Bridging the Gap: Caring for Adolescents and Young Adults with Type 1 Diabetes

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The Importance of Transition

- The issue
- Challenges for adolescents and young/ emerging adults
- Current approaches in literature
- Current research at the BDC
- Recommendations and resources
Disclaimer

- I have no financial disclaimers but...
Importance of Transition

Transition vs Transfer

>500,000 youth with special health care needs turn 18 years of age each year
Multiple Transitions

- Graduation
  - High school
  - College
  - Work
- Future career
- Leaving home
  - Taking over diabetes care
  - Loss of insurance
The Issue: Diabetes Prospective

- Highest risk population
- A1c increase in early puberty
  - Remain high until >25 yo
- More complications
  - Hospitalizations, DKA, increasing risk factors for vascular complications and comorbidities

http://www.t1dexchange.org/
6-7 years of poor glycemia matters

- DCCT - Short term improvement (6-7 years) was beneficial
  - intensive treatment = delayed complications
  - Poor control = earlier complications
- EDIC
  - Continued ↓ risk 10-25 years later
  - Even if diabetes control improves
Data on Adolescents and Young Adults from the T1D Exchange, SEARCH and the BDC

- T1D exchange is a registry of >25,000 individuals <1 to >90 years of age collected from 70 Diabetes centers in the US, Pediatric, Adult and Combined Centers
- SEARCH is a registry of those in 6 US clinical sites diagnosed <20 years of age with data collection from 2001- present
T1D Exchange Age Distribution

Beck R W et al. JCEM 2012;97:4383-4389

9518 are 13-<26 years of age
Mean HbA1c by age group.
HbA1c across # of SMBG per Day by insulin therapy

- P-value < 0.001 for each age group

**Pump Users**
- 1-12 year old
- 13-17 year old
- 18-25 years old
- ≥26 years old

**Injection Users**
- 1-12 year old
- 13-17 year old
- 18-25 years old
- ≥26 years old

Garg ATTD Barcelona 2012; Miller KM Diab Care in press
Why are 18-25 year olds not ‘real adults’?
Why teens and young adults cannot manage diabetes
Frontal Lobe Development Incomplete

- Problem solving
- Judgment
- Planning
- Inhibition risky behavior
- Organization
- Attention
- Emotional control
- Self-control
- Executive Functioning

Nitin Gogtay et al. Proceedings of the National Academy of Sciences, 2004
Inability to Assess Risk

- Is it wise to...
  - Swim with sharks?
  - Drink Drano?
  - Set your hair on fire?
- Are you surprised?

Interruption of Care with Transfer

- Worst metabolic control
  - ↓ follow up
  - ↑ hospitalizations
- More complications

Worsening A1c with Transfer of Care

- Transitioned - 2.5x ↑ risk A1c >9.0%
  - Compared to those still being seen in pediatrics
- Need for additional support once transitioned to adult care

BDC Transitioned Patients

- 51 patients, 2 year period
- Transition HbA1c
  - From last pediatric visit to first adult visit
    Statistically significant increase in HbA1c
    - $+0.41 \pm 1.19$, $p = 0.022$
- Transition time prolonged
  - $5.6 \pm 3$ months between visits
    - Range = 1.5 to $>12$ months

Presented at ADA Scientific Sessions, Chicago, June 2013.
Transition/transfer Models

- Patient and parent education
- Transition coordinators
- Transition clinics
  - Coordinator
  - Educational program
  - Pediatric and adult providers
- These reported approaches are not cost sustainable in the US health system

Shared Medical Appointments

- Change structure and method of clinical care delivery
- Successful
  - Chronic medical conditions
  - Prenatal care
  - Routine healthcare maintenance
  - Urgent care visits
  - Adolescent diabetes visits (personal communication)
Team Clinics

- Team High School = 14-17 years (high school)
- Team Beyond High School = 18-25 years (after high school)
SMA Game Plan
Appointments

- Every 3-6 months
- Discussion varies - Patient driven/ CDE facilitated
  - Myths/facts about diabetes
    - Sex, drugs, alcohol
  - Complications – why we care
  - Technology
    - Pumps, CGM, MDI, other
  - College, living away from family, etc.
Transition should move toward diabetes management – not mismanagement

- Not hate diabetes visits
- Come to visits more willingly and more regularly
  - Educated medical consumers
- Stay in system to make it to adult care
- Improve adherence
- Eventually impact A1c, complications, medical expense
SMA Approach

- Inexpensive to set up
- Minimal resources required
- Kids really like it
- Diverse personalities work well
- Applicable to most settings
- Informal environment works
- It seems more efficient

-Data to be presented at ISPAD Conference October 2013.
Summary

- Transition - important, challenging
  - Developmental reasons for struggles
- Current approaches not working
- Evidence-based research is needed
- Shared Medical Appointments may be one approach to achieve adolescent buy in to diabetes management
Acknowledgements

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Michelle Schweiger, DO, MPH

Thank you
Recommendations and Resources
Diabetes Care for Emerging Adults: Recommendations for Transition From Pediatric to Adult Diabetes Care Systems

A position statement of the American Diabetes Association, with representation by the American College of Osteopathic Family Physicians, the American Academy of Pediatrics, the American Association of Clinical Endocrinologists, the American Osteopathic Association, the Centers for Disease Control and Prevention, Children with Diabetes, The Endocrine Society, the International Society for Pediatric and Adolescent Diabetes, Juvenile Diabetes Research Foundation International, the National Diabetes Education Program, and the Pediatric Endocrine Society (formerly Lawson Wilkins Pediatric Endocrine Society)

Anne Peters, MD, CDE
Lori Laffel, MD, MPH
The American Diabetes Association
Transitions Working Group

highlighting the need for a framework of care and education for this population and a call for additional research in this area. Substantial challenges relating to the transitional period include the following:
Pediatric to Adult Diabetes Care Transition Planning Checklist

This checklist helps the health care provider, young adult, and family discuss and plan the change from pediatric to adult health care. While a variety of events may affect the actual timing when this change occurs, below is a suggested timeline and topics for review. The young adult, family, and health care provider can obtain a copy of this checklist and access many online transition resources at the NDEP website (www.YourDiabetesInfo.org/transitions).

Internally:

1 to 2 years before anticipated transition to new adult care providers
(Date completed ____________)
- Introduce the idea that transition will occur in about 1 year
- Discuss shared responsibility between the young adult and family for:
  - Making appointments
  - Refilling prescriptions
  - Calling health care providers with questions or problems
  - Making insurance claims
  - Carrying insurance card
- Review smoking, drugs, and alcohol

6 to 12 months before anticipated transition
(Date completed ____________)
- Discuss health insurance issues and encourage family to review options
- Assess current insurance plan, e.g., length time on family health insurance plan, COBRA, pre-existing conditions
- Explore new insurance options – college, employer
- Consider making an appointment with a case manager or social worker
- Discuss career choices in relationship to insurance issues
- Evaluate family to gather health information to provide to the adult care team (See Clinical Summary Page at www.YourDiabetesInfo.org/transitions)
- Review health status: diabetes control, retina (eye), kidney and nerve function, teeth and mouth, lipids (cholesterol), blood pressure, smoking status
- Discuss issues of independence, emotional ups and downs, depression, and how to seek help
- 3 to 6 months before anticipated transition
(Date completed ____________)
- Review the above topics
- Suggest that the family find out the cost of current medication(s)
- Provide information about differences between pediatric and adult health systems and what the young adult can expect at first visit
- Patient’s responsibilities

Last few visits
(Date completed ____________)

- Review and remind of above health insurance changes, responsibility for self-care, and link to online resources at www.YourDiabetesInfo.org/transition
- Obtain signature(s) for release of personal medical information and for pediatric care providers to talk with the new adult care providers
- Identify new adult care physician
  - If known – request consult (if possible) and transfer records
  - If unknown – ask teen to inform your office when known to transfer records and request consult
- Review self-care issues and how to live a healthy lifestyle with diabetes
  - Medication schedules
  - Self-monitoring of blood glucose schedule
  - Meal planning, carb counting, etc.
  - Physical activity routine and its effects on blood glucose
  - Crisis prevention, management of hypoglycemia (low blood glucose), hyperglycemia (high blood glucose), and sick days
  - Need for wearing/carrying diabetes identification
  - Care of the feet
  - Oral/dental care
  - Need for vision and eye exams
  - Preconception care (preparing for a safe pregnancy and healthy baby)
  - Immunizations
  - Staying current with the latest diabetes care practice and technology
- Suggest options for a diabetes “refresher” course

To learn more about living well with diabetes contact NDEP:
1-888-693-NDEP (6357), TTY: 1-866-569-1162 or www.YourDiabetesInfo.org

NDEP is jointly sponsored by NHl and CDC with the support of more than 200 partner organizations.
March 2010

Clinical Summary for New Health Care Team

Form to be completed, signed, and dated on back page by referring physician and patient. Patient and family to review and give completed form to new adult health care provider.

Patient Name: ___________________________ DOB: ___________________________

Diabetes type: Type 1 □ Type 2 □ Date diabetes diagnosed: ___________________________

Problem List and Date of Onset


Insulin Types

Pump:

Syringe or Pen:


Insulin Types

Dosage

Schedule


All Other Medications

Dosage

Schedule


Self-monitoring

Blood glucose? No □ Yes □ Method ___________________________ Frequency ___________________________

Continuous glucose sensor? No □ Yes □ Brand/Model ___________________________

Ketones? No □ Yes □ When ___________________________

Other: ___________________________

Recent Laboratory Values

Date

A1C (2 values)

Chol/LDL/HDL/Trig

Urine Albumin

eGFR


Recent Clinical Exam/Test Results:

Blood Pressure and Date

Dilated Eye Exam and Date

Sensory Foot Test and Date

Current Weight

Height

BMI

Other exam/test results:

Most recent diabetes education consult:

Most recent nutrition consult:

Diabetes-related hospitalizations:

History and cause of DKA:

Allergies/alerts:

Participation in clinical research? Past □ Current □ Which study?

Additional comments/information such as X-rays, biopsies, and other test results:

Patient/family comments:

Patient Signature and Date

Referring Physician Signature and Date

Contact Information

To learn more about living well with diabetes contact NDEP:
1-888-655-NDEP (65537), TTY: 1-866-555-1162 or www.YourDiabetesInfo.org

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Opening Doors to a Healthy Future

Welcome to the National Health Care Transition Center's Website

Got Transition? is a national resource for health care professionals, families, youth, and state policymakers focusing on a young adult's transition from pediatric to adult health care. This site serves as the basis for an information exchange about health care transition, particularly as pertaining to youth with special health care needs.

Transition tools and tips and other resources are available under each of the main categories of Youth, Family, Providers and States. These resources will grow and develop so visit us often.

If you are new to Got Transition, you might start with "I Need Help Finding..." Or, sign up for E-News to be notified of our quarterly webinars, monthly broadcasts and to stay informed about transition developments.

http://www.gottransition.org/
Six Core Elements Health Care Transition - Ped and Adult

http://www.gottransition.org/

<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. Young Adult Privacy and Consent Policy</strong></td>
</tr>
<tr>
<td>• Develop a practice health care transition policy and share with providers, staff, youth, and families.</td>
<td>• Develop a practice young adult privacy and consent policy; share with providers, staff, patients, families.</td>
</tr>
<tr>
<td>• Educate all staff about HCT best practices</td>
<td>• Educate all staff about privacy and consent practices</td>
</tr>
<tr>
<td><strong>2. Transitioning Youth Registry</strong></td>
<td><strong>3. Young Adult Patient Registry</strong></td>
</tr>
<tr>
<td>• Identify transitioning youth (current/future) and enroll in a transition registry; monitor all preparation, planning and outcomes (e.g. coordination of care)</td>
<td>• Identify/enroll young adults in a practice registry, indicate levels of complexity; monitor adaptation to young adult model of care; note health/wellness status</td>
</tr>
<tr>
<td><strong>3. Transition Preparation</strong></td>
<td><strong>4. Transition Planning</strong></td>
</tr>
<tr>
<td>• Assess and track all readiness for adult health care with youth and families</td>
<td>• 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:</td>
</tr>
<tr>
<td>• Use the Transition Readiness Assessment (youth, family) to address gaps in preparation, knowledge, and skills</td>
<td>- Health Care Transition (HCT) Action Plans:</td>
</tr>
<tr>
<td><strong>4. Transition Planning</strong></td>
<td>- Action Plan Example One</td>
</tr>
<tr>
<td>• Address all health care transition needs/gaps setting goals together with youth and family</td>
<td>- Action Plan Example Two</td>
</tr>
<tr>
<td>• Use the:</td>
<td>- Portable Medical Summary</td>
</tr>
<tr>
<td>- Health Care Transition (HCT) Action Plans:</td>
<td>- Emergency Care Plan (if needed)</td>
</tr>
<tr>
<td>• Action Plan Example One</td>
<td>• Name and notify adult primary care practice of youth’s pending transfer of care date (one year out) and arrange for individualized introduction</td>
</tr>
<tr>
<td>• Action Plan Example Two</td>
<td>• For all youth and young adult patients develop, use and update the HCT Action Plan, Portable Medical Summary, and Emergency Care Plan</td>
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## Six Core Elements

### Health Care Transition - Ped and Adult

### 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 *(pediatric, young adult)*
- 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: See Core Elements 3, 4, and 5 in the right-hand column

### 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

### 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; implement Core Elements 3 and 4 as indicated; assist on-going specialty care transfers

### 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

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http://www.gottransition.org/
State Innovations

Transition Websites
Many State Title V programs for Children with Special Health Care Needs (CSCN) have incorporated transition information and resources on their website while others have created a separate site or links to transition information. Most of these provide toolkits containing various guides and resources designed for youths, parents and caregivers, and medical providers.

These are some of the websites of interest or that states might consider replicating. This is just a starting point. We welcome our users to bring to our attention other state websites that offer useful transition information.

Florida
FloridaHATS
This site clearly states its mission, vision, and values in an easily-navigable design. It includes a directory for young adults, the latest news on transition, and a Transition Tool Box (that has education and training, health care provider information, and information on insurance).

Maryland
Maryland Transitioning Youth
This site clearly states its mission, vision, and values in an easily-navigable design. It focuses on the consumers, with links that include reference guides, locating physicians, and information on private insurance. It is a "one-stop" location for families of transitioning young adults.

Montana
MYTransitions
Montana has this separate, one-stop site for transition, which conveniently contains different drop-down bars for parents, professionals, and the young adults. It also contains info on transition related to employment, housing, transportation, education, recreation, money, and health.

New York
Healthy Transitions
This is a fun, interactive website with lots of great tools and videos developed by the New York State Institute for Health Transition Training. The site includes My PLACE, a social networking feature that links you to a personal transition team.

North Carolina
MAHEC CHAT Project
As part of the Mountain Area Health Education Center, the site provides information and guides for the CHAT (Carolina Health and Transition) project. The page includes a Tool Kit and guides for parents, youths, and providers on transition.

Washington
Adolescent Health Transition Project
Called the "Adolescent Health Transition Project," Washington's transition site includes information for young adults, providers, and parents, with medical summary information and adolescent autonomy checklists, to name a few resources. In addition, the site offers guides and information for education and employment.
Health Care Transition Planning Algorithm

From AAP, AAFP, ACP

Transition Planning Algorithm

From The American Academy of Pediatrics

Successful Diabetes Models Outside US

- Canada, UK, Australia
  - The Maestro Project
  - Drop out rate
    - 40% → 11%

- Components
  - Pediatric, adult clinic
  - Coordinator
  - Educational program