The Young Adult with Type 1 Diabetes: Opportunities to Improve Transition of Care

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Prevalence and Incidence of Type 1 Diabetes: Global
2010 International Diabetes Federation Estimates

- Approximately 480,000/1.9 billion children aged 0-14 years
- Increasing at 3% per annum
- 76,000 new diagnoses per year

Type 1 Diabetes in the US

- 15,000 US youth diagnosed with type 1 diabetes annually
  - 19 per 100,000 per year
- 3,700 youth diagnosed with type 2 diabetes annually
  - 5.3 per 100,000 per year.
- Tens of thousands are believed to be transitioning annually.

Adolescents are a Vulnerable Population

In DCCT:
Intensively managed subjects had a 3-fold increase in risk of severe hypoglycemia.
Compared with intensively treated adults, adolescents had:
- Higher Hgb A1c levels vs. similarly treated adults (8.1 vs. 7.1%).
- A 60% increase in the risk of severe hypoglycemia (86 vs. 54 events per 100 pt. years).


Attainment of Adulthood

- E Erikson, circa 1950:
  post high school = young adults
  - Based on interviews & questionnaires of heterogeneous group of 18-30 year-olds.

Search for Diabetes in Youth, 2003-2003 data.
Changing Demographics

<table>
<thead>
<tr>
<th>21 y/o in 1970</th>
<th>21 y/o in 2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Married</td>
<td>• Not married until late 20's.</td>
</tr>
<tr>
<td>• Parent or expecting</td>
<td>• No children until late 20's – early 30's</td>
</tr>
<tr>
<td>• Education completed</td>
<td>• Education ongoing</td>
</tr>
<tr>
<td>• Settled into long-term employment</td>
<td>• Changes in employment &amp; residence</td>
</tr>
</tbody>
</table>

Emerging Adulthood: 5 Main Features

1. **Identity exploration**
   - Trying various options, esp. relationships & employment.

2. **Instability**
   - Multiple relationships, highly mobile.

3. **Self-focused age**
   - Age of “feeling in-between”
     - Neither adolescent nor adult.
   - Age of possibilities.


Management Challenges in the Young Adult

- Shift of support group away from family and towards self and peers.
- Loss of support by pediatric diabetes team and shift to different care model.
- Feeling of invincibility and participation in high-risk behaviors
  - Alcohol, illicit drugs, driving, sexual activity.
- Shift of geographical locale.
- Potential loss of insurance.

Psychosocial Issues

- 1/3 of adolescents with type 1 DM suffer from psychiatric disorders
  - Mostly internalizing symptoms
  - Diabetic youth have greater rates of depression
    - Depression leads to worsening glycemic control
  - Diabetic youth, particularly females are at increased risk for eating disorders
  - Young adults with diabetes have lower self esteem


Insulin Omission

11-year follow-up study of 234 women with type 1 diabetes. Mean age was 45 years and mean diabetes duration was 28 years at follow-up:

- Mean age: 45 yrs
- Mean duration of diabetes at follow-up: 28 yrs
- 71 women (30%) reported insulin restriction at baseline.
- Insulin restriction conveyed a 3-fold increased risk of mortality (26 women died during follow-up).
- Those that died reported more frequent insulin omission and more eating disorder symptoms at baseline.
- Mean age of death was younger for insulin restrictors (45 vs. 58 years).
- Insulin omitters reported higher rates of nephropathy and podiatric concerns at f/u.


Retinopathy

- German registry study at University of Ulm
  - N=441
  - Median age: 15.5 yrs.
  - Median duration of diabetes: 6.3 yrs.
  - 19% on BID NPH/Reg, 42% on TID injections, 40% on QID injections
  - Median duration prior to dx of NPDR: 16.6 yrs.
  - Shortest duration prior to dx of NPDR: 2.2 yrs.
  - Youngest child with NPDR: 5.5 yrs.
  - Those with pre-pubertal onset developed DR a median of 10.9 yrs. after puberty compared to 15.1 yrs. with pubertal onset of DM.

Society for Adolescent Medicine Statement on Transition & ISPAD Guidelines

- The pediatric care provider should,
  - In partnership with the family:
    - Develop an up-to-date written transition plan to coordinate subspecialty care, addressing developmental, psychosocial, & vocational needs.
    - Ensure affordable, comprehensive health insurance into adulthood.
  - Collaborate with adult care providers to develop best practices for management of adults with diseases of childhood.
    - Combined clinics where possible.

Current State of Transfers

- Age of transfer:
  - Ranges from 15.9 to 19.8 yrs.
  - 37% of 18-25 year-olds still seen in pediatric clinics
    - (de Beaufort et al, 2010)
  - 22% of young adults with disabilities uninsured
    - (Callahan & Cooper, 2007)

Research on Transition Programs

- Generally, descriptions of single programs without evaluation or retrospective comparisons.

- No randomized controlled studies.

- Programs largely based on scant empirical findings of problems
  - Have multiple components without clear theoretical basis

Comparison of Structured vs. Unstructured Transition

- Retrospective examination of 62 adolescents and young adults transferred from the pediatric to adult diabetes service of the same hospital.
  - Program:
    - Structured (2000-4): transition coordinator, communication of expectation of transfer, coordination and continuity of HCP, last visit without parents.
  - Outcomes:
    - Significantly more of unstructured group had:
      - Break in care.
      - Longer time interval between last pediatric and 1st adult care visit.
      - Only 31% of unstructured group seen w/ 1 yr. vs. 100% of structured group.
      - Structured group had more clinic attendance and improved A1c at 1 year.

2005-6 National Health Survey

National telephone survey of 40,804 families with SHCN youth under the age of 18:

- 52% of families with SHCN youth ages 12-17 years stated their youth had not received the supports needed to make appropriate transitions to adult health care, work and independence

Regarding actions by their primary care providers:

- 50.7 % talked with them about having their child eventually see health care providers who treat adults
- 46.2% talked with them about the health care needs as their child becomes an adult
- 21.3% discussed with them how to obtain or keep some type of health insurance coverage as their child becomes an adult

www.cshcndata.com
Role of Pediatric Care Team

1. Prepare adolescent/young adult for transition.
   a) Assist patient in goal-setting.
   b) Assist in identification of support network.
   c) Assist in selection of adult care provider.
      - Agree on specific individual and directly assist in making appointment.
2. Knowledge/skill deficit assessment.
   a) Provide for re-training of those diagnosed at early age.
3. Prepare summary of diabetes history
4. Seek patient feedback (exit interview) regarding process.
   - Consider scheduling a final pediatric visit after the first adult visit.

Role of Adult Care Team

1. Provide care geared to the needs of the young adult.
2. Discuss practice logistics & access to team members.
3. Review pediatric history including course of diabetes, insulin regimen, laboratory results and potential early complications.
4. Review goals of therapy.
5. Discuss options.
6. Discuss potential obstacles to optimal care.
   - Identify and address knowledge/skill deficits.
7. Formulate management plan.

Screening Recommendations: Pediatrics

<table>
<thead>
<tr>
<th>Activity</th>
<th>Schedule</th>
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<tr>
<td>Routine eye exam</td>
<td>Annually ≥ 10 yrs, Diabetes x 3-5 yrs.</td>
</tr>
<tr>
<td>Urine microalbumin</td>
<td>Annually ≥ 10 yrs, Diabetes x 5 yrs.</td>
</tr>
<tr>
<td>Fasting Lipids</td>
<td>Family History: age &gt; 2 yrs. or Family History: age ≥ 10 yrs. If abnormal, recheck annually. If normal: every 5 yrs.</td>
</tr>
<tr>
<td>Anti-tissue transglutaminase or anti-endomysial antibodies</td>
<td>Measure if symptoms suggest Celiac disease.</td>
</tr>
<tr>
<td>Thyroid function tests</td>
<td>At diagnosis and every 1-2 yrs.</td>
</tr>
<tr>
<td>Blood pressure monitoring</td>
<td>Measure at routine visits.</td>
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Screening Recommendations: Adults

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<td>Annually</td>
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<tr>
<td>Urine microalbumin</td>
<td>Annually</td>
</tr>
<tr>
<td>Fasting Lipids</td>
<td>Annually every 2 years in those with low-risk lipid profiles.</td>
</tr>
<tr>
<td>Distal symmetric polyneuropathy testing</td>
<td>Annually</td>
</tr>
<tr>
<td>Blood pressure monitoring</td>
<td>Measure at routine visits.</td>
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Achieving Optimum Transition

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<th>Pediatric Setting</th>
<th>Adult Setting</th>
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<tr>
<td>Identify adult care providers that will accept transitioning patients.</td>
<td>Determine that the practice wishes to cater to young adult patients.</td>
</tr>
<tr>
<td>Develop a transition policy.</td>
<td>Develop a privacy &amp; consent policy.</td>
</tr>
<tr>
<td>- Share with providers, staff, youth &amp; families</td>
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<tr>
<td>Develop a list of current &amp; future transition candidates.</td>
<td>Develop process for accepting transitioning patients.</td>
</tr>
<tr>
<td>Prepare a transition curriculum that includes:</td>
<td>Process should include:</td>
</tr>
<tr>
<td>- Checklist of skills to master</td>
<td>- Assessment of skills</td>
</tr>
<tr>
<td>- Timeline</td>
<td>- Readiness Assessment</td>
</tr>
<tr>
<td>- Transition summary/package</td>
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<tr>
<td>Identify a transition coordinator that will:</td>
<td>Establish &amp; maintain communication with referring provider to continually assess &amp; improve process.</td>
</tr>
<tr>
<td>- Assist in coordinating &quot;handoff&quot;</td>
<td>- Serve as a liaison for pt. &amp; the adult provider.</td>
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Transition Resources

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<th>Location</th>
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<tr>
<td>&quot;Supporting the Healthcare Transition from Adolescence to Adulthood in the Medical Home&quot;</td>
<td>Pediatrics Vol. 128 No. 1 July 2011, pp. 182-200</td>
</tr>
<tr>
<td>National Healthcare Transition Center</td>
<td><a href="http://www.gottransition.org/">http://www.gottransition.org/</a></td>
</tr>
<tr>
<td>Florida Health and Transition Services</td>
<td><a href="http://www.floirdahats.org">www.floirdahats.org</a></td>
</tr>
<tr>
<td>National Diabetes Education Program</td>
<td><a href="http://www.YourDiabetesInfo.org/transition">www.YourDiabetesInfo.org/transition</a></td>
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Transitions: Online Tool
www.YourDiabetesInfo.org/transitions

Transitions: Checklist

Transitions: Resource List

Transitions: Clinical Summary Page

NDEP Focus Groups on Website

- 39 young adults with T1DM (avg. age 22.5 yrs.)
- 96% thought checklist would be helpful
- 96% thought timeline was realistic
- Most useful topic: T1DM in college
  - T1DM in college
  - Find a physician, CDE, dietitian, etc.
  - Visit to adult HCP
  - Preventing crises
  - Driving, pregnancy, alcohol, tobacco

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Transitions: Clinical Summary Page

- Collaborative program of the Florida Department of Health, Children's Medical Services Network, Florida Developmental Disabilities Council, and other partners throughout the state.

Mission:
To ensure successful transition from pediatric to adult health care for all youth and young adults in Florida, including those with disabilities, chronic health conditions or other special health care needs.

FloridaHATS "For Healthcare Providers" web page:
http://www.floridahats.org/?page_id=608

- Healthcare Transition Training Program
- Transition Assessment
- Medical Summary Forms
- General Checklists & Care Plans
- Condition-Specific Checklists & Care Plans
  - Diabetes
  - NDEP
  - U. of Wisconsin "Keys to Independence: Diabetes"
Summary

- The transition of diabetes care from pediatric to adult care providers is frequently disjointed and unsatisfactory for both patients and their care providers.
- Barriers: psychosocial, behavioral & systemic
- More concerted efforts to optimize transition are necessary.

Goals

- Develop & publish Anticipatory Guidance guidelines that emphasize self-advocacy with
  - an early start (acknowledgement at dx. and no later than 14 yo.)
  - a timeline to facilitate progression to transition
- Regular assessment of cognitive & behavioral needs
- Improve coordination of transition process
- Actively incorporate advances in technology & networking in education and communication in order to facilitate diabetes management.
  - e.g. Websites, Facebook, MySpace, Twitter.
  - Portable electronic medical record.
- Continue & expand multi-center collaboration to perform randomized controlled trials to permit development of best practices.