Crossing the Bridge: Transition Challenges in JDM

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Overview

• What is transition?
• Long-term outcomes: Establishing the need for effective transition in JDM
• Transition in Rheumatology: How are we doing?
• Provider, health care system and patient factors affecting transition
• Transition improvement programs
• Defining transition success: Outcomes measurement
What is Transition?

“The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems.”

- Blum, 1993
Transition in JDM: Is it important?

• Do JDM patients need ongoing care into adulthood?
• What is the risk of ongoing disease activity?
• What is the risk of ongoing disease-related damage?
Long-term outcomes in JDM

Before 1960:
• 1/3 died of disease-related causes
• 1/3 severely disabled
• 1/3 recovered without severe disability

2014:
• Mortality <2%
• Ongoing disease activity
• Calcifications
• Contractures
Long-term outcomes in JDM

• Huber et al., 2001
  – Multi-center Canadian inception cohort
  – Chart review and patient interview
  – 65/80 patients contacted at median 7.2 years after diagnosis (range 3 to 14)
  – Median age at diagnosis 5.8 years (range 1 to 16)
Long-term outcomes in JDM

• Huber et al., 2001
  – Ongoing disease activity common
    • 40% rash
    • 10% reported weakness
    • 22% reported pain
    • 35% remained on medication
  – One death
  – No participants indicated that JDM interfered with school or work at time of f/u
Long-term outcomes in JDM

- Huber et al., 2001

Disability according to Childhood Health Assessment Questionnaire (N=65)

- None: 72%
- Mild: 20%
- Moderate to severe: 8%
Long-term outcomes in JDM

• **Sanner, 2009:**
  – Cross-sectional study of patients with JDM in Norway
  – Data obtained from physical exam and chart review
  – Disease activity score (DAS), Myositis damage index (MDI), CHAQ/HAQ
  – 60/67 identified patients participated
    • 4 died
    • 3 declined
  – Median f/u time 16.8 years (range 2 to 38 years)
  – 65% age ≥ 18 years at f/u
Long-term outcomes in JDM

• Sanner, 2009:
  – 90% had disease-related damage (MDI < 1)
  – 61% had active disease with DAS ≥ 3 (range 0-20)
  – Increase in damage (MDI) seen between 1 year post-diagnosis and study visit (P<0.001)
  – Total follow up time correlated with damage
  – 36% reported some disability (HAQ > 0)
Long-term outcomes in JDM

• **Sanner, 2009**
  – Other autoimmune diseases in 15% (N=9)
    • Hypothyroidism (N=3)
    • Psoriasis (N=3)
    • Celiac disease (N=2)
    • Hyperparathyroidism (N=1)
    • Dermatitis herpetiformis (N=1)
    • Uveitis (N=1)
Long-term outcomes in JDM

• Sanner, 2010
  – Case control study based on same cohort
  – Sex- and age-matched healthy controls
  – Study assessed:
    • Muscle strength and endurance (Childhood Myositis Assessment Scale and manual muscle testing)
    • ESR and muscle enzymes (CK, LDH, AST, ALT)
    • Disease activity (DAS) and damage (MDI)
    • Disability (CHAQ/HAQ)
    • MRI of thigh muscles (cases only)
Long-term outcomes in JDM

• Sanner, 2010
  – Muscle weakness common
    • MMT: 42% of cases vs. 2% of controls
    • CMAS: 35% of cases vs. 5% of controls
  – No difference in muscle enzymes or ESR
  – 29% of patients still receiving immunosuppression
  – Damage and inflammation seen on MRI
    • Damage in 52%
    • Inflammation in 9%
  – Significant correlation between weakness and disability (CMAS/HAQ)
Do JDM patients need adult care?

• For most patients... YES
  – Ongoing disease activity
  – Continue to accrue disease damage
  – Continuing need for immunosuppression
  – Risk of additional autoimmune processes
Transition in Rheumatology: How are we doing?

• Scal, 2009:
  – Data from National Survey of Children with Special Health Care Needs
  – Only 50% of teens with JIA reported discussing transition-related issues with their doctor
  – 23% had discussed insurance coverage
  – 19% had discussed transfer to adult provider
Factors Affecting Transition

1. Health systems-level
   – Access to adult providers
   – Maintain health insurance coverage

2. Physician-level
   – Communication between new and old providers

3. Patient-level
   – Decreasing parental oversight
   – Increasing self-management expectations
   – Attitude towards disease, medications
Transition in Rheumatology: Pediatric provider perspectives

• Chira, 2014:
  – Email survey to assess transitional practices
  – 158 U.S. and Canadian pediatric rheumatologists at 74 sites
  – 1/3 of respondents had access to a structured transition program (Canada > U.S.)
  – 1/2 reported having a written transition policy, or using an informal but consistent approach
  – 83% desired rheumatology-specific transition guidelines
Transition in Rheumatology: Pediatric provider perspectives

• Chira, 2014:
  – Barriers to transition:
    • Inadequate training
    • Lack of time or resources
    • No reimbursement for time spent
Transition in Rheumatology: Adult provider perspectives

• Lawson, unpublished
  – Qualitative data from interviews with adult providers
  – Key transition-readiness components:
    • Appropriate age
    • Stable disease
    • Appropriate communication between pediatric and adult providers
    • Self-care competence
Health-systems factors: Understanding insurance at transition

• Title V of the Social Security Act of 1935
  – Children with Special Health Care Needs Program
  – Provides Federal support but administered by states

• Title V programs may have more generous financial eligibility requirements than Medicaid

• Patients covered under public programs may lose coverage between age 18-21
But what about Obamacare?

- Private insurance companies are now REQUIRED to allow young adults to remain on parents’ insurance until age 26
- But... does not apply to young adults whose parents are uninsured or insured via Medicaid
- Many young adults are now eligible to purchase coverage on the health insurance exchanges
Transfer from pediatric to adult rheumatology care is one of MANY simultaneous transitions

- High school to college or work
- Parents’ home to independent living
- Romantic relationships
- Insurance coverage
- New primary care physician
- May move to new part of the state or country
Asking the Experts: Exploring the Self-Management Needs of Adolescents With Arthritis

JENNIFER N. STINSON,1 PATRICIA C. TOOMEY,2 BONNIE J. STEVENS,4 SUSAN KAGAN,3 CIARÁN M. DUFFY,4 ADAM HUBER,5 PETER MALLESON,6 PATRICK J. McGRATH,7 RAE S. M. YEUNG,1 AND BRIAN M. FELDMAN8

- Information/knowledge
- Help with self-management strategies
  - Meaningful interaction with care providers
  - Managing pain
  - Managing emotions
- Social support from peers
How do we support our patients during transition?

• How should we prepare patients for transition?
• What do providers need to know and do?
• How do you know when patients are ready to transition?
• What is the responsibility of the patient, parent, pediatric provider, adult provider, institutions?
Formal Transition Programs

• Increasing focus on providing coordinated services to facilitate transition
  – Government
  – Health care institutions
  – Disease-specific organizations

• Center for Healthcare Transition Improvement (www.gottransition.org)
  – Six Core Elements of Health Care Transition
  – Resources for providers, youth and families
  – Sample documents (i.e. transition policies)
Six Core Elements of Health Care Transition

1. Development of transition policies
2. Creation of transitioning and young adult patient registries to monitor progress and outcomes
3. Transition preparation, including identification of gaps in transition readiness
4. Transition planning, including identification of adult providers and a Transition Action Plan
5. Transfer of care, including communication between providers
6. Transition completion
Got Transition aims to improve transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families.

**News & Announcements**

- **Editorial on Adolescent Engagement and Transition in JAH**
  An editorial on adolescent engagement in the September issue of the Journal of Adolescent Health discusses Got Transition’s new transition readiness assessment tool. [more>](#)

- **Got Transition in the Wall Street Journal!**
  “The Informed Patient” on the cover of the Personal Journal section of today’s Wall Street Journal discusses the transition from pediatric to adult health care, referencing the work of Got Transition. [more>](#)

- **Register Now! Fall Conference on Transition**
  The annual Baylor conference on Transition from Pediatric to Adult-based Care will take place on October 2-3, 2014 in Houston, Texas and will coincide with the Health Care Transition Research Consortium’s 6th Annual Symposium. [more>](#)

- **SAHM Annual Meeting to Focus on Transition**
  The 2015 Annual Meeting for the Society for Adolescent Health and Medicine will take place on March 18-21 in Los Angeles, CA and will focus on the transition to adulthood. [more>](#)

- **Got Transition’s New Home**
  Got Transition has moved to a new home on the JAMA Network website. [more>](#)

**Health Care Providers**

Find out about how to implement health care transition quality improvement in your practice or plan using the new Six Core Elements of Health Care Transition (2.0). Download accompanying clinical resources and measurement tools for use in any setting.

**Youth & Families**

Hear what young adult and parent experts have to say about common transition questions and discover new resources to make this process work easier.

**Researchers & Policymakers**

Find new transition policy developments, research and measurement approaches, and federal and state transition initiatives.
Arthritis Foundation Pediatric Transitions Program

• Designed to address the needs of adolescent patients and families who will transition to adult rheumatology care.

• Pilot program in the Bay Area, with nationwide implementation underway.
The Arthritis Foundation Pediatric Transitions Program

1. Provide young patients with the education and tools they need to successfully transition to adult health care.

2. Prepare pediatric and adult rheumatologists to assist their patients with transition.

3. Create social interactions to facilitate the sharing of young patients’ experiences and provide emotional support.
Welcome to the Arthritis Foundation Transition Toolkit

This website is designed to prepare youth with rheumatic diseases and their families for the transition to healthy adulthood.

Resource Library

Browse for health information and learn useful healthcare skills

LEARN MORE

Transition Toolkit

Test your healthcare skills and build your own Transition Toolkit

BUILD YOUR OWN TOOLKIT
Communicating with your Doctor and Scheduling Appointments

Depression and Anxiety

Finding an Adult Rheumatologist

Getting a Job

Getting Organized and Creating a Health Summary

Going to College

Health Insurance

Juvenile Dermatomyositis

Juvenile Idiopathic Arthritis
The following questions will assess whether you are learning important skills needed to manage your own health care.

START THE ASSESSMENT
Q3 Does your child know what each of his or her medications is for?

- Never
- Sometimes
- Always
Your Transition Toolkit

For Parents and Caregivers

As your child or teen prepares to transition to adulthood, you will want to be informed and involved as well. Your teen will probably need your help with reading and planning. The goal of this toolkit is to help your child build the skills needed to manage his or her health independently. Your guidance and encouragement is an essential part of this process. All good drivers need driver’s education, and you are the driving coaches!

Tips for Preparing your Teen for the Trip to independence

Start early and be positive about the future:

- Focus on your teen’s strengths and skills
- Dream big...encourage being all he or she can be
- Talk with your teen about what he or she wants in the present and the future
- Encourage your teen to express his or her opinions
Outcomes That Matter: Defining Transition Success

• What is “successful” transition?

• Patient measures:
  – Medication adherence
  – Disease control
  – Patient/family satisfaction

• Systems measures:
  – Transfer to adult provider without gaps in care
  – Decreased health care costs
## Do Transition Interventions Work?

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<tr>
<th>Intervention</th>
<th>Outcome</th>
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<tr>
<td>Transition preparation for young adults with DM 1 (Holmes-Walker, 2007)</td>
<td>Improved diabetes control</td>
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<td>Decreased hospital admissions</td>
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<tr>
<td>Transition curriculum in pediatric and adult cystic fibrosis clinic (Okumura, 2014)</td>
<td>Improved transition readiness scores</td>
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<td>Decreased in-hospital transfers to adult care</td>
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<td>“Holistic” transitional care for teens with chronic conditions, addressing medical, social and vocational issues (Shaw, 2013)</td>
<td>Increased patient satisfaction</td>
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Transition in JDM: The take-home

• Many patients with JDM will have ongoing disease into adulthood
• Not all patients are prepared for the transition to adulthood and adult rheumatology care
• Transition is affected by health-system, patient-level and physician-level factors
• Transition preparation may improve patient and systems outcomes
• Resources are available to help you successfully transition your patients
Thank you