Journey Across the Great Divide:
The Use of Diverse Transition Tools to Support the Transition from Pediatric to Adult Care

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Department of Hematology/Social Work

Disclosure Statement

• There is nothing to disclose

OBJECTIVES

1) Identify current challenges for patients and families impacted by acute or chronic illness to making a successful healthcare transition.
2) Identify the six core elements of a successful healthcare transition.
3) Adapt various transition tools to your own clinic practice setting.
Close your eyes and think back to being 17 or 18

What comes to mind when you hear these words

• Health Insurance
• Copay
• Deductible
• Consent for treatment
• Research
• Medical Decision Maker
• Adult Doctor
• Prescriptions

What is Health Care Transition?

• Transition is the "purposeful, planned movement for adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems". 
  Society for Adolescent Health and Medicine

Components of successful transition will focus on:
  - Self-Determination
  - Person Centered Planning
  - Prep for Adult health care
  - Work /Independence

Goal of Health Care Transition

• "The goal of transition in healthcare is for young adults with special healthcare needs to maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate healthcare services that continue uninterrupted as the individual moves from adolescence to young adulthood"

2002 Consensus Statement of the AAP, AAFP and ACP
National Initiatives in Transition

- 2001 Consensus Conference with HRSA and AAP
- 2002 Consensus Statement - AAP, AAFP and ACP
- 2011 Follow-up report - AAP, AAFP and ACP
- Multiple position papers from medical societies
- Healthy People 2020 Goal: Increase the proportion of youth with special health care needs whose health care provider has discussed transition planning from pediatric to adult health care

Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home

Patience H. White, Carl Cooley, TRANSITIONS CLINICAL REPORT AUTHORING GROUP, American Academy of Pediatrics, American Academy of Family Physicians and American College of Physicians
October 22, 2018

Barriers to a Successful Transition Provider’s Perspective

- Beginning the process too late
- Lack of insurance reimbursement for transition services
- Lack of staff training in transition planning
- Lack of time
- Resistance of patients/families to leaving familiar provider/staff
- Lack of available adult providers
- Lack of training in congenital and child-onset conditions
- Lack of adolescent medicine training
- Difficulty facing disability/end of life issues with youth
- Lack of needed social work or care coordination staff in the adult setting

Okumura MD et al Pediatrics 2010

Start early, Talk Often....Repeat
Medical consequences of not having a structured HCT program

- Limitations in health and well-being
- Lack of medication adherence
- Discontinuing of care
- Higher use of emergency room care
- Higher cost of medical care

White and Cooley et al Pediatrics October 21, 2018

Barriers to a Successful Transition Patient/Family Perspective

- Lack of Insurance
- Lack of available and qualified adult providers
- Misperceptions and misconceptions by health care providers on the needs of young adults with Special Health Care Needs
- Unpreparedness on the part of the patients and families to begin transition plan

Start early, Talk Often.....Repeat

Adolescent patient education programs have been demonstrated to increase a youth's likelihood to independently manage his or her own care.
— Vidal et al, 2004

http://www.gotttransition.org/
### Timeline for Introducing Six Core Elements

<table>
<thead>
<tr>
<th>Ages 12-18</th>
<th>Ages 14-18</th>
<th>Ages 18-21</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop Transition Plan</td>
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</tr>
<tr>
<td>Begin Progress</td>
<td>Begin Progress</td>
<td>Begin Progress</td>
</tr>
<tr>
<td>Discuss Skills</td>
<td>Discuss Skills</td>
<td>Discuss Skills</td>
</tr>
<tr>
<td>Transition Readiness</td>
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</tr>
<tr>
<td>Transition Planning</td>
<td>Transition Planning</td>
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</tr>
<tr>
<td>Transition and Integration to Adult Care</td>
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</tr>
<tr>
<td>Transition of Care</td>
<td>Transition of Care</td>
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### Six Core Elements for Health Care Transition

<table>
<thead>
<tr>
<th>Pediatric Health Care Setting</th>
<th>Adult Health Care Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Transition Policy</strong></td>
<td><strong>1. Privacy, Adult Centered and Shared Decision-Making</strong></td>
</tr>
<tr>
<td>Choose a positive health care transition plan and share it with patient, family, and caregivers.</td>
<td>Choose a positive adult centered and shared decision-making plan and share it with patient, family, and caregivers.</td>
</tr>
<tr>
<td>Discuss all about HCT best practices.</td>
<td>Discuss all about privacy and consent.</td>
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http://www.gottransition.org/

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<tr>
<td><strong>2. Transitioning Youth Rights</strong></td>
<td><strong>2. Young Adult Patient Rights</strong></td>
</tr>
<tr>
<td>Identify transition needs and goals in a transition plan.</td>
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</tr>
<tr>
<td>Develop all appropriate, patient-centered plan and share it with patient, family, and caregivers.</td>
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<tr>
<td><strong>5. Transition Preparation</strong></td>
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</tr>
<tr>
<td>Assess readiness for adult health care with youth and family</td>
<td>Ensure young adult needs for health care are met and transition readiness is assessed. Focus on preparing for transition to adult care.</td>
</tr>
<tr>
<td>Assess health literacy to address gaps in knowledge, skills, and attitudes</td>
<td>Be prepared to address gaps in knowledge, skills, and attitudes.</td>
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<td>Be prepared to address gaps in knowledge, skills, and attitudes.</td>
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<tr>
<td>Address identification of youth, self and family in transition readiness</td>
<td>Identify and address the health care needs of the young adult and their family.</td>
</tr>
<tr>
<td>Prioritize transition to adult care</td>
<td>Prioritize the transfer of care to adult care.</td>
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**SIX CORE ELEMENTS OF HEALTH CARE TRANSITION**

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<tr>
<th>Pediatric Health Setting</th>
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<tbody>
<tr>
<td><strong>5. Transition and Transfer of Care</strong></td>
<td><strong>5. Transition and Transfer of Care</strong></td>
</tr>
<tr>
<td>Transfer from pediatric to new adult care location:</td>
<td>Transfer from pediatric to new adult care location:</td>
</tr>
<tr>
<td>Ensure each transition is handled with youth and family</td>
<td>Ensure each transition is handled with youth and family.</td>
</tr>
<tr>
<td>Provide a “Transition Package” containing a Transition Plan and items noted above and in the Transfer of Care Checklist</td>
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</tr>
<tr>
<td>Initiate or coordinate specialty transitions as appropriate</td>
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</tr>
<tr>
<td>Transition to young adult model of care in same location</td>
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SIX CORE ELEMENTS OF HEALTH CARE TRANSITION

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<td><strong>6. Transition Completion</strong></td>
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</tr>
<tr>
<td>Pediatric PCP/team are a resource for each transferred/patient and their adult PCP/team following care transfer</td>
<td>Consult with pediatric PCP/team as needed; each young adult is integrated using a young adult model of care; the adult practice declares successful and complete HCT</td>
</tr>
<tr>
<td>Pediatric PCP/team makes contact with adult PCP/team 6 months post transfer to ensure success and continuity of care</td>
<td>Continue forward with a young adult model of care and appropriate care planning for all patients</td>
</tr>
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Current Transition Initiatives at St. Jude Children’s Research Hospital

**Infectious Disease and Hematology Clinics**
- Strong Multidisciplinary Approach to Transition involving the medical team, case manager, social worker, psychologist and academic coordinator
- Initiation of transition education beginning at age 12
- Evidence based transition readiness assessments (TRAQ)
- Sickle Cell Disease Personal Health Record
- Personal Health Record for YA with Bleeding Disorders
- Multidisciplinary Transition Readiness Meetings
- Hands on Skills Labs
- Coordination of assessments for patient’s decisional capacity
- Age of Majority preparation
- Transition Tours of the Adult Facilities

St. Jude Children’s Research Hospital Transition of Care Policy for Patients with Sickle Cell Disease

At St. Jude, we believe a smooth transition to young adulthood includes the move from pediatric to adult health care. Planning and preparing for this change should begin by age 12. At age 18, most young adults in our program will transition to adult health care.
Tools Used to Aid in Preparing Teens to Transition to Adult Care

St. Jude Teen Sickle Cell Clinic
- ~250 patients
- Ages 12 to 18 years
- Visits once every 6 months, or more often if on therapy
- Transfer to adult care at 18 years of age

Objectives of Teen Transition Program

- Continuing Independence Objectives 1
- Medical Transition to Adult Care
- Continuum of Medical Care from Adolescence to Adulthood
- Support Transition to Adult Care Objectives 2
**Transition to Adult Care Steps**

**Preparation phase**

**The “hand-off”**

**The young adult years**

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**Sickle Cell Disease Personal Health Record (PHR)**

Initially introduced as a way to open up communication between patient and parents about not only their SCD history, but their overall medical history, familial medical history and other important information such as insurance, finances, and proficiency in areas of independent living.

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**Personal Health Record**
The PHR examines the patients knowledge of:

- Symptomatic history
- Blood transfusions and any reactions to the procedure
- Hospitalizations
- Diagnostic testing and their results
- Immunizations
- Pertinent Personal Information (insurance, school-related information, referral information and level of ability with skills of independent living).

PHR Process

- Given to patient by the Hematology Social Worker at 2 age points: 16 and 17
- After completion, patients can ask for assistance from parents and/or care team
- Results will be discussed with the patient and parents by the Social Worker after completion
- Gaps in knowledge will be identified and plans for future education will be made

PHR Process Cont.

- Patients are given a copy of the form to take home with instructions to use as a tool to enhance communication with parents about their medical and personal information.
- The form can also be used as a source of information for future adult care clinic visits.
- Comparisons between the forms can be made in the future to assess for medical literacy and readiness.
Players in the Transition Clinic

- Attending MD
- Mid Level Provider
- RN Case Manager (ages 12-17)
- Transition RN Case Manager (ages 17-25)
- Academic Coordinator
- Social Worker
- Health Educator
- Pharmacist
- Psychologist

GETTING READY FOR THE HAND OFF PHASE:

ASSESSING FOR TRANSITION READINESS

TRANSITION READINESS OVERALL ASSESSMENT FORM

Instructions: Please complete the questionnaire for the child's transition needs. Early EFH is still needed for transition if the phase name change.

NAME: _________________________________     MRN #: ______________
DOB: _________________________    Teen Tour date: _______________
DIAGNOSIS:  _____________________  GRADE:   _________________
TX Therapies:  _____________________

MEDICAL
Responsible party: ________________________________

PSYCOSOCIAL
Responsible party: ________________________________

ACADEMIC
Responsible party: ________________________________

EMOTIONAL
Responsible party: ________________________________

READY FOR TRANSITION?
Yes:  ________________________________  No:  ________________________________

PLAN OF ACTION

<table>
<thead>
<tr>
<th>Domain</th>
<th>Objective (What do you want to see happening?)</th>
<th>Activity (How will you make it happen?)</th>
<th>Responsible Party</th>
<th>Start Date</th>
<th>End Date</th>
<th>Measurement (How will you know if you succeeded?)</th>
</tr>
</thead>
</table>

Reassessment Date: ________________________________
DO YOU KNOW...
HOW TO READ YOUR INSURANCE CARD

"As you get close to transitioning from St. Jude, it is important to learn to read your health insurance card. This card can be confusing until you learn how to read it. You and your new adult health care team need the information on your card to know how much your insurance company pays, what you pay, and more. This can help you understand your health insurance card."

“Lost in Transition: Care for Adults with Sickle Cell Disease ‘complex puzzle’ HemOnc Today Volume 14 Number 6 march 25, 2014

This extensive article might be briefly summarized; to wit: (1) Social workers trained in the disease are the key to effective transition.

Harry S. Jacobs, MD, FRCPath(Hon)

HemOnc Today Chief Medical Editor

Hematology Transition Branches Out
Hemophilia Insurance Pop Quiz

1. The name of my medicine is _____________________________________________________.

2. I take this medicine _______ times a month because I have ________________________________________.

3. I use _______ units in one dose of this medicine.

4. One unit of my medicine costs $ _______.

Let’s do some math

_________ (units in one dose) \* $ _______ (cost of one unit) = $ _______ per dose

$ _______ (cost per dose) \* _______ (how often I take the medicine) = $ _______ per month

This is why I need to know about ________________________________________________________________.

The name of my insurance company is __________________________________________________________.

Transition Continues to Catch On at St. Jude....

Future

Past

Institutional Initiatives

• Evidenced Based Practice Fellowship
• Year Long effort to look at the impact of Transition on Young Adults with Special Needs and how to establish a transition process in the Endocrinology Clinic
• Extensive Literature Review
• Development of the Transition Planning Checklist
Transition Planning Checklist for Endocrinology Clinic

DEVELOPMENT OF THE TRANSITION PLANNING CHECKLIST

- Time-line model
- Flexibility in application
- Visual roadmap in process
- Simple in design
- Patient self-directed

TRANSITION VISITS

2 years prior to transfer
Identify the following:
- Primary care physician
- Adult Endocrinologist
- Insurance coverage
- Primary healthcare decision maker (as appropriate)

1 year prior to transfer
Obtain the following:
- Health insurance referral
- Cancer treatment history
- Medication list
- Recent laboratory results
- Imaging (as appropriate)
- Endocrine risk-based screening recommendations
- Appointment with adult endocrinologist
LEARN AND PRACTICE

Healthcare Skills
- Make own appointments
- Manage own medications
- Obtain medications refills
- Carry insurance card
- Carry list of medications

Healthcare Literacy
- Know side effects of medications
- Describe medical condition to others
- Determine when condition worsens
- Review plan for emergencies

ADULT VISIT AND TRANSFER

Adult Endocrinologist Visit
- Treatment history
- Medical problems
- Medications
- Recent laboratories
- Risk-based screening

Last Pediatric Endocrinologist Visit
- Transfer prescriptions
- Share provider contact information
- Sign release of information, as needed

RESULTS

- The Transition Planning Checklist has been introduced to 75 patients/families.
- Introduction of the checklist takes approximately 10-15 minutes and was incorporated into a previously scheduled follow up visit.
- Follow up surveys have been completed with 60% of the patients/families.
- 88% thought the checklist would be useful in the transition planning process
CONCLUSIONS

• Use of the Transition Planning Checklist is feasible in the Endocrinology Clinic.
• Patients, families and providers report being satisfied with the introduction of the Transition Planning Checklist.
• Telephone survey supports continued need for discussions about the transition process.
Taking it to the next level

Types of Transitions Our Patients Experience

- Initial Diagnosis
- Initiation of Therapy
- Adjusting to life in treatment
- Therapy to Off Therapy
- Return to Home Community
- ACT (After Completion of Therapy)
- Survivorship
- Pediatric to Adult Care

Institutional Transition Initiatives

- Transition Oncology Program (TOP)
- Special Working Group was formed focusing on Transition and the issues surrounding Age of Majority
Transition Working Group

- Social Work: representing chronic and acute services
- Psychology
- School Program
- Patient Registration
- Legal
- HIMS
- Information Sciences
- Nursing Services
- Family Advisory Council
- Teen Advisory Council

Start early, Talk Often....Repeat

16 year old packet

- Feedback from multidisciplinary team including members of the St. Jude Family Advisory Council and Teen Advisory Council
- FAC presents feedback from patients and families highlighting the need to talk about transition as a way to prepare for the future
- Our goal is to normalize transition and knowledge of health care as a developmentally appropriate task for all 16 year olds regardless of treatment status
16 Year Old Packet

- Mailed out to all patients the month they turn 16
- Currently in English and Spanish
- Congratulations letter to the patient on turning 16 and information on how this will impact their care decisions in the future
- Letter to the parents outlining plans for preparing for the transition to adult care at 18
- Transition Planning Checklist
- Do You Know reviewing issues related to Age of Majority

Adaptation of the Transition Planning Checklist to be used across the institution

Accessibility to the Packet

- Social Work
- Patient Registration
- Electronically
- Plans to have it linked through the Patient Portal
18 year old packet

- A packet containing information on Age of Majority, Advanced Directives and Insurance
- Mailed or given to each patient when they turn 17.5 in preparation for their 18 year old visit
- Continuation of the information they received at age 16
- Conservatorship and Surrogate Decision Maker information is discussed when appropriate

Acknowledgements

- Hematology Social Workers
  Amanda Pullen, LCSW  Shyranda Jones, LMSW

- Department of Hematology
  Department of Social Work
  Department of Endocrinology
  Patients and Families of St. Jude

- Division of Psychosocial Services
  Emily Browne, DNP TOP Manager
  Katie Witsoe and FAC Members

- Department of Endocrinology
  Emily Browne, DNP TOP Manager
  Katie Witsoe and FAC Members

- Evidence Based Practice
  Fellowship and St. Jude Select

St. Jude Educational Material

- Available for download at [www.stjude.org](http://www.stjude.org)
- Free!!
References


Lemly DC, Weitzman ER, O’Hare K. Advancing healthcare transitions in the medical home: tool for providers, families and adolescents with special healthcare needs. Curr Opin Pediatrics 2013; 25: 16-8
