caregiving plan. • Children who are undergoing thoracic organ transplant evaluation may miss extended periods of school due to hospitalizations or appointments, and may experience school challenges due to neurodevelopmental or learning concerns.	• Assessment of cognitive function of patients may include screening measures or full assessment measures o Questionnaires: PedsQL Cognitive Functioning Scale, BRIEF, ABAS o Assessments: WASI, WRAT • Assessment of educational functioning should include current educational achievement and supports (e.g., IEP, 504 plan, homebound services)
5. Knowledge of medical condition and treatment options	• Knowledge about disease, transplant process, and the importance of adherence is critical for both caregivers and patients	• Assess patient's and family's understanding of medical illness and potential treatment options, as well as short term and long-term benefits, risks, and side effects of transplant medications • All information should be simplified, organized, and presented in primary language of patient and caregiver.
6. Coping with illness	• Active and accommodative coping strategies relate to better adjustment among patients and caregivers; whereas passive coping is linked with poorer outcomes.	• Patient and caregiver coping can be assessed via interview and self-report measures. o Patient self-report: RSQ, KidCOPE o Caregiver self-report: CHIP, BriefCOPE

(*continued on next page*)

Table 2 (*Continued*)

Content Domain	Background	Evaluation Recommendations and Possible Measures
7. Social support	• A healthy support system promotes patient treatment adherence and quality of life.	• Assess patient and family social support history including family dynamics, conflict, and support systems. • Encourage family involvement in development of a plan of care for managing patient medical needs.
8. Social history	• Hospitalizations, exposure to traumatic events, and socioeconomic challenges contribute to medical and psychosocial outcomes.	• 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.
9. Sociocultural considerations	• Limited social factors, including race, ethnicity, and socioeconomic status have been studies in pediatric solid organ transplant. • Black and non-White pediatric patients evidence poorer treatment adherence and outcomes.	• Consider factors such as discrimination and social and cultural biases. Consider use of structured interview questions. o Structural Vulnerability Assessment Tool • Consider social factors and support clinical care teams in minimizing the effects of implicit and explicit bias on transplant decision-making and care.

caregivers may under- or over-estimate their child's level of distress.[21] Patient and caregiver mental health history can be assessed via clinical interview by inquiring about current and past mental health diagnoses and treatments, including prescription of psychiatric medications and engagement in psychotherapy. Current mental health and psychological adjustment may also be assessed via clinical interview and/or use of patient- and caregiver-reported questionnaires. Frequently utilized patient-reported questionnaires include the Generalized Anxiety Disorder scale (GAD-7[22]), Patient Health Questionnaire-9 (PHQ-9[23]), and PROMIS measures.[24] Caregivers may report on their child's functioning using behavioral rating scales such as the Behavior Assessment Scale for Children, 3rd Edition (BASC-3[25]), and their own distress and mental health using PROMIS measures and the Parenting Stress Index/Short Form (PSI-SF[26]). Lastly, suicide risk assessment for patients undergoing evaluation for transplant is also critical and tools such as the Columbia Suicide Severity Rating Scale (C-SSRS[27]) may be utilized.

4.1.3. Substance use history

4.1.3.1. Background

Concerns regarding substance use among pediatric patients undergoing evaluation for transplant pose both ethical and medical challenges. Research suggests that substance use among adolescent and young adult transplant recipients is similar to or lower than that of their peers, although prevalence rates differ by substance type.[28] Among those undergoing evaluation for transplant/VAD, however, there are unique implications of substance use, including transplant eligibility and increased risk for adverse outcomes post-transplant. A recent review[28] of substance use and solid organ transplantation in adolescents and young adults suggested that although little research has examined patient substance use in relation to post-transplant outcomes, emerging evidence supports an association between substance use and medication nonadherence. The review also highlighted substantial variability in transplant centers' existence and content of policies around substance use. Less is known about substance use among caregivers of pediatric transplant patients; however, this domain is often cited as an important area to assess in the pre-transplant evaluation. In a study of non-adherence among pediatric liver transplant patients, children of caregivers with a history of substance abuse had greater nonadherence.[29] This work may suggest that caregivers with a substance abuse history have difficulties adequately supervising their child's post-transplant regimen.

4.1.3.2. Evaluation recommendations

Although some insurers and transplant programs may include toxicology screenings as part of the pre-transplant evaluation, psychosocial providers should assess current and past substance use via interview. Assessment should include both patient and caregiver report of patient's substance use history, given potential discrepancies in knowledge and reporting. Open-ended questions such as "What

substances have you tried in the past?" or "How often do you drink alcohol?" versus closed questions (e.g., "Have you engaged in any substance use/used any substances in the past?") may better normalize potential substance use and elicit more accurate responding. Substance use assessment should include alcohol, nicotine, inhalants, cannabis, and other illicit drugs.

4.2. Assessment of factors related to child and caregiver knowledge, understanding, and capacity to engage in shared decision making

4.2.1. Developmental status and educational functioning

4.2.1.1. Background

Another unique consideration for pediatric cardiothoracic transplant includes issues related to developmental status. For example, among typically-developing youth, adolescence is a higher risk stage for long-term medical adherence issues than are other developmental stages,[19,20] which directly impact the life of the allograft. Evaluation may reveal behavioral patterns that are developmentally common (e.g. adherence difficulties, substance experimentation) which may present as contraindications for listing when treatment options are not successful.[30,31] Furthermore, children with certain heart and lung diseases (e.g., complex congenital heart disease, cystic fibrosis, and/or diseases requiring extended hospitalization in infancy) are at heightened risk for neurodevelopmental delay or disorder, including difficulties with fine and gross motor skills, speech and language, attention, learning, social cognition, visual-perceptive integration, memory, and executive function.[32–34] Neurocognitive disabilities are not generally considered an absolute contraindication to pediatric thoracic organ transplant, as patients with cognitive delays can achieve comparable medical outcomes to youth without known delays.[35–38] However, listing may be contingent upon a strong social support system and caregiving plan for patients with neurocognitive disabilities, and an understanding of the potential need for lifelong care for the child.[39] Regardless of cognitive status, children who are hospitalized for long periods or who are frequently unable to attend school due to medical symptoms may have gaps in their formal education, which may interact with cognitive and social functioning.[40] The complex interplay of patient developmental stage, cognitive status, and degree of caregiver support is important to assess as part of the evaluation process.

4.2.1.2. Evaluation recommendations

Assessment of patient cognitive function is important to contextualize their ability to understand and care for their transplanted organ and identify areas for continued support (e.g., developmental intervention, special education services, need for future guardianship evaluation and planning). Assessment of the caregivers' ability to understand and follow post-transplant care responsibilities is also important. Assessment of patient cognitive functioning may include screening measures, such as the brief PedsQL Cognitive Functioning scale,[41] Behavior Rating Inventory of Executive Function (BRIEF),[42] and Adaptive Behavior Assessment System (ABAS)[43]; or, when available, full assessment batteries, such as the Wechsler Abbreviated Scale of Intelligence (WASI),[44] or the Wide Range Achievement Test (WRAT).[45] This information allows for an understanding of the patient's ability to take on age-appropriate post-transplant care responsibilities, as well as for customized transplant-related education and accommodations.[46] Furthermore, information regarding the patient's current educational achievement and supports should be included in the pre-transplant evaluation for all school-aged children, and can be used to guide post-transplant educational supports and school re-entry.[47] In general, child cognitive and academic delays should not be considered contraindications to transplant, but must be considered as areas for individualized intervention.

4.2.2. Knowledge of medical condition and treatment options

4.2.2.1. Background

Thorough and developmentally appropriate knowledge about the patient's underlying disease, transplant process, and the importance and function of immunosuppressive medications is important for good post-transplant adherence for both caregivers and patients.[48] Educational strategies to enhance knowledge of medication management can improve patient medication adherence,[49] as misconceptions about the transplant process are common.[50] Knowledge of medical condition and treatment options can be influenced by several factors, including language proficiency and health literacy. Given the association between caregiver health literacy and child health and wellbeing,[51,52] incorporating opportunity for interventions to address health literacy and improve knowledge during the evaluation process can be critical to reducing health disparities.[53]

4.2.2.2. Evaluation recommendations

The assessment should obtain information on the patient's and family's understanding of the medical illness and the potential treatment options, benefits, risks, and side effects of transplant medications at a developmentally appropriate level.[1,4] It is important to explore the patient's and family's expectations for transplant, both short-term and long-term, and to correct misconceptions they may have about the transplant process.[50] Provided information should be simplified, well organized, and presented in the primary language of the patient and/or caregiver, and providers are encouraged to use teach-back methods to assess and support understanding.[52]

4.2.3. Coping with illness

4.2.3.1. Background

Coping refers to an individual's efforts to adapt to challenges and may present in the form of active/primary coping (efforts to act on the source of stress or difficult

emotions), accommodative/secondary coping (efforts to adapt to the source of stress), or passive/disengagement coping (efforts to avoid or deny the stressor).[54] Disengagement coping is associated with adjustment difficulties in pediatric chronic illness populations, and may include denial of illness or avoidance of lab draws due to a specific phobia. Active and accommodative coping may be more adaptive and help to promote resilience and adjustment – for instance, using distraction or distress tolerance skills, such as deep breathing or guided imagery, to get through difficult medical procedures. Caregivers also engage in a variety of coping strategies to manage distress related to their child's medical condition, and caregiver engagement in adaptive coping strategies has been shown to relate to higher caregiver psychological quality of life.[55]

4.2.3.2. Evaluation recommendations

Patient ability to undergo medical care, such as needle-based procedures, pulmonary function tests, dressing changes, and echocardiograms, should be assessed given the frequent need for these interventions throughout transplant care. Information about supports (i.e., child life, pre-medication) and coping skills that are helpful to a patient when completing medical cares or procedures should be gathered as part of the evaluation. The patient's engagement in coping strategies may be assessed via interview and self-report measures, such as the Responses to Stress Questionnaire (RSQ[56]) or the KidCOPE,[57] which have both been widely used with pediatric chronic illness populations. Caregivers' engagement in coping strategies may be assessed via interview and self-report questionnaires, such as the Coping Health Inventory for Parents[58] or the Brief COPE.[59] Interviews with the patient and caregivers may include questions to elicit what they do to manage stress or cope during difficult times and what resources or supports are helpful. It is important to not only assess the presence of or engagement in coping skills, but also how the patient and caregivers appear to be coping more broadly. For example, this may include gathering information about the level and type of emotions the patient and caregivers are experiencing in the context of the child's medical condition and the degree to which their emotions may be impacting their ability to engage in activities and responsibilities. Past traumatic medical experiences that may adversely impact patient and caregiver coping with illness and procedures should be understood.

4.2.4. Social support

4.2.4.1. Background

Social support (both emotional and instrumental) of the patient and their caregivers plays a central role in health-related outcomes, as social support may influence patient adherence, coping and mental health, and overall patient quality of life.[60] Peer support and mentoring relationships can increase disease management of adolescent patients with chronic medical presentations.[61,62] Protective factors associated with greater medication adherence include a two-caregiver household, fewer children in the home, greater family cohesion, lower levels of conflict, and perceived family support.[20,63,64]

Pediatric thoracic organ transplantation can disrupt the family system and lead to psychosocial challenges and family functioning difficulties,[17] contributing to adverse patient outcomes.[65] Significant demands may be placed on the family system to support the transplanted patient.[66] Unlike adults who are generally responsible for their own adherence to the post-transplant protocol, pediatric adherence can be affected by caregiver and family functioning. Caregivers often endorse psychological distress and family disruption following transplantation[67] which contributes to pediatric patient medication non-adherence.[68]

4.2.4.2. Evaluation recommendations

It is essential to obtain social support histories for pediatric transplant candidates, including caregiver distress and patient/family support, to determine how to best support the patient and family system during transplant listing and following transplant.[69] Social support persons should be involved in a collaborative effort to develop a plan for post-transplant care. This plan should ensure caregivers are knowledgeable about transplant, rejection, long-term follow up plans, symptoms of clinical deterioration, disease impact on family, potential complications, guidelines for avoiding infection, and available resources. This care plan should also identify the primary person to manage medication, include strategies to manage aspects of patient care, and be sensitive to neurodevelopmental outcomes and interventions.[9,70]

4.2.5. Social history

4.2.5.1. Background

It is essential to understand the patient's social history to determine appropriate needs and support placement of essential resources before and following thoracic organ transplant. Traumatic experiences, including hospitalizations, can affect health and factors associated with transplant outcomes, such as following medical regimens post-transplant.[64,71,72] Infants and children with prolonged hospitalizations (> 6 months) have elevated risk for mortality and displacement from families after discharge.[40] Additionally, adverse childhood experiences (ACEs) can contribute to psychological and social challenges, compounding the risk for poor medical and psychosocial outcomes.[71,73,74] The physical environment where the child lives, plays, learns, and spends time can affect the patient's health (e.g., access to healthy foods, exposure to smoke/substances).[75] Lower socioeconomic status is associated with worse outcomes following pediatric heart transplant,[76] and lapses in insurance coverage are associated with increased risk of mortality when compared to continuous public or private coverage.[77] A family's ease of going to the transplant medical center frequently for follow-up appointments may vary based on distance from the center and family transportation resources.[14]

4.2.5.2. Evaluation recommendations

Patient and family social factors, or the contexts and conditions in which children and families live, learn and develop, embedded in broader systems of influence,[78] must be

evaluated. Clinicians should assess traumatic medical experiences and adverse childhood experiences (ACEs), including but not limited to, household dysfunction, violence, caregiver mental illness, and child maltreatment.[71,73] Evaluations should include a thorough assessment of resources, including but not limited to, insurance coverage, access to healthy foods, food security, physical activities/rehabilitation, transportation, basic utilities, and substance use exposure (e.g., tobacco), through multidisciplinary evaluation.

4.2.6. Sociocultural considerations

4.2.6.1. Background

Sociocultural factors provide a crucial context for understanding the child and family during the pre-transplant evaluation and throughout the process as a whole. As such, sociocultural factors including ethnicity, race, socioeconomic status (SES), geographic location,[79] disability, health literacy, family structure and spiritual/religious beliefs are important considerations during the transplant evaluation phase.[80] These factors coincide with healthcare disparities, posing unique ethical dilemmas and social justice concerns.[50] Despite policies against discrimination, health disparities across race, SES, sex and gender, and neurodiversity continue to impact the pediatric transplant process.[50,81,82] For instance, patients from historically marginalized communities have persistently inferior wait-list and post-transplant outcomes compared to White patients, including not only increased risk for waitlist mortality but also increased rejection episodes post-heart transplant.[83,84] The specific factors contributing to these group differences remain understudied. In general, lower treatment adherence and poorer transplant-related outcomes are observed among Black or non-White pediatric patients,[5,8,34,84–86] Hispanic patients,[86] and those of lower SES.[85,86] These data are largely derived from registry-based studies, which cannot assess sociocultural context or systemic factors, such as intergenerational mistrust of the healthcare system among Black Americans in the context of a long history of mistreatment and undertreatment.[87] As social constructs, race and ethnicity can give rise to implicit bias, racism and discrimination,[88] and can also serve as proxy variables for other factors that may dynamically influence health outcomes for pediatric heart transplant patients.

4.2.6.2. Evaluation recommendations

Pediatric thoracic transplant evaluation frameworks should consider systemic factors such as discrimination and social and cultural bias. Structural discrimination, including but not limited to, racism, sexism, ageism, ableism, and classism, can influence healthcare access, uptake, and outcomes,[89] and the contexts in which children and families live must be a key consideration throughout the transplant evaluation process. Interview questions or assessments regarding impacts of such discrimination may be informed by the Structural Vulnerability Assessment Tool,[90] which provides screening and follow-up questions to gauge aspects of patients' and family's structural vulnerability (e.g., risk factors for negative health outcomes such as financial security, residence safety, education, food access, discrimination). Recognition of socially- or culturally driven assumptions, biases, or expectations will assist in the development of socio-culturally appropriate recommendations, more sensitive and attuned interventions, and better patient-family-healthcare team relationships. Advocating for understanding of patient and family sociocultural factors to the broader transplant team is an important role of the psychosocial clinician. During pediatric thoracic organ transplant evaluation, every effort must be made to integrate consideration of social factors and to support clinical care teams in minimizing the effects of implicit and explicit bias on patient/family care-team relationships, transplant decision-making and care.[91,92]

5. Recommendations for psychosocial evaluation process

5.1. Qualifications and experience of evaluator

Pediatric patients undergoing evaluation for thoracic organ transplantation and their caregivers are typically grappling with numerous stressors related to acute or chronic illness and the evaluation process can be an added stressor. Therefore, it is important that clinicians completing the transplant psychosocial evaluation have completed training in a healthcare discipline that has prepared them to assess for risk and protective factors for transplant while remaining sensitive to the inherently stressful nature of the evaluation itself. Qualified individuals are typically psychosocial providers (i.e., psychologists, social workers, psychiatrists) who are licensed in their discipline and have completed additional specialized accreditation deemed relevant by the country and/or state in which they are licensed. For pediatric transplant, the evaluator should have training in child development and family systems to effectively assess for risk and protective factors in these areas.[93,94] Evaluators should take care to develop a therapeutic alliance by adopting an honest, collaborative, and supportive approach with children and their families.[95] Involvement in continuing education in the areas of pediatric transplantation, child development, medical traumatic stress, and family systems in addition to continuing education requirements to maintain licensure is strongly recommended.

5.2. Conducting the psychosocial evaluation

As has been discussed in the adult thoracic organ transplant psychosocial evaluation literature, patients and caregivers should be informed about the purpose and goals of the psychosocial evaluation, including that results will be shared with the multidisciplinary transplant team and may be taken into consideration when determining transplant candidacy.[2] As noted in the introduction, it is important that the psychosocial clinician explain to patients and caregivers that the goal of the psychosocial evaluation is to identify areas of strength, in addition to areas that may benefit from additional intervention or resources. Encouraging open and honest discussion can help to facilitate optimal supports for patients and families throughout the transplant process. The evaluation should be conducted in

the family's native language with the use of hospital-approved interpretation services when needed, so that all family members present can fully participate.[2] Patients who are ultimately listed for transplant should complete subsequent psychosocial evaluations at regular intervals at a time frame determined by individual centers (e.g., six months, annually) to ensure psychosocial information is updated at the time of transplant.[2]

Specific to pediatric transplant, an identified adult caregiver must participate in the evaluation interview to ensure they are willing and able to care for a child with a transplanted organ and to support the longevity of the organ. As pediatric patients under age 18 years are unable to legally consent for transplant (at least in the US), a caregiver (legal guardian) must also be available to consent for transplant and other medical interventions as necessary. To be able to make medical decisions on behalf of the child, caregivers must demonstrate they are (1) competent to make reasoned judgment, (2) possess adequate knowledge and information, (3) are emotionally stable, and (4) are committed to the child's best interests.[96] Information regarding a caregiver's ability to consent for transplant for their child can be gathered via multimodal assessment including interview questions demonstrating they are able to articulate the risks/benefits of transplant and an understanding of why transplant is being recommended for their child, in addition to completion of assessment measures which screen for emotional health and health literacy. Alternate caregivers with legal rights to make medical decisions for the patient should be explored for the purpose of consenting to medical treatment should a caregiver be determined to be incapable of making informed decisions on their child's behalf.

Careful assessment of the patient and family's separate and unified understanding of goals and values of care and existing end-of-life wishes and advanced care planning provides context to the pre-surgical assessment and sets the stage for future shared decision making. Communication tools such as the MyCHATT[97] and Voicing My Choices[98] can be used to begin the conversation about patients' communication needs and preferences regarding decision-making and advance care planning. A detailed analysis of the ethical issues around assent to transplant is beyond the scope of this paper, but clinicians should have a foundational awareness and attentiveness to principles of patient autonomy, capacity to make decisions, assent/consent, and justice.[99,100]

The patient's medical or developmental status may preclude their participation in the evaluation, but when able, the patient should also be directly interviewed, and complete assessment measures as previously discussed. Assent to transplant – especially in the case of adolescents – is an important consideration for the psychosocial evaluation as children aged 14 years and older are generally thought to be competent to make informed treatment decisions.[101] Adolescents prefer to be involved in the transplant decision-making and as a partner in their care.[102] With the demand for suitable organs exceeding the supply, adolescent assent to transplant should be considered as part of the evaluation process and lack of assent should be taken seriously.[103] When patients and legal guardians agree with the medical team as it relates to transplant decision-making, this process is more straightforward. However, if the psychosocial evaluation reveals an adolescent patient or caregiver is not agreeable to transplant, time should be taken to explore reasons for refusal and provide relevant supports or intervention (e.g., further education, evidence-based treatment of anxiety or depression). Should the caregiver or adolescent maintain disagreement with transplant or goals of care, the transplant team is then tasked with an ethical quandary that involves determining whose preference takes precedence.[7] In these cases, consultation with hospital ethics committees is strongly recommended.

When patients are unable to participate due to medical or developmental status, caregivers are used as proxy and other sources of information (e.g., school records, prior neuropsychological evaluations) should be considered. When psychosocial evaluations are completed urgently, however, gathering information from outside sources may not be feasible. If a patient has a previously established relationship with the hospital where the evaluation is taking place and/or medical records from the referring hospital are available, documentation regarding appointment attendance and medication adherence are additional sources of information that should be taken into consideration and can be more easily accessible during urgent, time-limited evaluations.

5.3. Use of templates or checklists as adjuncts for completing the psychosocial evaluation

Regardless of the psychosocial assessment measures used by individual transplant centers, each center should take care to implement a standard approach to their evaluation. A set note template and/or checklist completed by the psychosocial clinician that includes the areas of the psychosocial evaluation can assist in standardizing the assessment across patients and with summarizing findings.[2] Standardized rating instruments which provide an overall summary score of pediatric transplant psychosocial risk have been developed but have not demonstrated acceptable reliability and validity to date.[104] As such, the authors do not endorse the use of a summary tool. Further, a standardized approach to how psychosocial evaluations are conducted (i.e., age of patient, discipline(s) conducting evaluations, timeframe of evaluation) should be determined and adhered to at each transplant center.

5.4. Reporting evaluation recommendations to the transplant/medical team

5.4.1. Part A: Writing of evaluation report into the patient's medical record

After conducting a thorough pre-transplant evaluation and any follow-up assessments and testing, psychosocial clinicians are tasked with conveying these results through documentation and discussions with the medical team. In terms of documenting the results of the pre-transplant

evaluation, there are several considerations that present unique challenges and considerations. First, one may consider the timing of sharing their report with the patient and family. This is particularly relevant in the United States in light of the 21st Century CURES Act, which gives patients and families immediate access to their medical records.[105] Aspects to be considered include (1) whether the transplant evaluation is complete, (2) whether the medical team has met for selection committee to determine transplant candidacy, and (3) whether these recommendations have been discussed with the family. It may be helpful to have these conversations prior to sharing notes with the patient and family that may feel surprising to them; however, this is not always possible given the timing of more urgent or acute cases. In those cases, preparing the family during the pre-transplant evaluation that the report will document psychosocial recommendations may be helpful.

Further, confidentiality concerns may arise given the sensitive nature of the psychosocial pre-transplant evaluation report. Again, it is helpful to inform the patient and family as part of the informed consent process that the information gathered during the pre-transplant evaluation will be documented in the evaluation report, and shared with the patient's healthcare team. While assessment of parental mental health is critical during pre-transplant evaluation, documenting detailed information about parental mental health in a patient chart is typically not permissible. In the pediatric setting, however, this information is necessary in the context of transplant candidacy and recommendations or requirements for transplant listing and thus may be considered differently, as the information is often necessary for insurance authorization for transplant listing. This may be an area where a discussion with an institution's audit, compliance and documentation team(s) may be helpful in terms of how to handle documentation as this may vary across institutions.

Integrated psychologists, social workers, and/or psychiatrists often attend multidisciplinary transplant selection committee meetings to relay their pre-transplant evaluation findings. These meetings present opportunities for each discipline to present their perspective on the relevant factors for the patient and family's transplant candidacy. It is often helpful for these psychosocial providers to discuss their pre-transplant evaluation among colleagues who also conduct a pre-transplant evaluation, to compare perspectives and formulate a plan for psychosocial recommendations. Ideally, psychosocial providers will present patient and family risk and resilience factors that may impact post-transplant outcomes. Psychosocial providers would also provide and suggest recommendations and/or requirements for transplant listing during selection committee meetings and the multidisciplinary teams would discuss as a group to come to a consensus about the psychosocial recommendations and/or requirements. While this is optimal, not all psychosocial providers are embedded within transplant teams in a manner that makes this feasible. Finally, a plan should be presented to the patient and family by the multidisciplinary team, which may include medical providers and the psychosocial provider(s) if there are specific requirements related to psychosocial aspects of care.

5.4.2. Part B: Psychosocial contraindications to and/or risk factors for transplant

In terms of specific psychosocial recommendations and requirements for transplant listing, processes and criteria for listing may vary significantly across centers and even across solid organ transplant teams within centers. Further, cases within thoracic organ transplant may be considered differently according to patient acuity and urgency of listing. However, it is especially important to evaluate any provider biases that may impact care and may cause different patient groups, especially individuals from marginalized groups, to be treated differently in the transplant listing process.[103,106] Team communication and ongoing professional development, such as training in diversity, equity, and inclusion, is crucial, and considering the whole person, comprehensive care and additive influence of various risk factors is key.[107]

Psychosocial clinicians may use their clinical judgment in terms of determining how concerning risk factors are and whether they present absolute or relative contraindications to transplant listing. Furthermore, there can be considerable variation between and within teams as to how psychosocial concerns impact listing decisions.[108] When team members disagree on how to move forward with listing, it is important to have open and honest communication among multidisciplinary providers. Outside parties such as hospital ethics committees may be helpful in certain circumstances. Medical acuity may at times outweigh psychological risk factors and recommendations or requirements; however, this may be a case-by-case basis group decision, which should be monitored for any biases or differences across patients as well. It is recommended that teams identify and use a consistent process across patients for discussion of patient transplant candidacy, as a way of reducing bias.

5.4.3. Part C: Monitoring follow-up treatment recommendations or requirements

Once the pre-transplant evaluation has been completed and recommendations have been determined, it is important that multidisciplinary teams discuss how recommendations will be shared with patients and their families, and how they will be implemented after the evaluation. Some multidisciplinary teams may decide that psychosocial recommendations (e.g., specific school-based accommodations, neuropsychological evaluations) are not time-sensitive and do not require close follow-up. However, if a caregiver or a child is presenting with significant psychosocial concerns requiring follow-up with a mental health provider, it may be appropriate for either a member of the medical or psychosocial team to follow-up with that family as they seek additional support. If a family is already receiving intervention from a community behavioral health provider, it may be helpful to obtain a release of information for the purposes of care coordination.

Certain types of recommendations may require providers and families to engage in goal-setting and utilize objective markers of progress as they work toward these goals. For example, recommendations for behavior change (e.g.,

greater engagement in healthy habits, improved adherence to a medication regimen) are best addressed utilizing a SMART goal framework that promotes setting specific, measurable, achievable, relevant, and time-bound goals. Small steps toward a larger goal of seeking behavioral health treatment might include scheduling an intake, attending weekly visits, or following through with a psychiatric medication evaluation if indicated.[108,109] To address engagement in healthy habits, goal-setting may consist of a behavioral plan to increase physical activity, water intake, or the establishment of a sleep hygiene routine to promote both sleep quality and duration. To address adherence, psychosocial providers should assess specific barriers to adherence, and then utilize motivational interviewing and problem-solving skills training to create an adherence promotion plan in accordance with recommendations from the medical team. Providers may also consider monitoring improvements in labs, reviewing pharmacy refill records, or logging clinic visit attendance or frequency of labs to track progress toward improved adherence over time. If families demonstrate significant difficulty following through on recommendations to the extent that it may impact a child's listing status, multidisciplinary team members may consider coordinating with their local mechanism for child protective services to increase supports/resources in the best interests of the child in need of transplant.

6. Considerations for ventricular assist devices (VADs)

While no formal guidelines exist regarding the psychosocial evaluation of pediatric VAD candidates, the 2021 ISHLT consensus statement for the selection and management of pediatric and congenital heart disease patients on VAD does state that a psychosocial assessment of patient and family treatment adherence, facilitators and barriers to VAD and disease management, VAD and disease-related knowledge, neurodevelopmental functioning, mental health and substance abuse history, family and social support and abuse and legal history should be gathered pre-VAD implant.[110] Additionally, the 2018 ISHLT recommendations for psychosocial evaluation of adult heart transplant and VAD candidates recommends psychosocial evaluation of device knowledge (i.e., how to operate, signs of device malfunction), cognitive and/or physical limitations that would interfere with device operation (e.g., responding to alarms), and the appropriateness of the home environment for device operation, such as access to electricity and emergency personnel.[111] The U.S. Centers for Medicare and Medicaid Services (CMS) require a social worker be present on VAD teams as well as a psychosocial evaluation to be conducted pre-implant.

VADs can be utilized for several reasons for pediatric patients, including as a bridge to transplant, a bridge to decision, a bridge to recovery, or as "destination" therapy. Given unpredictability of the medical course in many cases, the purpose of the VAD is not always known at the time of the VAD evaluation. When it is known (i.e. a patient deemed ineligible for transplant who is being evaluated for destination therapy), this importantly influences the evaluation conversation around long-term goals and impact of long-term VAD placement. Sometimes, the evaluation for VAD is co-occurring with the evaluation for transplant; when these time points are separated, psychosocial clinicians will need to be a complete a separate, updated psychosocial evaluation with specific assessment of transplant-related domains.

6.1. Patient and caregiver mental health

Both the pediatric[112] and adult psychosocial VAD literature underscore the importance of the psychosocial evaluation prior to VAD implantation. Emerging research suggests that children bridged to transplant with VAD experience higher rates of psychiatric conditions with increased need for psychopharmacologic treatment when compared with transplanted peers not requiring VAD support. Nearly half (40%) of pediatric patients bridged to transplant with VAD in a national database sample had a psychiatric diagnosis, most commonly adjustment, mood, and/or anxiety disorders.[15] These findings are supported by patient-reported data from the ACTION Learning Network pediatric VAD database, with sadness commonly reported by patients themselves, along with VAD-specific concerns, such as worries related to dressing changes and limitations in activity due to VAD.[113] A recent systematic review of the pediatric VAD literature concluded that pre-implant psychological assessments are critical given notable risk for mental health concerns during VAD course, and underscored a need for psychological intervention throughout VAD course, particularly during periods of transition (e.g., discharge home, transplantation).[112]

Caregiver mental health and ability to manage VAD care are also important considerations in the pre-VAD evaluation. Strong social support has been linked to improved quality of life in adults with VAD.[114] Parents of children on VAD endorse considerable worry, sadness, and challenges regarding balancing caregiver demands.[113] Thus, given the critical role of parents/caregivers in VAD management and care, pre-implant assessment of their own mental health, coping, and social support needs is important for intervention planning throughout the entirety of the VAD course.

6.2. Additional considerations

6.2.1. Knowledge of VAD indication, strategy and risks

It is critically important that patient (pending age and developmental level) and parent/caregiver understanding of VAD indication and strategy is assessed prior to implant. Further, use of VAD is associated with increased risks. Bleeding events are a more common adverse event in VAD use, including early and late bleeding episodes following implantation and cardiac tamponade. Infection and stroke risks are elevated in VAD use.[115,116] Neurological impairment, ranging from minor stroke

and functional impairment to debilitating or fatal strokes, are a common complication associated with pediatric VADs.[116] Thus, it is important that patient (when possible) and family understanding of VAD-related risks are also assessed prior to implant. It has been recommended that advance care planning discussions be considered prior to implant, given the ethical considerations around VAD device deactivation.[117–119]

6.2.2. VAD management and discharge readiness

Overall, VAD implantation requires significant patient/caregiver involvement and investment in health maintenance. Patients have to attend frequent cardiology appointments, manage complex medication routines, closely monitor and maintain VAD battery life, engage in problem-solving in an emergent situation (e.g., loss of power during a thunderstorm), and provide adequate overall device care. While patients and families are unlikely to have complete knowledge of VAD management or home discharge needs prior to implant, it is important that that the psychosocial evaluation examine domains that may impact safe VAD management outside of the hospital setting prior to implant, so that interventions and supports can be implemented early. For younger patients who have devices that require hospitalization for the duration of implantation (i.e. Berlin Heart), pre-implantation education to families about a potentially lengthy hospital stay is important.

6.3. Conclusions

While the VAD psychosocial evaluation content and process largely mirror the pre-thoracic transplant psychosocial evaluation, there are some additional considerations that warrant discussion in the evaluation process. These include assessment of understanding of VAD-specific risks, patient and caregiver understanding of the health maintenance commitment involved with VAD implantation, and ability of the home environment to support safe discharge on VAD when relevant. Likewise, content will need to be tailored to the intended purpose of the VAD (bridge to transplant vs bridge to decision vs. bridge to recovery vs. destination) as feasible.

7. Conclusions

The purpose of this document is to provide an up-to-date, consensus-based framework, developed by an international team of content experts, in the pre-thoracic transplant and pre-VAD implantation psychosocial evaluation. Unlike previously published guidelines, these focus on pediatric populations and are specific to thoracic organ transplantation and VAD. Furthermore, the recommendations in this paper reflect an increased recognition of the importance of understanding the child in the context in which they live, as well as of the historical and current impact of health disparities on transplant eligibility and outcomes. By providing a framework to encourage consistency in how pediatric transplant and VAD programs approach the evaluation, we aim to increase equity in the access to and outcome of the use of these life-extending resources.

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