TRANSITION FROM PEDIATRIC TO ADULT CARE FOR TRANSPLANT RECIPIENTS: GROWING UP IS HARD TO DO

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Vanderbilt Transplant Symposium
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OBJECTIVES

Identify current state of transition for chronic illness populations.

Identify transition resources.

Identify role of outcomes as a transition resource.
18 million U.S. adolescents 18-21 years of age
- In transition process
- Approximately 7,000 young adults
  - Ages 15-24 years
  - Functioning heart, kidney, liver, or lung transplant
  - Australia, US and Canada
Growing number of children with complex health conditions

Transfer from pediatric to adult facility is another milestone
TRANSITION: WHAT DO WE KNOW?

- Literature
  - Solid organ transplant
  - Human immunodeficiency virus
  - Cystic fibrosis
  - Diabetes
  - Other chronic illness populations
- National practice and research priority
BACKGROUND

National Research and Practice Priority

Transplant and other chronic illness populations

Transition
Adolescent Transition to Adult Care in Solid Organ Transplantation: A consensus conference report

There are close to 1500 late adolescent/young adult solid organ recipients with at least 5-year graft survival in the United States alone, the majority having received a kidney (Table 1, Organ Procurement and Transplantation Network (OPTN) data as of July 11, 2008).

Building consensus on transition of transplant patients from paediatric to adult healthcare

Nicholas Webb,1 Paul Harden,2 Clive Lewis,3 Sarah Tizzard,4 Grainne Walsh,5 Jo Wray,6 Alan Watson7
Limitations

- Lack of consistency
- Few approaches for improvement have been empirically tested

Insufficiencies are related to adverse outcomes

- Acute rejection
- Graft loss
WHERE DO WE START?
TRANSITION RESOURCES
TRANSITION RESOURCES

- Internet Resources
- Literature
- Transition Programs
- Readiness Instruments
Transition planning between youth, family, and provider has been associated with improvements in satisfaction, continuity of care, and greater adherence to care.

— Gabriel et al, 2017; McDanagh et al, 2007; Wojciechowski et al, 2002
WEB RESOURCES ON TRANSITION TO ADULT CARE

This is a selected list of resources that the AST Pediatric Community of Practice Joint Transition Work Group considers helpful and user-friendly. This resource will be updated regularly.

Jump to...
Transition Literature Database
Articles, Brochures, and Tools
Transition Programs
Hospital-Based Transition Programs

TRANSITION LITERATURE DATABASE


- Transition Literature Database created by Parag Shah MD. Dr. Shah is the Chronic Illness Transition Team Medical Director for SAILS (Supporting Adolescents with Independent Life Skills) and a hospitalist physician who works primarily with children with chronic illness at the Lurie Children’s Hospital of Chicago. This database contains 657 citations in PubMed from 1967-2013.
ARTICLES, BROCHURES, and TOOLS


http://onlinedigeditions.com/allarticle/15191/125764/125764/allarticle.html

- The September 2012 edition of the ASN’s Kidney News includes 10 articles by experts in transition including readiness for transition, adherence, insurance issues, young adult clinics and insurance gaps.

http://aji.sagepub.com/content/5/1/85.full.pdf+html


http://pediatrics.aappublications.org/content/131/6/1090.full.pdf+html


Current Status of Transition Preparation Among Youth With Special Needs in the United States

WHAT'S KNOWN ON THIS SUBJECT: The importance of transition from pediatric to adult health care for youth with special health care needs has gained increasing attention over the past decade, but fewer than half of this population received needed transition preparation in 2005-2006.

WHAT THIS STUDY ADDS: This study reports on transition findings from the 2009-2010 National Survey of Children with Special Health Care Needs and finds no discernible improvements since 2005-2006. New clinical recommendations and care processes should help to accelerate transition improvements in the future.

AUTHORS: Margaret A. McManus, MHS, Lauren R. Pollack, W. Carl Cooley, MD, Jeanne W. McAllister, BSN, MS, MHA, Debra Lotstein, MD, MPH, Bonnie Strickland, PhD, and Marie Y. Mann, MD, MPH

The time of transfer is one of clinical concern. The pediatric population, although largely compliant, do demonstrate a significant frequency of nonadherence with immunosup-
Internet Resources

Literature

Transition Programs

Readiness Instruments
TRANSITION PROGRAMS (Includes specific resources for transition)

http://www.gotttransition.org/

- An excellent site representing the National Health Care Transition Center. The aim of this center is to advance access to effective transition support from pediatric to adult health care for all youth, including those with special needs. The site has sections for health care professionals, families, youth, and health policy makers and includes transition tools, tips and other resources in each category.

http://depts.washington.edu/healthtr/

- This website is a resource for teens and young adults with special health care needs, chronic illness, physical or developmental disabilities. It is a comprehensive website, with links to many facets of transition. It contains resources for health care providers including toolkits, guides, a health history summary template that the youth prepares with the assistance of a parent and information regarding special education needs.

http://www.mahec.net/quality/chat.aspx?a=10

- This is a comprehensive site developed by the North Carolina Division of Public Health, Children and Youth Branch. It contains many downloadable resources and toolkits for health care providers, youth with special health care needs, and families and also includes UNC Chapel Hill self and provider assessment tools for transition preparedness.

http://ndep.nih.gov/transitions/

- The National Diabetes Education Program. Transitions from Pediatric to Adult Health Care
- NDEP has assembled materials to help teens with diabetes make a smooth transition to adult health care. Families and health care professionals will also find these materials helpful. NDEP has also developed a slide set with information about transitioning from pediatric to adult health care for health care professionals and community organizations to help explain and promote this resource.

http://www.youthhood.org/index.asp

- A website for youth with disabilities to help them with transition planning. The Youthhood provides a holistic, web-based curriculum that teachers, community service providers, parents, and mentors can use with young adults to develop skills, increase knowledge, and implement a personal life plan that will help young adults achieve their goals. The Youthhood was developed by the National Center on Secondary Education and Transition (NCSET), headquartered at the Institute on Community Integration, within the College of Education and Human Development at the University of Minnesota.
HOSPITAL-BASED TRANSITION PROGRAMS

http://www.chla.org/site/c.iplNKTOAJsG/b.8278947/k.59F/Adolescent_and_Young_Adult_Transition_Care.htm

- Children's Hospital of Los Angeles, Transition of Care - Adolescents and Young Adults

http://www.pamf.org/teen/health/transitionadultcare.html

- Palo Alto Medical Foundation, Sutter Health. Information on transition for adolescents and young adults. This site contains handouts on "Transition to Adult Care" and "My Health Online Enrollment."

http://www.kosairchildrenshospital.com/bridge/transitionalcare

- Kosair Children's Hospital, Bridges Transitional Care Program for chronic conditions.
- Resources Include: A section on basic health information, care schedule and nutrition notes; Medical history; Procedure/treatment history, medications, vaccine records and family medical history; Care providers: Current physicians, preferred hospitals and other important care providers;
- Insurance and legal documents: All information needed for insurance and secondary insurance coverage; Contact information for guardians, details of special guardian approvals and power of attorney;
- State resources: Guide to local and regional resources for patients with special health care needs; and
- Transition: Detailed guide of key developmental milestones and tips for ages birth to 21 years old.


- Lurie Children's SAILS (Supporting Adolescents with Independent Life Skills) program offers a six-week program to teach teens to prepare for their future in work, college and managing their healthcare. There are also sessions for parents for more information and support. The Chronic Care Transition Team helps teenage patients ease into new surroundings with a transition program that includes various resources for transition and other website, particularly in Illinois. Includes a resources section with information on: Transition Facts, Adult Healthcare Provider Resources, Insurance and Benefits Resources, Community Resources, Knowledge and Responsibility Resources.

http://www.sickkids.ca/Good2Go/ and http://www.sickkids.on.ca/myhealthpassport/

- A very good comprehensive website with multiple resources for adolescents transitioning from pediatric to adult care. The website includes an extensive list of resources including transitions tools, readiness checklists, health passport, and information for the adolescent and parents.
Good 2 Go Transition Program

Young people leave SickKids by the time they are about 18. Many have been coming here as long as they can remember. Some have spent more time at the Hospital than they have in school, or even in their own homes. These teens have many similar experiences, but also come from a multitude of cultures and family constellations. The transition from paediatric care, with its own distinct culture and ways of doing things, into the adult health-care system can be a challenge for teens and their families.

Our goal is to prepare all youth with chronic health conditions to leave SickKids by the age of 18 years with the necessary skills and knowledge to advocate for themselves (or through others), maintain health-promoting behaviors and utilize adult health-care services appropriately and successfully.

We believe that children and youth with chronic health conditions can acquire skills while in the paediatric system that will assist them in successfully managing their health care now and in the future. Paediatric health-care professionals are in a position to facilitate developmental transition in a number of different ways.

Our work is based on a Shared Management Model.

We would like to acknowledge the inspiring work done by the ON TRAC program at British Columbia’s Children’s Hospital, Helen Healy at Holland Bloorview Kids Rehabilitation Hospital, Gail Kreechkefer of the University of Washington and Patience White of George Washington University, all of who have shared their time, ideas and resources with us.
Transition Tools and Supports

The Good 2 Go team members are available to assist individual programs in developing and integrating transition related practices and customizing tools within their programs. Since starting our program in 2006, over 50 different ambulatory programs at SickKids have sought support or education, used Good 2 Go resources and/or have identified a Transition Champion—someone who leads efforts to provide quality transition programming to patients and families at SickKids. Are you the next Transition Champion?

The following section includes links to a number of interventions that health-care providers can use at various stages of the transition process. For example, Clinical Pathways and Help Them Grow...so They're Good 2 Go* Timelines in the Easy Intervention section can be used with families to identify ways to encourage young children and youth to participate in their own health care. We are starting to develop ways for bedside health-care providers to discuss transitions during inpatient stays with Activities for Inpatients. In some cases, programs have utilized Good 2 Go to get support in organizing events such as a “Graduation Day” or “Transition Workshops” for all patients with upcoming transfers—see the section on Patient and Family Education Events for more ideas. Program-Specific Transfer Clinics, Graduation Ideas and Preparing for First Adult Appointments tools can also be used with older patients, as they get closer to graduating from SickKids, to help them get ready to enter the adult health care system. We’ve included some other ideas for supporting patients, for example, Developing a Transition Website and links to Guidelines for Transition developed by provincial and national organizations.

See the following links for ideas on how to improve your clinic’s transition programming:

Clinical Pathways
"Easy" Interventions
Activities for Inpatients
Patient and Family Education Events
Program-specific Transfer Clinics
Graduation Ideas
Preparing for First Adult Appointments
Developing a Transition Website
Guidelines for Transition
MYHEALTH Passport
Please, cut passport and fold it to wallet size.

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<th>Name</th>
<th>Transplant</th>
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</thead>
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<tr>
<td>DOB</td>
<td>xx-xx-xxxx</td>
</tr>
<tr>
<td>Transplant</td>
<td>Liver, Transplant date</td>
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<tr>
<td>Diagnosis</td>
<td>Biliary atresia</td>
</tr>
<tr>
<td>Rejection history</td>
<td>No rejection</td>
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<tr>
<td>Operations</td>
<td>NO surgery</td>
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<tr>
<td>Medical problems</td>
<td>Hypertension</td>
</tr>
<tr>
<td>Current immunosupp.</td>
<td>Tacrolimus</td>
</tr>
<tr>
<td>Drug allergies</td>
<td>None</td>
</tr>
<tr>
<td>Other allergies</td>
<td>NOOne</td>
</tr>
<tr>
<td>WARNING</td>
<td>THIS PERSON IS ON IMMUNOSUPPRESSANT MEDICATION. IF THEY PRESENT WITH FEVER, PLEASE CALL THEIR TRANSPLANT TEAM.</td>
</tr>
<tr>
<td>Date Created</td>
<td>4/26/2015 <a href="http://www.sickkids.ca/myhealthpassport">www.sickkids.ca/myhealthpassport</a></td>
</tr>
</tbody>
</table>
Internet Resources

Literature

Transition Programs

Readiness Instruments
Transition Readiness Assessment Questionnaire

- University of Florida
- 20 item questionnaire
- Measures critical skills needed for successful transition
  - Managing Medications
  - Appointment Keeping
  - Tracking Health Issues
  - Talking with Providers
  - Managing Daily Activities
- Assessment that can enhance conversations and preparation for the transition process
- Registration and use
Transition Readiness Assessment Questionnaire 5.0

**Directions:** Please check the box that best describes your skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

<table>
<thead>
<tr>
<th>No, I do not know how</th>
<th>No, but I want to learn</th>
<th>Yes, I am learning to do this</th>
<th>Yes, I started doing this</th>
<th>Yes, I always do this when I need to</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

**Managing Medications**
1. Do you fill a prescription if you need to?
2. Do you know what to do if you are having a bad reaction to your medications?
3. Do you take medications correctly and on your own?
4. Do you reorder medications before they run out?

**Appointment Keeping**
5. Do you call the doctor’s office to make an appointment?
6. Do you follow-up on any referral for tests or check-ups or labs?
7. Do you arrange for your ride to medical appointments?
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?
9. Do you apply for health insurance if you lose your current coverage?
10. Do you know what your health insurance covers?
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?

**Tracking Health Issues**
12. Do you fill out the medical history form, including a list of your allergies?
13. Do you keep a calendar or list of medical and other appointments?
14. Do you make a list of questions before the doctor’s visit?
15. Do you get financial help with school or work?

**Talking with Providers**
16. Do you tell the doctor or nurse what you are feeling?
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?

**Managing Daily Activities**
18. Do you help plan or prepare meals/food?
19. Do you keep home/room clean or clean-up after meals?
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?
Assessment of transition readiness skills and adherence in pediatric liver transplant recipients


Abstract: To examine transition readiness, adherence, and health outcomes in pediatric liver transplant recipients using a clinically administered screening measure. Seventy-one pediatric liver transplant recipients completed the Transition Readiness Assessment Instrument (TRAI), and 70.9% demonstrated readiness for the transition to adult care. Adherence to medications, medical appointments, and smoking status was evaluated over the previous 12 months. Eighty percent of the recipients were adherent to medications, 70.9% attended one or more medical appointments, and 83.7% were nonsmokers. There were no significant differences in readiness scores between those who adhered to medications and those who did not. Further research is needed to examine the impact of transition readiness on health outcomes in pediatric liver transplant recipients.

Emily M. Fredericks¹, Dawn Dore-Stites¹, Andrew Well¹, John C. Magee², Gary L. Freed¹, Victoria Shieck¹ and M. James Lopez¹

¹Department of Pediatrics, University of Michigan Health System, Ann Arbor, MI, ²Department of Surgery, University of Michigan Health System, Ann Arbor, MI, USA
**Fredricks et al.**

Table 1. Domains of the TRS

<table>
<thead>
<tr>
<th>Domain</th>
<th>Number of items</th>
<th>Example item(s)</th>
</tr>
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<tbody>
<tr>
<td><strong>Adolescent report (TRS:A/YA)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-management</td>
<td>12</td>
<td>I wear a Medicalert ID; Who notices when prescriptions needs to be refilled?</td>
</tr>
<tr>
<td>AoR</td>
<td>5</td>
<td>In the past two wk, how often did you remember to take your medications without an adult reminding you?</td>
</tr>
<tr>
<td>Perceived regimen knowledge</td>
<td>10</td>
<td>How often did your parent remind you to take your medication?</td>
</tr>
<tr>
<td>Demonstrated skills</td>
<td>9</td>
<td>I can name all of my medications; I know how often I need to come to appointments</td>
</tr>
<tr>
<td>Psychosocial adjustment</td>
<td>11</td>
<td>Name your medications; John took his morning dose of medicine at 7 AM. He takes his 2nd dose 10 h later. What time does he take his 2nd dose?</td>
</tr>
<tr>
<td><strong>Parent report (TRS:P)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adolescent self-management</td>
<td>11</td>
<td>I have no control over my health in the future; I am limited in what I can achieve in the future because of my transplant</td>
</tr>
<tr>
<td>AoR</td>
<td>5</td>
<td>My child wears a Medicalert ID; Who notices when prescriptions need to be refilled?</td>
</tr>
<tr>
<td>Adolescent regimen knowledge</td>
<td>7</td>
<td>In the past two wk, how often did you remind your child to take his/her medication?</td>
</tr>
<tr>
<td>Demonstrated skills</td>
<td>5</td>
<td>My child can name all of their medications; My child knows how often they need to come to their appointments</td>
</tr>
<tr>
<td>Adolescent psychosocial adjustment</td>
<td>11</td>
<td>John took his morning dose of medicine at 7 AM. He takes his 2nd dose 10 h later. What time does he take his 2nd dose?</td>
</tr>
<tr>
<td>Regimen knowledge</td>
<td>2</td>
<td>My child feels they have little control over their health; Because of their transplant, my child cannot pursue certain jobs in the future</td>
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</tbody>
</table>

Fredricks et al., 2010
RESOURCES BY AGE

Internet Resources
Literature
Transition Programs
Readiness Instruments

EARLY ADOLESCENT
(11 - 13)

MIDDLE ADOLESCENT (14 - 16)

- MIDDLE ADOLESCENT READINESS ASSESSMENT
  This tool employs an interview format for the provider to assess the AYA's weaknesses
  [DOWNLOAD]

- MIDDLE ADOLESCENT CHECKLIST
  This short self-report checklist assesses the AYA's perceptions of their care
  [DOWNLOAD]

- MIDDLE ADOLESCENT TRANSITION ACTION PLAN
  This teaching plan can be used by providers to strategize AYA progress towards achieving self-efficacy
  [DOWNLOAD]

- MIDDLE ADOLESCENT PARENT ACTION FORM
  This form can be used by providers and parents in helping the AYA take an increasing role in their care
  [DOWNLOAD]
LATE ADOLESCENT (17 - OLDER)

- LATE ADOLESCENT READINESS ASSESSMENT
  This tool employs an interview format for the provider to assess the AYA's weaknesses
  [DOWNLOAD]

- LATE ADOLESCENT CHECKLIST
  This short self-report checklist assesses the AYA's perceptions of their care
  [DOWNLOAD]

- LATE ADOLESCENT TRANSITION ACTION PLAN
  This teaching plan can be used by providers to strategize AYA progress towards achieving self-efficacy
  [DOWNLOAD]

- LATE ADOLESCENT PARENT ACTION FORM
  This form can be used by providers and parents in helping the AYA take an increasing role in their care
  [DOWNLOAD]
TRANSITION ROADBLOCKS
OBSTACLES TO SUCCESSFUL TRANSITION

- Patient
- Hospital Systems
- Family
- Adult Team
- Pediatric Team
UNOS DATA: KIDNEY

Figure 2: Lost to Follow-up Rates at 1 through 10 Years after Transplant for Kidney Transplants Performed during 2000 - 2010 by Age at Transplant\(^{30}\)

- Ages 0-5
- Ages 6-11
- Ages 12-17
- Ages 18+

Lost to follow-up rates:
- 21.3% after 10 years
- 16.0% after 5 years
- 12.1% after 3 years
- 9.6% after 1 year

Years Post-Transplant vs. Lost to Follow-up Rate
UNOS DATA: LIVER

Figure 3: Lost to Follow-up at 1 through 10 Years after Transplant for Liver Transplants Performed during 2000 - 2010 by Age at Transplant

- Ages 0-5
- Ages 6-11
- Ages 12-17
- Ages 18+

Percentages per year:
- Ages 0-5: 5.9%
- Ages 6-11: 6.8%
- Ages 12-17: 9.0%
- Ages 18+: 14.6%
Figure 4: Lost to Follow-up at 1 through 10 Years after Transplant for Heart Transplants Performed during 2000 - 2010 by Age at Transplant\(^{29}\)

- Ages 0-5
- Ages 6-11
- Ages 12-17
- Ages 18+

<table>
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<tr>
<th>Years Post-Transplant</th>
<th>Ages 0-5</th>
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<th>Ages 18+</th>
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<td>16.5%</td>
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OUTCOMES

Clinical
- Rejection
- Readmission
- Death

Psychosocial
- Adherence: medication and follow-up
- Engagement
- Support and Coping

Systems or Program
- Satisfaction: Internal and external
IMPLEMENTING OR REFINING A TRANSITION PROGRAM
MAKING IT WORK AT YOUR CENTER

- Individualized program design
  - Size of transplant program
  - Staff
  - Hospital support
POLICY AND PLANNING

Transition Policy

Written and available to discuss with patients and families

State expectations and process for transition

Transition Planning

Readiness: parent, adolescent and provider

Curriculum

Collaboration
Children’s Hospital and Health System
Patient Care Policy and Procedure

This policy applies to the following entity(s):
☒ Children’s Hospital and Health System

SUBJECT: Transition Planning for Youth with Special Health Care Needs (YSHCN) to Adult Health Care Setting

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V. Documentation ..................................................................................................5
V. Supporting Documents: Family Education Documents –Teaching Sheets ........4
VI. References ......................................................................................................5
Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home (2011)

Practice guidelines to support the transition from pediatric to adult care with a focus on the medical home.
TRANSITION CLINICS

One visit
- Adult MD or RN meeting family at pediatric facility

Alternating visits
- Pediatric and adult facility

Shared clinic
- Clinic staffed by pediatric and adult transplant team members
Out come evaluation

Formal framework

Performance standards: defined and monitored
CONCLUSION

- Important transplant and chronic illness issue
- National efforts
  - AST portal
- Numerous resources
- Center specific
  - Various size programs
  - Just start 😊
- Goal
  - Successful transition is an important factor in achieving long term survival