

# Health Care Transition for Adolescents and Young Adults With Pediatric-Onset Liver Disease and Transplantation: A Position Paper by the North American Society of Pediatric Gastroenterology, Hepatology, and Nutrition

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## ABSTRACT

Advances in medical therapies and liver transplantation have resulted in a greater number of pediatric patients reaching young adulthood. However, there is an increased risk for medical complications and morbidity surrounding transfer from pediatric to adult hepatology and transplant services. Health care transition (HCT) is the process of moving from a child/family-centered model of care to an adult or patient-centered model of health care. Successful HCT requires a partnership between pediatric and adult providers across all disciplines resulting in a transition process that does not end at the time of transfer but continues throughout early adulthood. Joint consensus guidelines in collaboration with the American Society of Transplantation are presented to facilitate the adoption of a structured, multidisciplinary approach to transition planning utilizing The Six Core Elements of Health Care Transition™ for use by both pediatric and adult specialists. This paper provides guidance and seeks support for the implementation of an HCT program which spans across both pediatric and adult hepatology and transplant centers.

**Key Words:** emerging adulthood, nonadherence, transfer of care, transitions of care

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Advances in both medical therapies and pediatric liver transplantation (LT) have resulted in a greater number of adolescent and young adult (AYA) patients entering adult-centered hepatology and transplant services. There are an estimated 1500–1800 solid organ transplantation (SOT) recipients between the ages of 16 and 22 in the United States (1,2). Based on Organ Procurement and

Transplantation Network data (September 2021) nearly 18,000 LTs have been performed on recipients less than 18 years of age while the exact prevalence of AYA with chronic liver disease (CLD) remains unknown. There is an increased risk for medical complications and morbidity following transfer from pediatric to adult health care services in patients with childhood-onset chronic illness (3–5). Despite this inherent risk, there has been no formal, standardized approach to transition planning for pediatric patients with CLD and transplantation.

Health care transition (HCT) is the process of changing from a pediatric to an adult model of health care (6). The goal of a transition program is to help facilitate this process and optimize the likelihood of sustained well-being in young adults by fostering their ability to achieve physical, social, and psychosocial potential (1,6,7). Transfer of care is an event, or the purposeful, planned movement of a patient from pediatric to adult health care facilities (8). For most adult LT recipients, 20–25-year patient and allograft survival equates with a full life. In stark contrast, 20–25 years brings a pediatric recipient to young adulthood, a time of increased risk and vulnerability. This risk appears to intensify approximately 10 to 15 years after transplantation, right around the time of HCT (9). Ineffective transition increases the risk of chronic rejection and graft failure resulting in higher health care costs, a diminished ability to perform activities of daily living and maintain employment, and augmented use of scarce resources such as organs for retransplantation (5,6,10).

The purpose of this position paper is to provide the framework for a structured, multidisciplinary approach to transition planning for AYA with CLD and LT that will result in improved adherence, self-management skills, and long-term medical outcomes, similar to those observed in primary care practices (4). In addition, the

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authors seek to emphasize the importance of partnership between pediatric and adult colleagues. The transition process does not end at the time of transfer but must continue throughout early adulthood. Continued multidisciplinary efforts in the adult practice are essential for long-term success. To date, there has been no formal position statement from the North American Society of Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) acknowledging the importance of HCT for AYA following LT. Joint consensus guidelines in collaboration with the American Society of Transplantation (AST) are presented to facilitate this mission of a standardized, multidisciplinary approach to HCT spanning across both pediatric and adult transplant and hepatology centers. This practice may allow for decreased rates of rejection, graft loss, and an improvement in long-term clinical outcomes.

## PEDIATRIC-ONSET CLD

Advances in medical and surgical treatment have also led to an increasing number of patients with CLD surviving into adulthood and transitioning to adult care. The true prevalence of pediatric liver disease in the United States is unknown, but it is estimated that there are approximately 15,000 hospitalizations each year attributed to complications of CLD (11). The etiology of CLD in childhood is significantly different when compared to adult-onset CLD. These patients require life-long care for ongoing medical management, progressive portal hypertension (especially during pregnancy), and the possibility of hepatic deterioration or development of hepatocellular carcinoma requiring LT. A summary of pediatric-onset CLD and recommendations for ongoing surveillance are provided in Table 1.

## METHODS

In discussion with members of the NASPGHAN hepatology committee and the AST Liver and Intestinal Community of Practice, it was deemed necessary to provide a guiding document addressing key elements of the transition of care process with emphasis on the importance of partnership between pediatric and adult providers. A multidisciplinary working group with expertise in HCT was formulated. Members included both pediatric and adult hepatologists, transplant surgeons, advanced practice providers, and psychologists caring for patients with pediatric-onset liver disease and transplantation.

Relevant literature was reviewed using PubMed/MEDLINE/Google Scholar databases applying the following terms: HCT, transition of care, transfer of care, pediatric liver disease, pediatric LT, adherence, transition readiness, emerging adulthood, AYAs, quality of life, transplant outcomes, retransplantation. Literature searches were conducted through June 2021. Non-English literature was excluded. Sections were completed by individual authors with review and editing of each draft by the coauthors. The available literature and expert opinion were used by the authors to formulate suggested guidance for each section. These recommendations were modified and ultimately agreed upon by the multidisciplinary HCT working group members via virtual meetings and electronic communications. Through group consensus, reference tables and a "Post-Transfer Self Care and Skills Assessment for Young Adults" (Table 4) were created. A formal grading method was not used.

## BARRIERS TO TRANSITION OF CARE

### Pediatric Providers

Barriers to transition from pediatric to adult care should include reflections by the pediatric provider (Fig. 1) (12). Pediatric providers are often considered "family" by patients and parents, and providers may struggle with "letting go" of this long-standing

and unique relationship leading to difficulties in relinquishing care (13,14). Pediatric provider ambivalence or negative beliefs surrounding adult care may inadvertently communicate to AYAs and their families that transfer of care is something to be feared. The unintended consequences of such uniquely strong attachments between families and their pediatric providers may contribute to challenges or impaired ability for pediatric graduates to develop new relationships with adult providers (3), thereby delaying preparation for transfer (15). Studies have also reported that pediatric providers are overly accommodating and engage in "hand holding" behaviors, thereby interfering with the development of age-appropriate self-management skills (16).

### Adult Providers

Adult providers may lack sufficient knowledge and familiarity in caring for young adults in various stages of development. A poor understanding of the impact of childhood chronic disease on development, insufficient training in the management of congenital diseases, and a lack of formal training in adolescent medicine, have all been cited as barriers to transition at the level of the adult provider (17). In addition to a lack of familiarity and exposure, the busy and faster-paced adult practice model which places emphasis on disease management, rather than a holistic, family-centered focus, has also been perceived as a significant barrier to HCT. Providers in busy adult practices may have limited time to devote to the young adult and their family (1).

### Adolescent and Young Adults

AYA SOT recipients demonstrate significant levels of executive dysfunction (18) particularly in skills necessary for planning, organizing, initiating, and maintaining future-oriented problem-solving. It should be noted that the prefrontal cortex, which is responsible for executive functions such as decision-making, organization and planning, and impulse control, is remodeled during adolescence. These neurodevelopmental changes continue until about 25 years of age (19,20).

Pediatric transplant recipients experience increased levels of emotional difficulties, most commonly depression and anxiety, as compared to their healthy peers (21), and these psychological factors can negatively impact patient adherence (22,23). It is of critical importance to recognize and identify barriers to adherence. Potential barriers that may be mitigated before transferring care include, but are not limited to, access to care, health literacy, and challenged cognitive or executive functioning. Neighborhood deprivation is another contributing factor that may increase nonadherent behaviors and jeopardize best outcomes (24).

### System Barriers

Having adequate health insurance coverage during young adulthood can be a significant system barrier during transition. Although teens with disabilities and chronic conditions often have access to health insurance coverage, transition to adulthood is a time when coverage is often insufficient or non-existent (25).

Pediatric hepatology and transplant recipients should have access to a mental health specialist with expertise in adolescents with chronic illness. Transferring care to an adult transplant or hepatology center which offers these services is a challenge as there is a severe shortage of mental health professionals in the United States (26).

### Best Practice Recommendations and Summary

1. Barriers to transition are multifaceted and include individual, family, and system-wide factors.
2. Transition planning should be initiated by the pediatric team in early adolescence.

TABLE 1. Summary of pediatric-onset chronic liver disease and ongoing surveillance: a quick reference guide for adult providers

Condition	Clinical Features and Considerations	Extrahepatic Manifestations	Surveillance	Inheritable Condition
<b>Biliary Atresia</b>	<p>Progressive, idiopathic, fibro-obliterative disease of extrahepatic biliary tree that presents with biliary obstruction exclusively in the neonatal period</p> <p>70% develop progressive fibrosis/cirrhosis, portal HTN, recurrent cholangitis following HPE</p>	<p>Biliary atresia splenic malformation (BASM) 15%</p> <ul style="list-style-type: none"> <li>• Situs inversus</li> <li>• Asplenia or polysplenia</li> <li>• Malrotation</li> <li>• Interrupted IVC</li> <li>• Cardiac anomalies</li> </ul> <p>Other congenital anomalies 10%</p> <ul style="list-style-type: none"> <li>• Intestinal atresia</li> <li>• Imperforate anus</li> <li>• Kidney anomalies</li> <li>• Cardiac malformations</li> </ul>	<ul style="list-style-type: none"> <li>• Portal HTN</li> <li>• HCC</li> <li>• Cholangitis</li> <li>• FSV Deficiency</li> <li>• Progression to ESLD with indications for LT</li> </ul>	No
<b>Alagille Syndrome</b>	<p>Characterized by paucity of intrahepatic bile ducts</p> <p>Multisystemic disease with potential for cardiac and vascular anomalies, renal involvement, pancreatic insufficiency, bone health</p>	<ul style="list-style-type: none"> <li>• Cardiac anomalies</li> <li>• Butterfly vertebrae</li> <li>• Posterior embryotoxon</li> <li>• Dysmorphic facies (broad nasal bridge, triangular facies, deep-set eyes)</li> <li>• Renal involvement</li> <li>• Short stature</li> <li>• Cerebral and systemic vascular malformations (intracranial abnormalities may predispose to hemorrhage/stroke)</li> </ul>	<ul style="list-style-type: none"> <li>• Portal HTN</li> <li>• HCC</li> <li>• Nutrition</li> <li>• FSV Deficiency</li> <li>• Pruritus</li> <li>• Brain MRI – low threshold for imaging in setting of head trauma or symptoms</li> <li>• Multidisciplinary care: cardiology, nephrology, gastroenterology, ophthalmology, endocrinology, neurology</li> </ul>	Yes, autosomal dominant with variable penetrance
<b>Progressive Familial Intrahepatic Cholestasis (PFIC)</b>	<p>Chronic liver disease with hallmarks of cholestasis and pruritus due to defects in bile acid transporters</p> <p>Increased risk for HCC and hepatic decompensation</p>	<ul style="list-style-type: none"> <li>• PFIC 1 associated with extrahepatic manifestations – sensorineural hearing loss, diarrhea, pancreatic insufficiency, short stature.</li> <li>• PFIC 1 hepatic steatosis, worsening diarrhea noted following transplant</li> </ul>	<ul style="list-style-type: none"> <li>• Portal HTN</li> <li>• HCC (esp. PFIC 2)</li> <li>• FSV Deficiency</li> <li>• Pruritus</li> <li>• Counseling: importance of nutrition, OCP contraindicated, cholestasis in pregnancy</li> </ul>	Yes, autosomal recessive

(Continued)

TABLE 1. (Continued)

<p><b>Alpha-1 Antitrypsin Deficiency</b></p>	<p>Chronic liver disease with variable phenotype  Clinical presentation ranges from abnormal LFTs to cirrhosis and HCC</p>	<ul style="list-style-type: none"> <li>• Pulmonary involvement typically beginning in adulthood</li> </ul>	<ul style="list-style-type: none"> <li>• Portal HTN</li> <li>• HCC</li> <li>• Pulmonary function testing</li> <li>• Counseling: avoidance of alcohol, smoking, vaping and secondhand smoke</li> </ul>	<p>Yes, autosomal recessive</p>
<p><b>Autoimmune Liver Disease</b></p>	<p>Chronic liver disease, variable phenotype with increased risk of relapsing disease</p>	<ul style="list-style-type: none"> <li>• Dependent on underlying disease, may have systemic involvement</li> </ul>	<ul style="list-style-type: none"> <li>• Portal HTN</li> <li>• HCC</li> <li>• Disease relapse</li> <li>• Treatment adherence</li> <li>• Side effects of immunosuppression</li> <li>• Bone health</li> <li>• Indications for LT</li> </ul>	<p>Familial patterns</p>
<p><b>Wilson’s Disease</b></p>	<p>Impairment of copper transport resulting in accumulation in liver, brain and cornea</p>	<ul style="list-style-type: none"> <li>• Neurologic and psychiatric manifestations</li> </ul>	<ul style="list-style-type: none"> <li>• Portal HTN</li> <li>• HCC</li> <li>• Dietary and treatment adherence</li> <li>• Side effects of treatment</li> <li>• Indications for LT</li> <li>• Neurocognitive testing</li> </ul>	<p>Yes, autosomal recessive</p>

ESLD = end stage liver disease; FSV = fat-soluble vitamin; HCC = hepatocellular carcinoma; HTN = hypertension; HPE = hepatoportoenterostomy; IVC = inferior vena cava; LFTs = liver function tests; LT = liver transplant; MRI = magnetic resonance imaging; OCP = oral contraceptive pill.

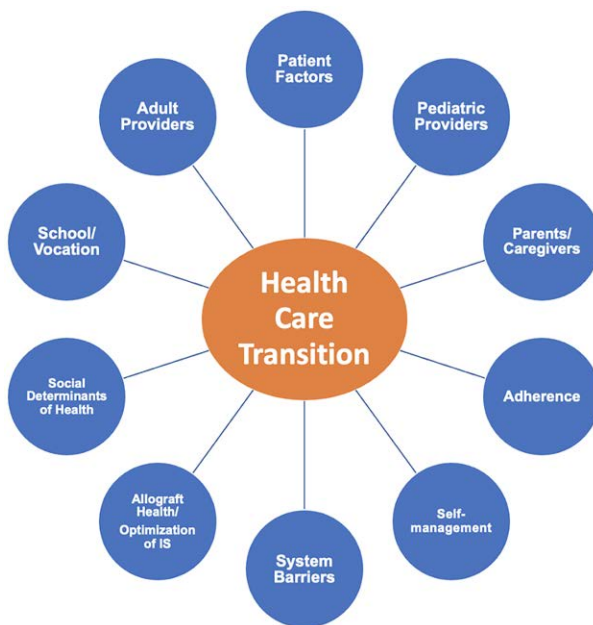


FIGURE 1. Complex interplay of factors impacting health care transition.



3. Pediatric hepatology and transplant recipients should have access to a mental health specialist with expertise in adolescents with chronic illness.
4. Barriers to HCT are best overcome by a multidisciplinary, standardized approach to transition planning with an emphasis on partnership and collaborative practice between pediatric and adult providers.

## RECOMMENDED APPROACH TO TRANSITION OF CARE

### A Structured Approach Utilizing the Six Core Elements of Health Care Transition™

A recent systematic literature review of youth with special health care needs to be reported that a structured transition program is associated with improved health, patient experience, and utilization of health care (Table 2) (30). Got Transition<sup>®</sup>, a federally funded national resource center on HCT, provides guidelines for program development through The Six Core Elements of Health Care Transition™ as recommended by the AAP/AAFP/ACP Clinical Report on HCT (31). These elements define a sequential clinical process with tools and templates for use by pediatric and adult practices. Quality improvement using the Six Core Elements of Health Care Transition™ has resulted in the development of a systematic clinical transition process in pediatric and adult academic primary care practices. Implementation of this system may improve the delivery of transition services and result in important long-term gains in patient-centered outcomes when incorporated into both pediatric and adult hepatology and transplant practices. Each core element and its applicability to transitioning youth with CLD and LT is discussed. An algorithm for HCT is summarized in Figure 2.

#### Transition Policy

The initial step of an HCT program is policy statement development to formalize program goals and reflect a systems approach to transition. Input from the hospital system, the medical team, youth, and parent/caregiver should reflect a consensus on the approach to HCT including target age range for initiation of the process, information to be communicated to the adult team, how the youth will be prepared for the changes of privacy and consent that occur at 18 years of age, and if needed, information and assistance on supported decision-making and guardianship.

#### Tracking and Monitoring

Developing a flow sheet to track the youth's progression through HCT is an essential component of program design and provides data on overall program participation, access to HCT tools and services, the timeline for transfer, and outcomes after transfer. A tracking record through the EMR can be created and maintained to follow the youth's participation and completion of each core element. Sample flow sheets are available on the Got Transition<sup>®</sup> website (<https://www.gottransition.org/>). Additionally, tracking HCT aligns with quality improvement projects such as monitoring the percentage of patients enrolled in the HCT program and core element completion.

#### Transition Readiness

Being "ready" for transfer to adult care is a critical outcome of HCT. Readiness is defined as making specific decisions and operationalizing a plan to build the capacity of the youth, parent, and health care providers to participate in HCT from the start of the process through transfer (32). Participation in a transition readiness

skills program for LT recipients was reported to improve outcomes after transfer to adult care in regard to adherence in taking medications and attending post-transfer clinic appointments (33).

Through TRA, the provider, youth, and parents/caregivers work collaboratively to identify and discuss self-care goals, plan strategies to achieve these goals, and operationalize skill-building activities. TRA should be completed at enrollment in the transition program and repeated at routine intervals to assess progress, evaluate strengths and weaknesses, and to update the plan of care for achieving self-efficacy and progressive independence in care (34). The final TRA should be shared with the adult team and included in the transfer package. TRA can be completed with validated tools used for chronic conditions, such as the Transition Readiness Assessment Questionnaire (35), the UNC STARx Questionnaire (36), or the Got Transition<sup>®</sup> Readiness Assessment for Youth (34). Although these tools are frequently cited in the transplant transition literature, they are not specific to LT or CLD. There are currently no validated TRA tools for AYA LT recipients, although transition templates have been developed through the AST that can be adapted to the needs and population of individual transplant centers. A checklist and a qualitative interview tool for early, middle, and late adolescence and an Action Plan for the teen and parent/caregiver have been developed (<https://www.myast.org/education/specialty-resources/peds-transition>). Reliability and validity have not yet been established.

#### Transition Planning

Through collaboration with youth, parents/caregivers, and pediatric and adult health care providers, a transition plan should be established to set goals and target dates within the transition process. The plan of care includes routinely scheduled TRA, updated goals and an action plan to achieve those goals. Transfer planning also involves developing a medical summary for transfer, an emergency care plan, and preparing the youth and parents for the changes in privacy and consent that occur at age 18. Youth should be oriented to consents for treatment, advanced directives, and release of medical information. Determinations are made for legal decision-making support and guardianship if needed. Medical insurance, community support services, and specialty practices for the youth's needs after transfer should also be established. Sample templates for these processes are available through Got Transition<sup>®</sup> (<https://www.gottransition.org/6ce/?leaving-full-package>).

#### Transfer of Care

Coordination of care and communication are essential components of HCT. Through pediatric and adult team collaboration, a transfer "package" should be compiled containing a medical summary, the final TRA, an updated plan of care, verification of insurance coverage, an emergency care plan, legal documents (if needed), and a medical condition fact sheet. Maintaining a transfer checklist is helpful. Following confirmation of the first adult provider appointment, the teams should participate in a final review of care and confirm the pediatric provider's responsibility for care until the youth is seen by the adult provider. A virtual "Meet and Greet" can be scheduled before the first adult clinic appointment for the young adult to meet members of the adult team, ask questions about transfer, and to experience pediatric and adult team collaboration to optimize transfer of care (Telehealth Toolkit [gottransition.org]). Collaboration has been reported as a factor of resilience for youth during transition (37).

#### Transfer Completion

The final core element assesses HCT by confirming that care has been established with an adult provider, evaluates the youth's experience with transition, and assesses outcomes. The pediatric

TABLE 2. “Six Core Elements of Transition™” for adolescents and young adults (AYA) with pediatric-onset liver disease and transplantation

Core Element	Pediatric Team	Adult Team	Transition Tools and References
<b>I. Transition policy</b>  <i>Adult Care: Policy development with adult approach to care</i>	<ul style="list-style-type: none"> <li>Describe transition process</li> <li>Review goals of HCT program</li> <li>Discuss privacy/consent</li> <li>Assistance on supported decision-making and guardianship</li> <li>Anticipated age of transfer</li> </ul>	<ul style="list-style-type: none"> <li>Awareness of and/or participate in pediatric policy development</li> <li>Adult policy development                             <ul style="list-style-type: none"> <li>Approach to patient care</li> <li>Practice standards</li> <li>Privacy and consent</li> </ul> </li> <li>Educate staff on HCT process</li> </ul>	<ul style="list-style-type: none"> <li><a href="https://www.gottransition.org/">https://www.gottransition.org/</a></li> </ul>
<b>II. Tracking and Monitoring</b>  <i>Adult Care: Tracking and monitoring integration into adult care after transfer</i>	<ul style="list-style-type: none"> <li>Develop tracking record for EMR</li> <li>Track progress of AYA through HCT                             <ul style="list-style-type: none"> <li>AYA database: demographics, clinical information, psychosocial data</li> <li>Track progress/completion of each Core Element</li> </ul> </li> <li>Monitor program through QI projects</li> </ul>	<ul style="list-style-type: none"> <li>Develop tracking record for EMR</li> <li>Track progress of AYA integration into adult care (ongoing HCT)                             <ul style="list-style-type: none"> <li>Young Adult database: demographics, clinical information, psychosocial data</li> <li>Track progress/completion of each Core Element to goal of optimal independence in healthcare</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li><a href="https://www.gottransition.org/">https://www.gottransition.org/</a></li> </ul>
<b>III. Transition Readiness</b>  <i>Adult Care: Assessing progress in improving self-care and engagement</i>	<ul style="list-style-type: none"> <li>Conduct regular transition readiness assessments (TRA)                             <ul style="list-style-type: none"> <li>Determine frequency, type, responsible team members, parent/caregiver participation, documentation</li> <li>Assess adherence, self-management skills</li> </ul> </li> <li>Provide education and resources</li> </ul>	<ul style="list-style-type: none"> <li>Assess “readiness” through orienting and engaging in adult care                             <ul style="list-style-type: none"> <li>Determine frequency, type of assessment, responsible team members, need of support person, documentation</li> <li>Assess and identify need for improving adherence, self-management skills</li> </ul> </li> <li>Provide education and resources</li> <li>Provide a welcome document with information about the</li> </ul>	<ul style="list-style-type: none"> <li><a href="https://www.gottransition.org/">https://www.gottransition.org/</a></li> <li><a href="https://www.myast.org/education/specialty-resources/peds-transition">https://www.myast.org/education/specialty-resources/peds-transition</a></li> <li>Transition Readiness Assessment Questionnaire (TRAQ)<sup>[41]</sup></li> <li>UNC STARx Questionnaire<sup>[42]</sup></li> <li>Got Transition<sup>®</sup> Readiness</li> </ul>

(Continued)

TABLE 2. (Continued)

		adult practice, expectations of provider and patient, FAQs about care management and new team	Assessment for Youth <sup>40]</sup>
<b>IV. Transition Planning</b>  <i>Adult Care: Developing a collaborative plan to improve skills within adult practice</i>	<ul style="list-style-type: none"> <li>• Develop and regularly update plan of care for HCT with targeted dates and checklists               <ul style="list-style-type: none"> <li>○ Ongoing TRA</li> <li>○ Update goals based on assessment</li> </ul> </li> <li>• Prepare youth for adult approach to care</li> <li>• Prepare medical summary and information packet</li> <li>• Discuss timing of transfer</li> <li>• Assist youth in identifying adult providers</li> <li>• As needed, establish insurance providers, community resources, specialty practices, legal decision-making or guardianship</li> <li>• Communicate with adult providers</li> <li>• Schedule virtual appointment for AYA, pediatric and adult teams</li> <li>• Obtain consent for release of records to adult provider</li> </ul>	<ul style="list-style-type: none"> <li>• Collaborate with pediatric team for transfer planning: contents of transfer package, consents, date of transfer and upcoming appointments</li> <li>• Participate in a virtual appointment with AYA and pediatric team</li> <li>• Welcome the AYA to adult practice with a pre-visit reminder</li> <li>• Develop collaborative plan with AYA and adult team with goals to help improve self-care skills</li> <li>• Within adult practice, orient to consent for treatment, advanced directive, release of medical information, insurance coverage, community resources, as needed referrals</li> </ul>	<ul style="list-style-type: none"> <li>• <a href="https://www.gottransition.org/">https://www.gottransition.org/</a></li> <li>• <a href="https://www.gottransition.org/6ce/?leaving-full-package">https://www.gottransition.org/6ce/?leaving-full-package</a></li> </ul>
<b>V. Transfer of care</b>  <i>Adult Care: Conducting the initial visit</i>	<ul style="list-style-type: none"> <li>• Transfer of care: maintain transfer checklist               <ul style="list-style-type: none"> <li>○ Send completed transfer package</li> <li>○ Communicate with adult team for final review of care</li> <li>○ Confirm date of first adult appointment</li> <li>○ Confirm pediatric responsibility until first adult appointment</li> <li>○ Obtain AYA consent for monitoring</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Review transfer package prior to transfer</li> <li>• Initial visit:               <ul style="list-style-type: none"> <li>○ Address young adult's needs/concerns</li> <li>○ Orient to adult practice; review differences between pediatric and adult practices</li> <li>○ Update medical plan of care</li> <li>○ Establish preferred method of communication</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• <a href="https://www.gottransition.org/">https://www.gottransition.org/</a></li> <li>• <a href="https://www.gottransition.org/telehealth-toolkit">Telehealth Toolkit (gottransition.org)</a></li> </ul>

(Continued)

TABLE 2. (Continued)

	outcomes data from adult center	o Complete self-care assessment and update routinely	
<b>VI. Transition completion</b>  <i>Adult Care: Ongoing HCT and care with adult providers</i>	<ul style="list-style-type: none"> <li>• Confirm attendance at first adult appointment</li> <li>• Track outcomes                             <ul style="list-style-type: none"> <li>o Clinical and psychosocial data points</li> <li>o Obtain feedback from AYA on HCT process</li> <li>o Communicate with adult team for feedback on transfer</li> <li>o Offer consultative services as needed</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Adult practice assumes full care of AYA</li> <li>• Confirm transfer completion with pediatric team</li> <li>• Obtain feedback from AYA on transfer process</li> <li>• Communicate with pediatric team to assess outcomes and for consultative services as needed</li> </ul>	<ul style="list-style-type: none"> <li>• <a href="https://www.gottransition.org/">https://www.gottransition.org/</a></li> </ul>

AYA = adolescent and young adult; EMR = Electronic Medical Record; HCT = health care transition; QI = quality improvement; TRA = transition readiness assessments.

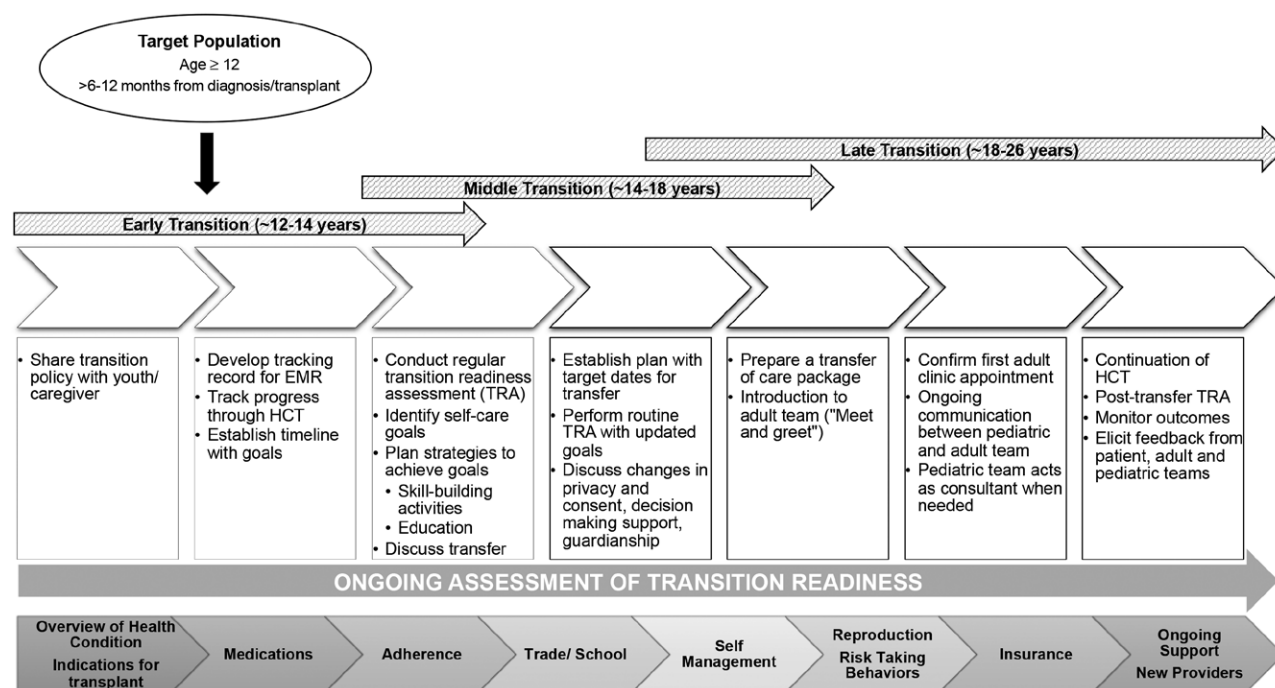


FIGURE 2. Health care transition (HCT) algorithm for adolescents and young adults with pediatric-onset liver disease and transplantation. Adapted from: *Transitioning Youth to an Adult Health Care Clinician*; Six Core Elements of Health Care Transition™ 3.0 1© 2020 Got Transition®

team should confirm the youth’s attendance at the first adult provider appointment and have a plan on how to work with the youth and adult provider if the youth fails to attend the appointment. Measuring health outcomes after transfer as well as eliciting feedback from the youth and parents about their experience may contribute to transition program improvements. Communicating with the adult team for feedback on the transfer event and to offer consultative services may help improve and streamline the transfer process while encouraging continued collaboration and growth among the stakeholders.

With increasing evidence that a structured and formalized transition program may improve outcomes in youth with chronic conditions, The Six Core Elements of Health Care Transition™ comprehensively provide the structure and tools for developing

goals, interventions, assessment, and quality improvement analysis in HCT and are applicable to AYA with CLD as well as LT recipients. Additionally, the educational needs of parents/caregivers should be included in program development with a focus on understanding how to create, provide, and encourage opportunities for youth to increase independence in health care. An adaptation of the Six Core Elements pertaining to AYA with pediatric-onset liver disease and transplantation is summarized in Table 2.

**Best Practice Recommendations and Summary**

1. A structured transition program is associated with improved health outcomes, patient experience, and utilization of health care.



2. The Six Core Elements of Health Care Transition™ are applicable to AYA with CLD as well as LT recipients and should be utilized to establish a HCT program.
3. An adaptation of the Six Core Elements pertaining to AYA with pediatric-onset liver disease and transplantation is summarized in Table 2.
4. Regular assessment of transition readiness utilizing TRA tools is an essential component of transition planning.

## TRANSITION CLINIC IMPLEMENTATION

### Transition Focus Areas and Assessment of Transition Readiness

Although there is evidence that a structured transition program improves outcomes for youth transitioning to adult providers (30), a better understanding is needed of the health topics, skill-building strategies, and behavior skills that are most closely associated with positive outcomes after transfer. Knowledge of the youth's medical condition and self-care skills are almost universally cited in descriptions of HCT. In a systematic review of transition programs in chronic illness, components of HCT were generalized into 3 categories: planning for transition, transfer assistance, and integration into adult care. Planning for transition included readiness assessment and education that focused on disease knowledge and self-care skills (38). Examples of these may be found in Table 3.

ESPGHAN and EASL published a position paper proposing a transition process for youth with liver disease (39). In regard to preparation and training during transition, the recommended educational topics included an understanding of the youth's liver disease, symptoms and rationale for treatment, monitoring strategies, treatment-related problems (side effects of medications and treatments; adherence), sexuality, and healthy lifestyle (immunizations, weight control, and risky behaviors).

The validated transition tools commonly cited in the literature focus on the youth's chronic health condition and self-care skills. The Got Transition® (<https://www.gottransition.org/6ce/?leaving-readiness-assessment-youth>) and Transition Readiness Assessment Questionnaire readiness questionnaires assess knowledge of the health condition, self-care skills, tracking health issues, talking with providers, insurance, support, and health advocacy (35). The UNC STARx additionally assesses reproductive health, trade/school status, and nutrition (36).

Although some transplant HCT programs report better outcomes following educational interventions, this is not consistently observed and associations with specific aspects of transition and transition topics are not known. With continued program development and outcomes monitoring during transition and after transfer, it will be important to assess the educational topics and interventions that can affect outcomes after transfer to adult providers. Recommendations for topics to be included in educational sessions with HCT based on current literature are included in Table 3 (29,33,40–42).

### The HCT Multidisciplinary Team

HCT requires a coordinated, multidisciplinary effort with a core transition team comprised of hepatologists, advanced practice providers, surgeons, pharmacists, nutritionists, social workers, nurses, psychologists, and psychiatrists from both the pediatric and adult teams. Consideration should also be made for the inclusion of a neuropsychologist and financial coordinators. The composition of individual HCT programs is center-specific and will largely depend upon the availability of local personnel and support at each center.

### Psychologists

Given the myriad of patient and family psychosocial stressors, psychologists are valuable members of the pediatric hepatology team. Psychologists working within outpatient specialty clinics tend to provide brief psychosocial assessment with emphasis on identifying patients in need of additional intervention services (27). Psychologists are also likely to focus on issues related to nonadherence (e.g. mood, sleep issues, lack of parental monitoring), learning and school-based concerns (28), risk assessments and safety planning, and promoting readiness for transition to adult-based care (33). With respect to HCT, psychologists can routinely assess self-management skills, track and monitor progress toward goals, and develop strategies to mitigate modifiable barriers to transferring care.

### Social Workers

Social workers are an instrumental part of the HCT team and help to address socioeconomic determinants of health, including housing, transportation, and food insecurities. They are familiar with the availability of local and statewide resources and supportive services. Including social workers in HCT interventions may reduce barriers by providing improved linkages to health care and community-based services as well as greater psychosocial support leading to sustainable positive health outcomes (43). Prior studies have demonstrated that increased social work support services are associated with lower total hospital costs and increased probability of physician follow-up (44,45).

### Transplant Pharmacists

The United Network for Organ Sharing (UNOS) and the Centers for Medicare and Medicaid Services specifically cite the transplant pharmacist as a mandatory component of the multidisciplinary care team (46,47). The clinical transplant pharmacist may make a positive impact during HCT through medication management, patient medication education, motivational interviewing, and by suggesting strategies to promote medication adherence. Pharmacists can identify patient-specific risk factors for nonadherence and tailor interventions to modify these risk factors in each patient (48). Pharmacists can also help facilitate continuity of prescriptions as the AYA changes providers and health care systems.

### Nursing and HCT Coordinators

The Pediatric Committee of the AST has recommended that pediatric transplant recipients have a designated HCT coordinator to facilitate the transition process (1). According to national policy statements, an identified care coordinator is an essential component to transitional care (49,50). Nurse practitioners, clinical nurse specialists, and certified clinical transplant coordinators (CCTC) are in a position to take a leadership role in transitional care programming (51). Specifically, a CCTC can assist in patient education about self-management skills, facilitate communication regarding transition milestones, and anticipate barriers related to the transfer from pediatric to adult-centered care. As transition coordinators, CCTCs can assist with the development of a written HCT plan that sets forth a timeline for the achievement of self-management skills to promote independence in health care. Transition coordinators can also prepare parents for their role in HCT by providing them with strategies to increase the adolescent's responsibility for health care tasks in a developmentally appropriate manner (52). Transplant nurses and transition coordinators are likely the primary facilitators of monitoring the transition process and the transfer of care.

### Adult Providers

The adult transplant team should be engaged early in the transition process whenever feasible. Early integration in care

TABLE 3. Suggested topics for health care transition and assessment of transition readiness

<b>Overview of health care transition (HCT) and transfer to adult care</b>
<ul style="list-style-type: none"> <li>• Review transition policy</li> <li>• Provide overview of HCT</li> <li>• Privacy/consent changes at 18 years of age</li> <li>• Anticipated age of transfer</li> <li>• Differences in pediatric and adult provider approach to care</li> </ul>
<b>Disease knowledge</b>
<ul style="list-style-type: none"> <li>• Chronic liver disease</li> <li>• Indication(s) for liver transplant</li> <li>• Comorbidities</li> <li>• Disease inheritance</li> </ul>
<b>Medication knowledge</b>
<ul style="list-style-type: none"> <li>• Name, indications for use, dose, administration, side effects</li> <li>• Use of over the counter (OTC) medications, herbal remedies</li> </ul>
<b>Adherence</b>
<ul style="list-style-type: none"> <li>• Medications (use of list, pill container, smart phone-based apps)</li> <li>• Office visit attendance</li> <li>• Laboratory monitoring</li> </ul>
<b>Self-management skills</b>
<ul style="list-style-type: none"> <li>• Medication administration, refills</li> <li>• Scheduling appointments</li> <li>• Communicating with care team</li> <li>• Participating in shared decision-making</li> <li>• Emergency plan of care</li> <li>• Travel planning and health care needs</li> </ul>
<b>Healthy lifestyle</b>
<ul style="list-style-type: none"> <li>• Nutrition, dietary adherence</li> <li>• Activity and exercise</li> <li>• Preventative medicine (i.e. immunizations, cancer screening, dental hygiene)</li> <li>• Identification of a primary care provider</li> </ul>
<b>Reproductive health</b>
<ul style="list-style-type: none"> <li>• Fertility</li> <li>• Pregnancy                         <ul style="list-style-type: none"> <li>◦ Outcomes and risks</li> <li>◦ Teratogenic medications</li> </ul> </li> <li>• Routine gynecology care</li> </ul>

(Continued)

TABLE 3. (Continued)

<b>Risk-taking behaviors</b>
<ul style="list-style-type: none"> <li>• Alcohol, cannabis, illicit drug use</li> <li>• Tobacco use, vaping</li> <li>• Tattoos</li> <li>• Sexual practice, sexually transmitted infections</li> </ul>
<b>School/Employment</b>
<ul style="list-style-type: none"> <li>• Future plans, vocation</li> <li>• Individualized education plans for high school students up to 21 years of age</li> <li>• Student Services Accommodation Plan (post-high school)</li> <li>• Implications of underlying health condition</li> </ul>
<b>Insurance</b>
<ul style="list-style-type: none"> <li>• Understanding importance of health insurance</li> <li>• Current plan and length of coverage</li> <li>• Has a copy of insurance card and/or access to contact information</li> <li>• Co-pays, deductibles, out of pocket expenses</li> <li>• Future access to insurance</li> </ul>
<b>Support system</b>
<ul style="list-style-type: none"> <li>• Developing coping strategies</li> <li>• Stress management</li> <li>• Accessing community resources</li> </ul>
<b>Psychosocial health</b>
<ul style="list-style-type: none"> <li>• Health-related quality of life                         <ul style="list-style-type: none"> <li>◦ Physical</li> <li>◦ Psychosocial</li> </ul> </li> <li>• Assessing for mental illness (i.e., anxiety, depression, post-traumatic stress disorder)</li> <li>• Identifying need for additional intervention</li> <li>• Accessing behavioral and mental health resources</li> </ul>
<b>Introduction to adult care and new providers</b>
<ul style="list-style-type: none"> <li>• Timing</li> <li>• Anticipated changes in practice</li> <li>• Finding a new provider</li> </ul>
<b>Health Maintenance - long-term effects of immunosuppression</b>
<ul style="list-style-type: none"> <li>• Hypertension</li> <li>• Hyperlipidemia</li> <li>• Diabetes</li> <li>• Kidney function</li> <li>• Bone health</li> <li>• Immunizations</li> <li>• Cancer screening</li> </ul>

will help to familiarize adult providers with this unique patient population and allow for opportunities to participate in education and assessment of transition readiness. This provides an opportunity for patients to meet with the adult team while still under the care of pediatric providers. Adult providers can help clarify differences in the approach to patient care under the adult care model. This may help to assuage patient fears and anxiety that often surround transfer of care by allowing them to become better acquainted with their new care team. The role of

the adult transplant team and continuation of the HCT process is discussed in further detail below.

### Best Practice Recommendations and Summary

1. Recommended topics for HCT educational sessions are summarized in Table 3.
2. HCT requires a coordinated, multidisciplinary team comprised of hepatologists, advanced practice providers, surgeons,

- pharmacists, nutritionists, social workers, nurses, psychologists, and psychiatrists from both the pediatric and adult teams.
- HCT is a time and resource-intensive undertaking that lacks the recognition, support and reimbursement necessary for program development and outcomes assessment.
  - Widespread implementation of comprehensive HCT programs will require the endorsement and support from governing organizations such as NASPGHAN and AST.

### CONTINUATION OF HCT FOLLOWING TRANSFER: THE ROLE OF THE ADULT PROVIDER

The transition process does not conclude when the AYA presents for their first adult office visit. Transfer of care is merely one component of HCT which will need to be continued by the adult team throughout young adulthood. Although there is no one ideal model for post-transfer care, an adult team approach that supports ongoing development of self-management skills adapted to the youth's unique needs is essential. Many young adults will transfer to adult centers that are affiliated with a specific pediatric program, thereby facilitating opportunities for joint transition programs and ongoing collaborations. Changes in insurance coverage, and/or opportunities for employment or post-high school education, however, may necessitate migration away from prior pediatric providers. Even in the absence of an affiliated pediatric center, the adult LT or hepatology program must be prepared to accept these patients from their prior pediatric centers. The Six Core Elements of Health Care Transition™, previously detailed, provide a framework for adult hepatology and transplant teams to continue the transition process within the adult setting. These Core Elements are outlined in Table 2 and may help guide the adult provider's approach to HCT with suggested goals and strategies.

At the initial visit, the adult team should address any concerns the young adult may have in transferring care and discuss potential differences between pediatric and adult care practices. The adult provider and young adult should clearly and mutually establish the method and expectations of routine communication between appointments. Youth should be oriented to confidentiality issues, release of medical information, shared decision-making, and having an advanced directive. Discussions surrounding medical insurance, any anticipated changes in coverage, and the need for community services and other referrals are also warranted. It may also be helpful to complete a self-care skills assessment at the initial visit and periodically thereafter (Table 4).

The initial transfer of care appointment and labs should be scheduled within an appropriate time frame, ideally within 3 months from the last pediatric appointment. In a single center study of 31 patients with CLD and/or LT who were transferred to an adult service, 47% of patients were seen within 2–6 months following their last pediatric visit and 20% were not seen for 6–12 months. The Emergency Department (ED) was the point of first contact with adult services for 20% of patients and 19% reported being out of medications during this transition (10). These findings highlight the importance of scheduling the initial transfer visit within an appropriate time frame based on the youth's medical status, last pediatric contact, and level of adherence. It is also essential to ensure that the pediatric team is responsible for the patient's ongoing care until the youth attends the first appointment at the adult center. A multidisciplinary team approach with care coordination is needed to successfully integrate these young adults into the adult health care system.

Adult providers caring for young adult LT recipients should also be familiar with topics that may not be routinely addressed in an otherwise typical follow-up visit. These topics include sexual

and reproductive health (contraception, avoidance of teratogenic medications in females of childbearing age), risk-taking behaviors (alcohol and tobacco use, vaping, street drugs and cannabis, tattoos), and long-term medication side effects or comorbidities including skin cancer, hypertension, diabetes, hyperlipidemia, and bone health. Psychology-based screening tools are available that can assist in structuring visits with youth to assess and address some of these issues during adult clinic appointments. HEADS (Home, Education, Activities, Drugs, Sexuality) or THRxEADS (Transition, Home, Medication and Treatment, Education, Activities and Affect, Drugs, and Sexuality) are easily remembered mnemonic screening tools that were developed for adolescents, but are also applicable to young adults (53). Adult providers should consider adding these tools to their routine assessment of LT or CLD patients during clinic appointments.

Utilizing The Six Core Elements of Health Care Transition™, adult transplant and hepatology centers can develop interventions to continue the transition process in adult practice. The adult perspective of HCT should be a multidisciplinary effort with a holistic approach to patient care focusing not only on disease processes but also on psychosocial and behavioral aspects of care.

### Best Practice Recommendations and Summary

- The transition process does not conclude at the time of transfer.
- Transfer of care is one component of HCT which will need to be continued by the adult team throughout young adulthood.
- Adult transplant and hepatology centers should utilize The Six Core Elements of Health Care Transition™ to develop interventions to continue the transition process in the adult practice.
- Adult providers should complete a self-care skills assessment at the initial visit and periodically thereafter (Table 4).
- HCT in the adult practice should be a multidisciplinary effort with a holistic approach to patient care focusing not only on disease processes but also on psychosocial and behavioral aspects of care.

### OUTCOMES MEASURES

The lack of a standardized approach to HCT has led to difficulties in identifying successful outcomes measures. These outcomes must look beyond mere patient and graft survival and gauge important measures such as adherence, health care costs, and health-related quality of life (HRQOL). Objective, reliable metrics exist to assess allograft health, adherence, and complications of immunosuppression. Attention should also be made to establish such metrics for determinants of HRQOL. Consistent and reliable outcomes measures are critical to drive strategies to help improve the transition process and best outcomes. Proposed outcomes measures are summarized in Table 5.

### Medical Outcomes

The overarching goal for children who undergo LT is for sustained well-being, a goal directly dependent on ensuring allograft health and avoiding the complications of immunosuppression. A query of the UNOS database revealed that late allograft loss and late mortality occurred in 10-40% and 20-60% of patients respectively. The former is attributed most commonly to immune-mediated injury, arguably too little immunosuppression, and the latter to infection, a result of too much immunosuppression (9,54). Even in the setting of normal liver function tests, silent allograft damage is detected in almost 50% of stable, long-term pediatric LT recipients. For allograft health, liver tests are neither sensitive nor specific, so direct or indirect assessment by liver histology or vibration controlled transient elastography, is required and soon to be validated,



TABLE 4. Post-transfer self-care and skills assessment for young adults

	Does Not Know	Has an Idea	Knows	N/A
<b>Underlying Medical Knowledge</b>				
What is the name of your liver condition and/or underlying indication for liver transplant? Please describe this condition. How would you explain this condition to a friend or family member?				
List your prescribed medications, current doses, time of administration, indications for use and potential side effects				
Are you allergic to any medications? Please list them and your reaction.				
Do you have any family medical history that is important to know for your health?				
Do you know if you can get someone pregnant or become pregnant given your history of chronic liver disease and/or liver transplant?				
Do you know if any of your current medications may be harmful to an unborn baby if you were to become pregnant? (female patients only)				
Do you know if your underlying liver disease is hereditary and can be passed along to your children?				
<b>Self-Management Skills</b>				
What is the name, phone number and address of your pharmacy?				
How do you obtain medication refills when your supply is low?				
Are you comfortable asking your hepatologist and/or transplant team questions?				
Do you know how to reach your hepatology team? Do you know how to use the emergency contact line?				
Do you know when and where to seek emergency care?				
Do you carry important health information, including your emergency contact information and insurance card, with you?				
Discuss how privacy and consent issues change when you turn 18 years of age.				
Who is your primary care physician? Can you provide their contact information?				

(Continued)

TABLE 4. (Continued)

Do you know how to make and cancel your office visit appointments?				
Do you have transportation to and from your medical appointments? What type of transportation do you use?				
Describe how to access your medical information through the hospital's online portal?				
Are you able to complete medical forms?				
Do you know how to obtain a referral for sub-specialty visits?				
Can you describe why health insurance is important to have? What is the name of your current insurance provider?				
Do you know how to maintain your health insurance? When will your current coverage end?				
What are your future school, job or family plans? What do you think you will need to do to be financially secure?				
Do you know how and where to seek assistance if you have concerns for accessing food, housing or safety?				

respectively. Complications of immunosuppression including cancer, impaired renal function, and risk of cardiac disease are also critical metrics in assessing medical outcomes.

### Adherence

Adherence is defined as the extent to which an individual's behavior corresponds with the recommendations of the health care team. Variation in tacrolimus levels predict allograft rejection, especially for adolescents (55). Although health care providers cannot reliably assess adherence (56), variation in immunosuppressive drug levels, the Medication Level Variability Index, can be used as a validated marker of nonadherence (55). Given that most of the pediatric LT population received organs before age 5, transition and transfer will occur during periods of increased nonadherence and at a time when silent allograft injury is prevalent.

### Health Care Utilization and Costs

HCT has been associated with increased resource utilization and health care costs. These come in the form of increased ED visits, hospitalizations, procedures, and management of medical complications such as acute cellular rejection (5). Predictors of health care utilization in patients undergoing transfer are limited. Among adolescents with chronic kidney disease undergoing TRA, several patient factors, including insurance status (private vs public) and the presence of a 504 Plan or individualized education program predicted health care utilization (57). Those with private insurance had fewer ED visits and fewer inpatient stays. Interestingly, having an individualized education program or 504 plan was also predictive of decreased health care utilization. This would suggest that financial and/or educational support may improve a patient's transition pathway. A comprehensive transition care model focused on AYA with complex care needs may serve to reduce total costs and acute care utilization among pediatric patients with CLD or LT.

### Health-Related Quality of Life

HRQOL is a multidimensional construct that encompasses domains related to physical, mental, emotional, social, and functional status, and thereby highlights how an individual's well-being is affected over time, such as after undergoing a LT. Although

HRQOL has been cited as a critical outcome metric in evaluating the success of pediatric LT (58), systematic utilization in clinical practice is not universal (59).

A systematic review focusing on assessment tools and factors associated with HRQOL after pediatric LT highlighted impaired HRQOL compared with healthy age- and gender-matched controls, identified similarities to children who have undergone other SOT, and articulated factors affecting quality of life for this patient population to include nonadherence, sleep disturbances, lower school functioning, and reduced general health perception domains scores (60). Important functional outcomes unique to pediatric chronic conditions include educational needs, school performance, and school absenteeism (61).

The availability of disease-specific tools in the armamentarium of HRQOL instruments for clinical and research use opens opportunities for enhanced representation of HRQOL in this patient population. The Pediatric Quality of Life Inventory 3.0 Transplant Module (PedsQL TM) is one such disease-specific tool (62). Targeting children who are more than 1-year post isolated LT, the Pediatric Liver Transplantation Quality of Life tool is a 26-item questionnaire that can be completed by each member of a parent-patient dyad. The subdomain scores provide insight into the patient's and parent's views on future health, including health team transition, future health problems, family finances, and social-emotional and coping/adjustment themes, with higher scores representing better HRQOL (63).

### Best Practice Recommendations and Summary

1. Outcome assessments should include important measures such as adherence, health care costs, and HRQOL in addition to patient and graft survival.
2. Medication Level Variability Index can be used as a validated marker of nonadherence.
3. Validated HRQOL instruments should be incorporated into standardized longitudinal surveillance and follow-up care of pediatric LT recipients to amplify the patient and parent voice.
4. A comprehensive transition care model focused on AYA with complex care needs may serve to reduce total costs and acute care utilization among pediatric patients with CLD or LT.

TABLE 5. Summary of successful outcomes measures for health care transition (HCT)

Outcome	Measure	Assessment Tools
<b>Medical Outcomes</b>		
<ul style="list-style-type: none"> <li>• Patient Survival</li> </ul>		
<ul style="list-style-type: none"> <li>• Allograft Survival</li> </ul>		
<ul style="list-style-type: none"> <li>• Allograft Health</li> </ul>	Liver function tests Synthetic function Episodes of ACR Fibrosis stage	Laboratory assessment Physical examination Liver biopsy VCTE
<ul style="list-style-type: none"> <li>• Complications of immunosuppression</li> </ul>	Renal Cardiac  Diabetes Cancer Bone health	GFR, Urine Protein/Cr BP monitoring, Lipid panel, ECHO, cardiac catheterization HgA1C Physical exam, imaging, histology DEXA scan, vitamin D levels
<b>Adherence</b>		
<ul style="list-style-type: none"> <li>• Medication</li> </ul>	SD of IS levels	MLVI Transition-readiness assessment survey
<ul style="list-style-type: none"> <li>• Follow-up</li> </ul>	LTFU	Office visit attendance Laboratory monitoring adherence
<b>Health Care Utilization</b>		
	Invasive procedures Emergency Department visits Hospitalizations Hospital length of stay	
<b>Health-Related Quality of Life</b>		
	Patient satisfaction Caretaker satisfaction School/vocation Skills necessary for independent living Anxiety/Depression Substance Abuse	PedsQL, PedsQL TM, PeLTQL  High school diploma, employment Housing, financial security  PHQ-9, GAD-7 NIDA Quick Screen
<b>Retransplantation</b>		
	Indications for retransplantation Evaluation and approval for retransplantation	Multidisciplinary evaluation including education, psychosocial assessment

ACR = acute cellular rejection; BP = blood pressure; Cr = creatinine; DEXA = Dual-energy X-ray absorptiometry; GAD-7 = General Anxiety Disorder-7; GFR = glomerular filtration rate; HgA1C = Hemoglobin A1C; IS = immunosuppression; LTFU = lost to follow-up; MLVI = Medication Level Variability Index; NIDA = National Institute on Drug Abuse; PedsQL = Pediatric Quality of Life Inventory Transplant Module; PeLTQL = Pediatric Liver Transplantation Quality of Life; PHQ-9 = Patient Health Questionnaire 9; SD = standard deviation; VCTE = Vibration Controlled Transient Elastography.

### ADDITIONAL CONSIDERATIONS

Whether a patient transfers care to an adult program within the same institution or chooses to relocate to a new center or city, the transfer of care process is only as strong as the relationship between pediatric and adult providers. Clinical outcomes following transfer are contingent upon this essential partnership and vital communications. Transitioning from parent-supervised pediatric care to a patient-centered adult care model not only requires a transfer of records, but also a transfer of trust. When pediatric providers

actively identify adult partners to the patient, that trust is more easily assumed.

Geography may play a role in the strength of these partnerships, and the success of transition programs within the same medical center should be compared to those that refer patients to outside centers. That said, survival measures for pediatric heart transplant recipients did not vary according to distance from the transplanting center (64). Similarly, travel time did not result in impactful delays in receipt of care or outcomes for pediatric patients undergoing

particle beam therapy for medulloblastoma (65). Hence, increasing the distance a young adult travels to visit a new provider may not necessarily impact outcomes, though the potential challenge of geography should be more clearly assessed in LT patients.

Independent of location and geography continued attention to the HCT process both before and after arrival in the adult care setting is imperative. Current literature surrounding HCT is primarily derived from pediatric population studies. While it is essential that pediatric providers appreciate the need to begin the transition process early in adolescence, it is equally important that adult providers understand the need to continue these efforts throughout young adulthood.

There is a widespread misconception that transition of care is a problem tasked solely to the pediatric team to be resolved before the time of transfer. Undoubtedly, pediatric providers will need to devote considerable time and resources to address this long-standing problem and significant efforts are currently being made to attend to these gaps in patient care. But ownership is not exclusive to pediatrics. A continuation of these efforts must be assumed by the adult care team. We must increase awareness among adult providers regarding the need to continue the transition process following transfer of care to ensure that early efforts on the pediatric side are not carried out in vain. Future studies should focus on examining transition efforts on the part of adult providers and the results of these combined efforts on long-term patient outcomes.

Increased awareness and implementation will require the support and backing from governing institutions given current limitations surrounding time, resources, and funding. Early implementation is only the first step. Ongoing and continuing efforts must follow. Multidisciplinary HCT programs must become the standard of care for all pediatric CLD and LT patients both before and after transfer.

### Best Practice Recommendations and Summary

1. Clinical outcomes following transfer of care are contingent upon the relationship between pediatric and adult providers.
2. Adult providers must appreciate the need to continue transition efforts throughout young adulthood.
3. Multidisciplinary HCT programs must become the standard of care for all pediatric CLD and LT patients both before and after transfer.

### CONCLUSIONS

Increased attention to the HCT process for individuals with CLD and LT is imperative. Until the importance of HCT is appropriately recognized and addressed, these patients will remain highly vulnerable to poor long-term outcomes. A focus on HCT must be routinely adopted across programs to facilitate multicenter collaborations and determine best practice. This paper outlines a framework for the implementation of a standardized, multidisciplinary approach to HCT which spans across both pediatric and adult hepatology and LT services. Successful transition can only be achieved by way of partnership between pediatric and adult providers to ensure continued success following transfer of care.

### FUTURE DIRECTIONS

1. Gain further recognition and support from governing organizations at the national and international level for the importance of HCT.
2. Standardize the approach to transition of care across centers.

3. Mandate that multidisciplinary transition programs become standard practice for all LT centers. This may require the inclusion of HCT programs in the UNOS bylaws.
4. Increase funding for HCT.
5. Assess the cost of HCT services and create a reimbursement (CPT) code for transition of care.
6. Increase awareness among adult providers regarding the need for continuation of HCT following transfer of care.
7. Expand the availability of transition resources for adult providers.
8. Establish formal education training in transition of care (i.e. CME course)
9. Explore the role of technology to help improve adherence and self-management skills for AYA.
10. Identify important outcomes measures to help facilitate future research collaborations and analysis. Outcomes measures should include an assessment of changes in health care costs and HRQOL.
11. Conduct randomized, multicenter controlled trials examining the impact of multidisciplinary transition programs on long-term patient outcomes.

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