Journey Across the Great Divide:

The Use of Diverse Transition Tools to Support the Transition from Pediatric to Adult Care

Margery R. Johnson, MSW, LCSW
St. Jude Children's Research Hospital
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 health care 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*

PEDIATRICS

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

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 MJ et all ***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 all *Pediatrics* October 22, 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 planr

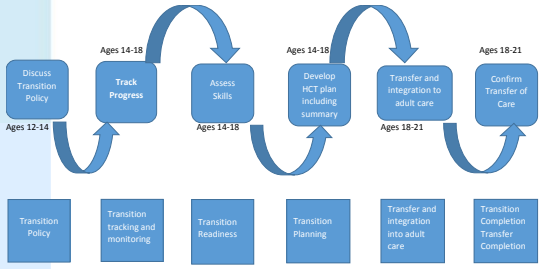
Start early, Talk Often….Repeat

got transition

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.gottransition.org/

Timeline for Introducing Six Core Elements



White and Cooley et all. *Pediatrics* October 22, 2018

Six Core Elements for Health Care Transition

Pediatric Health Care Setting	Adult Health Care Setting
1. Transition Policy •Develop a practice health care transition policy and share with providers, staff, youth, and families •Educate all staff about HCT best practices	**1. Young Adult Privacy and Consent Policy** •Develop a practice young adult release and consent policy; share with providers, staff, patients, families •Educate all staff about privacy and consent practices

http://www.gottransition.org/

Six Core Elements for Health Care Transition

Pediatric Health Care Setting	Adult Health Care Setting
2. Transitioning Youth Registry Identify transitioning youth (current/future) and enroll in a transition registry; monitor all preparation, planning and outcomes (e.g. coordination of care)	**2. Young Adult Patient Registry** Identify/enroll young adults in a practice registry; indicate levels of complexity; monitor adaptation to young adult model of care; note health readiness status

http://www.gottransition.org/

Six Core Elements for Health Care Transition

Pediatric Health Care Setting	Adult Health Care Setting
3. Transition Preparation Assess and track all readiness for adult health care with youth and families Use the Transition Readiness Assessment (youth, family) to address gaps in preparation, knowledge, and skills	**3. Transition Preparation** Discuss young adult model of health care (see definition) explain how to use the primary care practice including all access options Use/continue to use the Transition Readiness Assessment (youth, family) to address gaps in knowledge/skills

http://www.gottransition.org/

Six Core Elements for Health Care Transition

Pediatric Health Care Setting	Adult Health Care Setting
4. Transition Planning Address all health care transition needs/gaps, setting goals together with youth and family Use the: –Health Care Transition (HCT) Action Plans: –Portable Medical Summary –Emergency Care Plan (if needed). Name and notify adult primary care practice of youth's pending transfer of care date (one year out) and arrange for individualized introduction	**4. Transition Planning** Offer transitioning youth pre-transfer 'get acquainted' materials and/or encounter(s) up to a year before transfer Prior to their first visit, request their: –Health Care Transition (HCT) Action Plans: –Portable Medical Summary –Emergency Care Plan (if needed) For all youth and young adult patients develop, use and update the HCT Action Plan, Portable Medical Summary, and Emergency Care Plan

http://www.gottransition.org/

SIX CORE ELEMENTS OF HEALTH CARE TRANSITION

Pediatric Health Care Setting	Adult Health Care Setting
5. Transition and Transfer of Care Transfer from pediatric to new adult care location: Assure direct communication with adult PCP and team (email, phone, in person "handshake") Use the tool - Transfer of Care Checklist Send a "Transition Package" containing a transfer letter and items named above and in the Transfer of Care Checklist Initiate or coordinate specialty transitions as appropriate Transition to young adult model of care in same location	**5. Transition and Transfer of Care** Transfer from pediatric to new adult care location: Review Transfer of Care Checklist (pediatric, young adult) sent in the "Transition Package" to prepare for initial visits Talk with and receive communications from pediatric PCP/team (email, phone, in person "handshake") Provide office visit/encounters for transitioning young adults and continue with transition preparation and planning as needed Transition to young adult model of care in same location: Clarify PCP and coordinator of care contacts for young adult patient;

http://www.gottransition.org/

SIX CORE ELEMENTS OF HEALTH CARE TRANSITION

Pediatric Health Care Setting	Adult Health Care Setting
6. Transition Completion Pediatric PCP/team are a resource for each transferred patient and their adult PCP/team following care transfer. Pediatric PCP/team makes contact with adult PCP/team ~3 months post transfer to ensure success and continuity of care Transition/transfer is declared complete	**6. Transition Completion** 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 Continue forward with a young adult model of care and appropriate care planning for all patients

http://www.gottransition.org/

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
ALSAC • Danny Thomas, Founder

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

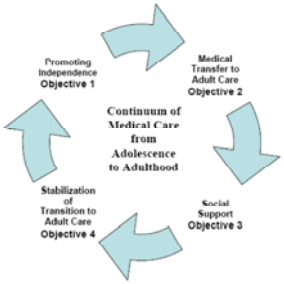
At St. Jude, we believe a smooth transition to young adulthood includes the move from pediatric to adult health care. Planning and preparing for this change should begin by age 12. **At age 18**, most young adults in our program will transition to adult health care.

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



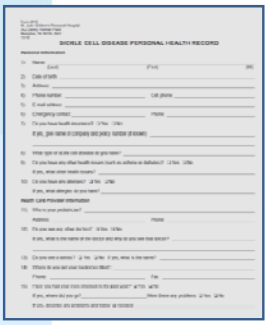
Transition to Adult Care Steps

- Preparation phase
- The "hand-off"
- The young adult years

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 over all medical history, familial medical history and other important information such as insurance, finances, and proficiency in areas of independent living.

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.

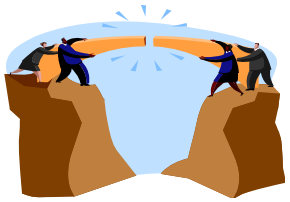
- Patients are given a copy of the form to take home with instructions to use as a tool to enhance communication with parents about their medical and personal information.
- The form can also be used as a source of information for future adult care clinic visits.
- Comparisons between the forms can be 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 appropriate section based on the child's readiness for transition. Check YES or NO if ready for transition. If NO, please write reason briefly. *Teens will be referred for readiness assessment during the month of their 17th birthday.*

NAME: _____ **MRN #:** _____ **DIAGNOSIS:** _____ **GRADE:** _____

DOB: _____ **Teen Tour date:** _____ **TX Therapies:** _____

MEDICAL	Responsible party: *Medical Team*	**PSYCOSOCIAL**	Responsible party: *Social Work*
Yes:	No:	Yes:	No:
Score:___(max 12) *If no, reason:*		*Score:___(max 5)* *If no, reason:*	
EMOTIONAL	Responsible party: *Psychology*	**ACADEMIC**	Responsible party: *Academic Coordinators*
Yes:	No:	Yes:	No:
Score:___(max 5) *If no, reason:*		*Score:___(max 5)* *If no, reason:*	
READY FOR TRANSITION?	Yes: No:	Responsible party: *Entire Team*	

PLAN OF ACTION

Domain	Objective (What do you want to see happening?)	Activity (How will you make it happen?)	Responsible Party (Who will make it happen?)	Start Date	End Date (No latter than 6 months from start date)	Measurement (How will you know if you succeeded?)	Reassessment Date: (If applicable):

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. Jacob, MD, FRCPath(Hon)
HemOnc Today Chief Medical Editor

Hematology Transition Branches Out

Hemophilia Insurance Pop Quiz

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) #3

□ $ _____ (cost of one unit) #4

= $ _____ per dose

This is why I need to know about

_____

$ _____ (cost per dose)

□ $ _____ (how often I take the medicine) #2

= $ _____ per month

_____ . The name of my

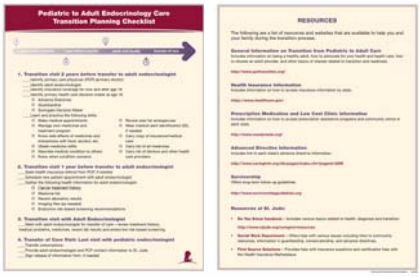
insurance company is _____ .

Transition Continues to Catch On at St. Jude….

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


Pediatric to Adult Endocrinology Care
Transition Planning Checklist

RESOURCES

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

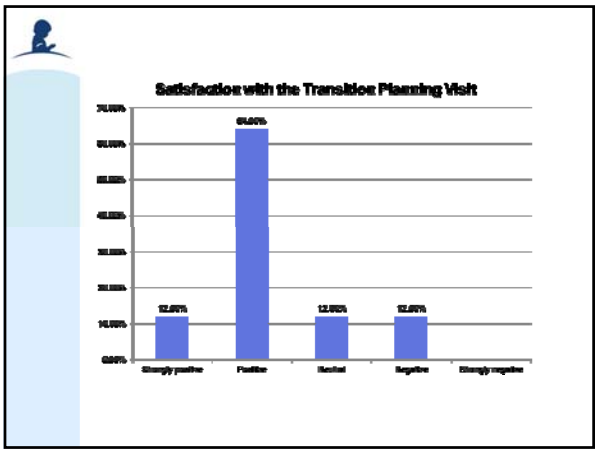
- ✓ Treatment history
- ✓ Medical problems
- ✓ Medications
- ✓ Recent laboratories
- ✓ Risk-based screening

Last Pediatric Endocrinologist Visit

- ✓ Transfer prescriptions
- ✓ Share provider contact information
- ✓ Sign release of information, as needed

RESULTS

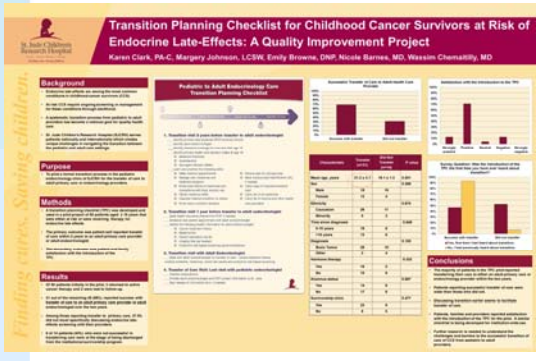
- The Transition Planning Checklist has been introduced to 75 patients/families.
- Introduction of the checklist takes approximately 10-15 minutes and was incorporated into a previously scheduled follow up visit.
- Follow up surveys have been completed with 60% of the patients/families.
- 88% thought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

Transition Pilot in Endocrinology



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

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Evidence Based Practice Fellowship and St. Jude Select

St. Jude Educational Material

- Available for download at www.stjude.org
- Free!!

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