Transitional from Pediatric to Adult Diabetes Care: Developmental and Psychological Dimensions

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Objectives

I. What do contemporary developmental theories suggest about “when to transition” from pediatric to adult Type 1 diabetes (T1D) care?

II. What is the recent research evidence about persons with T1D after adolescence?

III. What do we know about clinical challenges of the post-high-school-aged person with T1D?

IV. What resources are available for providers, older teens with T1D, and their parents who want to know more about “transitioning with T1D”?

Older Developmental Theories of the Post-High School Period

- Older theories of the post-high school period based on sociological definitions of the “transition to adulthood” as:
  - 1. finishing education
  - 2. entering full-time work
  - 3. marriage
  - 4. parenthood

- Examples of older theories based on above defn:
  - 1. E. Erikson’s (1950) post high school period = young adulthood;
  - 2. K. Keniston’s (1971) post high school period = youth;

Contemporary Developmental Theory

- Jeffrey Arnett’s (2000, 2004) theory of the post-high-school period as “Emerging Adulthood”

- Based on data documenting
  1. changing demographics of the post-high-school age person
  2. interviews & questionnaire data from groups of 18-30-yr-olds, heterogeneous as to cultural, socio-economic, educational, and geographic characteristics
Changing Demographics

21 yr. old in 1970
- Married
- Parent or Expecting
- Education completed
- Settled into long-term job

21 yr. old in 2004
- Not married - late 20’s
- No kids - late 20’s-30’s
- Education on-going
- Job & living changes

Median U.S. Marriage Age 1950-2000 by gender (men: darker line; women: lighter line)

Arnett’s Interview/Questionnaire Data

- Asked large, diverse samples of 21-34-year-olds: what are the most important criteria for adulthood?
  1. Accepting responsibility for one’s actions,
  2. Making independent decisions,
  3. Becoming financially independent.

“Do You Feel that You have reached Adulthood?” (No=white; Yes=gray; Yes & No=black)

Emerging Adulthood

- This is a distinct developmental period post-high school, from late teen’s to late 20’s.

- “Emerging Adulthood” is becoming more pervasive world-wide with the increasing globalization of the world economy driving shifting demographics around the globe.

- What are the psychological tasks of this developmental period?

5 Psychological features of ‘emerging adulthood’

- Peak in the first half of the ‘emerging adulthood’ period (18-25 yrs.) and gradually stabilize:
  1. Age of Identity explorations (trying out various possibilities, esp. in love & work),
  2. Age of Instability (multiple relationships, highly mobile, revising ‘the Plan’),
5 main features of ‘emerging adulthood’

3. Self-focused age (normal, healthy, & temporary),

4. Age of feeling in-between (in transition neither adolescent nor adult),

5. Age of Possibilities.

Emerging Adulthood: Self-Focused

How does ‘emerging adulthood’ theory inform us about diabetes care transitions during this period?

In the immediate post high-school period:

- Multiple transitions- geographically/socially, economically, emotionally (away from parental home).
- Many changes, distractions, & competing scholastic, economic and social demands.

How does ‘emerging adulthood’ theory inform us about diabetes care transitions during this period?

In the immediate post high-school period:

- If you have several competing priorities (education vs. work), this can detract from a focused commitment to chronic disease management.
- If you have significant distractions & insecurities, it may be unrealistic to expect you to intensify your regimen and/or transition to a new adult diabetes provider.
- Important to individualize T1D recommendations based on the post-adolescent's circumstances.

How does ‘emerging adulthood’ theory inform us about diabetes care transitions during this period?

In the later phase of emerging adulthood (25-30 yrs):

- More “adult-like roles” are beginning to be assumed.
- Focus shifts to making choices about-- & more movement toward-- stability in relationships, work directions, & lifestyle behaviors.

Rates of Moving by Age

Figure 1.2. Rates of Moving, by Age
What does ‘emerging adulthood’ theory suggest about diabetes health care transitions during this period?

The later phase of emerging adulthood (25-30+ yrs.)

- May provide a ‘window of opportunity’ for the provider to intervene and collaborate with the older ‘emerging adult’ to set healthy life-long routines of self-care.
- Re-orient the provider-pt. model where provider is the pt’s “guide” in making informed choices about living their life with diabetes.

II. Recent Research Evidence: Youth with T1D after Adolescence

Summary:

1. The post-high school period presents unique demands from- and has fewer supports than during adolescence.
2. For a subgroup of patients, there is continuity between the adolescent mental health, diabetes adherence, and glycemic control problems and the problems they experience in the post-adolescent period.

Recent empirical studies-1

- From Canada:
  - Youth with T1D did not differ from healthy peers in psychosocial maturation (Pacaud et al, 2007)
- From the U.K.
  - Youth with T1DM have normal levels of psychosocial maturation
  - High level of family support is strongest predictor of adherence in post-adolescent youth (Gillibrand & Stevenson, 2006)

Recent empirical studies-2

- Bryden et al. (1999, 2001) – longitudinal studies U.K. subgroup with psych. & beh. problems in adolescence only worsened in next 8 years, esp. depression & disordered eating (9 risk of microvascular complications & death)
- Rydall et al (1997) - longitudinal study in Canada, adolescent females with disordered eating at higher risk for complications in their 20’s and worsening of eating disorder without intervention

Recent empirical studies-3: DCCT follow-up EDIC Study (NEJM, 2000)

<table>
<thead>
<tr>
<th>Adolescents (both arms, 4 yrs after DCCT end)</th>
<th>Adults (both arms, 4 yrs after DCCT end)</th>
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<tbody>
<tr>
<td>Mean age = 26 yrs.</td>
<td>Mean age = 38 yrs.</td>
</tr>
<tr>
<td>Mean $A_1C$ = 8.4%</td>
<td>Mean $A_1C$ = 8.0%</td>
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Models of Transition Programs

- Van Wallieghem et al (2006): Manitoba CN Health navigator service coordinated access to support services for 18-30 yr-olds & offered group education, website, newsletter to keep communication open with cohort—acceptable to pts.
- In U.S. No published evaluations of different models of transitioning T1DM adolescents
  a. Barbara Davis Center (Denver) & Joslin Diabetes Center (Boston): for local patients, pediatric to adult under one roof
  b. Markham-Stouffville Hospital (Ontario, CN) & Nemours Clinic (Orlando, FL): Written Transition Guide
Recent empirical studies of T1D 16-25-year olds: Conclusions

- Overall, psychosocial maturation similar to peers
- Parents continue to provide imp. supports
- Sub-group with psych. problems during adolescence (depression, eating disorders) deteriorate during post adolescent-period. ø adherence, ø control, ø risk for complications.
- Very few studies of U.S. cohorts or evaluations of U.S. models of care

III. Evidence for Clinical Challenges in Emerging Adulthood Period

1. Depression and diabetes burnout
2. Loss to medical follow-up
3. ↓ options for health insurance

“Burn-Out”

“A common response to a chronically difficult and frustrating job, where the individual works harder and harder each day and yet has little sense that these actions are making a real difference.”

Psychological Sx of “Diabetes Burn-Out”

- Feeling chronically over-extended and depleted by the burdens of living with and managing DM.
- Feeling a sense of inadequacy, or guilt that I am failing at this job of managing DM.
- Feeling helpless and hopeless, acting irritable and hostile with family and providers.

Loss to medical follow-up

- Due to the gap between pediatric and adult diabetes services ø medical visits & loss to follow-up care and lost opportunity to screen for early signs of complications

Kipps et al (2003): UK
- At & after transfer to adult providers, there is loss to follow-up care and ø medical visits.

Impact of Loss to Medical Follow-Up

- Loss to medical follow-up was the strongest predictor of complications and mortality in British Diabetic Assoc. Cohort Study in 20-29-year-old group. (Laing et al, 1999).
Recent News for the “Emerging Adulthood” Cohort about Health Insurance

IV. Transition Resources: Youth, Families, Providers

- Wolpert HA, Anderson, BJ, Weissberg-Benchell J. Transitions in Care: Meeting the Challenges of Type 1 Diabetes in Young Adults. American Diabetes Association, 2009. (www.diabetes.org online bookstore)
- National Diabetes Education Program (NDEP) Transition Tools (www.ndep.nih.gov)

Transitions: Online Tool
www.YourDiabetesInfo.org/transitions

Transitions: Checklist

- Transitions: Clinical Summary Page

Transitions: Resource List
Website Resources

- [http://www.childrenwithdiabetes.com](http://www.childrenwithdiabetes.com): offers education and support to families living with type 1 diabetes; updates on current research and reviews of new diabetes technologies. Online groups for parents, teens and young adults.


- [http://www.jdrf.org](http://www.jdrf.org): The website of the Juvenile Diabetes Research Foundation has an excellent section on Type 1 diabetes in College. Also has information on latest research advances and clinical trial participation.

Website Resources-2

- [http://studentswithdiabetes.health.usf.edu/](http://studentswithdiabetes.health.usf.edu/): to create a community and connection point for students with diabetes on college campuses.

- We want to simplify life for college students with diabetes! College life presents new situations and experiences for the student with diabetes.

- **Students With Diabetes** wants to equip students with the tools and information they need to succeed. We aim to contribute to the education of college students by providing skill sets that will help them navigate college life with diabetes safely and effectively.

Summary

- The post-high school period is a time of identity exploration, instability, mobility, self-focus and feeling in-between.

- For youth with T1D, important to individualize the transition plan based on number of simultaneous transitions & competing priorities.

- Continuity of glycemic control and emotional problems across adolescence-post adolescence

Summary-2

- Vulnerable to ‘diabetes burnout’ and loss to follow-up!

- Support is critical: family, social, & medical team.

- Be familiar with transition resources (of NDEP) and websites.

Thank you for your attention!

Questions?