Assessing Transition Readiness in Adolescents & Young Adults with IBD:

Progress toward meeting institutional benchmarks of readiness & future opportunities for improvement

Wendy N. Gray, Ph.D.
Auburn University & Cincinnati Children’s Hospital Medical Center
Disclosures

- Career Development Award - Crohn’s and Colitis Foundation of America (CCFA)
  - Development of the Self-Management Transition Program (STEP)
Background

- Inflammatory bowel disease (IBD) is a chronic condition affecting the gastrointestinal tract
  - 25% of IBD cases diagnosed prior to adulthood
  - Mean age at diagnosis: 15 years

- 79% of adult gastroenterologists report inadequacies in patients transferred from pediatrics

- Self-management deficits in adolescents/young adults with IBD
  - 15% managing health independently
Transition Task Force

- Benchmarks for Transition Readiness:
  - 90% mastery of transition readiness skills
  - Mild or quiescent disease
  - Patient has identified a PCP
  - Pediatric staff confidence in transition readiness
Purpose

• Examine transition readiness skill acquisition in adolescents and young adults

• Identify correlates of readiness skill acquisition (age, gender, disease activity, self-efficacy)

• Identify gaps in transition readiness that should be addressed prior to transfer to adult care
Method

• Inclusion criteria:
  • Patient with Crohn’s or colitis
  • Treated at Cincinnati Children’s Hospital Medical Center
  • Age 16 or older

• Data collected through routine clinic appointments
  • Transition Readiness Assessment Questionnaire (Version 5.0)
  • From medical chart:
    • Age
    • Diagnosis
    • Physician Global Assessment
    • Patient and parent confidence rating
Participant Characteristics

- N = 196
- Age
  - M = 18.06 years
  - SD = 1.86
- 53.1% male
- 75.1% Crohn’s Disease
- Disease activity
  - Quiescent = 79.1%
  - Mild = 14.4%
  - Moderate = 6.4%
- Self-efficacy
  - Patient = 8.74 / 10
  - Parent = 8.85 / 10
Results: % pts hitting Benchmark

• Number of patients meeting transition readiness benchmark

<table>
<thead>
<tr>
<th>Pt. Age</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 18</td>
<td>3/86</td>
<td>3%</td>
</tr>
<tr>
<td>≥ 18</td>
<td>8/110</td>
<td>7%</td>
</tr>
</tbody>
</table>

- Meeting Benchmark
- Not meeting Benchmark
Results: Readiness by Age

Number of transition skills acquired by age

# skills mastered

Age
Results: Readiness by Age

Number of transition skills acquired by age

Age vs. # skills mastered graph
Results: Readiness by Gender

- Gender differences in transition readiness (controlling for age)

F(1, 193) = 14.06, p < .001

F(1, 193) = 10.35
F(1, 193) = 7.99
Results: Readiness, disease activity, self-efficacy

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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</thead>
<tbody>
<tr>
<td>1. Number of tasks mastered (TRAQ)</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2. Disease activity (PGA)</td>
<td>-.05</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Self-efficacy (patient)</td>
<td>.14</td>
<td>-.30**</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>4. Self-efficacy (parent)</td>
<td>-.02</td>
<td>-.47**</td>
<td>.50**</td>
<td>-</td>
</tr>
</tbody>
</table>

** p < .01

Transition readiness skill acquisition NOT associated with disease activity or patient/parent-reported self-efficacy.
### Results: What patients do well

<table>
<thead>
<tr>
<th>Skills Patients are Mastering</th>
<th></th>
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<tbody>
<tr>
<td>Answering questions from medical providers</td>
<td>Telling doctor or nurse what you are feeling</td>
</tr>
<tr>
<td>Taking medications correctly and independently</td>
<td>Know what to do when having a bad reaction to medication</td>
</tr>
<tr>
<td>Filling out medical history form including allergies</td>
<td>Arranging for rides for medical appointments</td>
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<tr>
<td>Keeping home/room clean and cleaning up</td>
<td>Utilizing neighborhood stores and services (e.g., grocery, pharmacy)</td>
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<tr>
<td>Helping to plan/prepare meals</td>
<td></td>
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</tbody>
</table>
## Results: Room for improvement

<table>
<thead>
<tr>
<th>Areas to Target in Clinical Care</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>How to apply for health insurance coverage</td>
<td>Knowing what health insurance covers</td>
</tr>
<tr>
<td>Seeking financial help with school/work</td>
<td>Calling doctor about unusual changes in health</td>
</tr>
<tr>
<td>Calling doctor’s office to make an appointment</td>
<td>Following up on referrals for tests or check-ups or labs</td>
</tr>
<tr>
<td>Making a list of questions before the doctor’s visit</td>
<td>Keeping track of medical and other appointments</td>
</tr>
<tr>
<td>Filling a prescription when needed</td>
<td>Reordering medications before they run out</td>
</tr>
</tbody>
</table>
Conclusion

- Few patients on verge of transfer to adult care are meeting our benchmark

- Females are demonstrating more readiness than males, taking age into account

- Readiness not related to disease activity or self-efficacy

- Specific deficits exist in self-management and self-advocacy/health care utilization
Implications

• Critical to address deficits in adolescence

• Deficits observed are all **modifiable behaviors** amenable to intervention

• Routine assessment of transition readiness skills is needed to identify gaps in skills

• Guidance needed for patient and parents in order to build skills
## Healthcare Provider Transitioning Checklist

### Early Adolescence

**New knowledge and responsibilities**

- I can describe my GI condition
- I can name my medications, the amount and times I take them
- I can describe the common side effects of my medications
- I know my doctors' and nurses' names and roles
- I can use and read a thermometer
- I can answer at least 1 question during my health care visit
- I can manage my regular medical tasks at school
- I can call my doctor's office to make or change an appointment
- I can describe how my GI condition affects me on a daily basis

### Mid Adolescence

**Building knowledge and practicing independence**

- I know the names and purposes of the tests that are done
- I know what can trigger a flare of my disease
- I know my medical history
- I know if I need to transition to an adult gastroenterologist
- I reorder my medications and call my doctor for refills
- I answer many questions during a health care visit
- I spend most of my time alone with the doctor during visit
- I understand the risk of medical nonadherence
- I understand the impact of drugs and alcohol on my condition
- I understand the impact of my GI condition on my sexuality

### Health Care Team

- Discuss the idea of visiting the office without parents or guardians in the future
- Encourage independence by performing part of the exam with the parents or guardians out of the examining room
- Begin to provide information about drugs, alcohol, sexuality and fitness
- Establish specific self-management goals during office visit

### Discuss in More Depth:

- The impact of drugs, alcohol and non-adherence on their disease
- The impact of their disease on sexuality, fertility
- Future plans for school/work and impact on health care including insurance coverage
- How eventual transfer of care to an adult gastroenterologist will coordinate with future school or employment plans
<table>
<thead>
<tr>
<th>AGE 17+</th>
<th>PATIENT</th>
<th>HEALTH CARE TEAM</th>
</tr>
</thead>
<tbody>
<tr>
<td>LATE ADOLESCENCE</td>
<td>Taking charge</td>
<td></td>
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<tr>
<td>□ I can describe what medications I should not take because they might interact with the medications I am taking for my health condition</td>
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<tr>
<td>□ I am alone with the doctor or choose who is with me during a health care visit</td>
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<tr>
<td>□ I can tell someone what new legal rights and responsibilities I gained when I turned 18</td>
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<tr>
<td>□ I manage all my medical tasks outside the home (school, work)</td>
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<tr>
<td>□ I know how to get more information about IBD</td>
<td></td>
<td></td>
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<tr>
<td>□ I can book my own appointments, refill prescriptions and contact medical team</td>
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<tr>
<td>□ I can tell someone how long I can be covered under my parents’ health insurance plan and what I need to do to maintain coverage for the next 2 years</td>
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<tr>
<td>□ I carry insurance information (card) with me in my wallet/purse/backpack.</td>
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<tr>
<td>□ Remind patient and family that at age 18 the patient has the right to make his or her own health choices</td>
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<tr>
<td>□ Develop specific plans for self-management outside the home (work/school)</td>
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<tr>
<td>□ Provide the patient with a medical summary for work, school or transition</td>
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<tr>
<td>□ Discuss plans for insurance coverage</td>
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<tr>
<td>□ If transitioning to an adult subspecialist, provide a list of potential providers and encourage/facilitate an initial visit.</td>
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Acknowledgements

• Erin Holbrook, MSW, LSW
• Pamela Morgan, BSN, RN
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• Lee Denson, MD
• Kevin Hommel, PhD
Questions/Comments welcomed!
**Transition Readiness Assessment Questionnaire 5.0**

**Directions:** Please check the box that best describes your skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

<table>
<thead>
<tr>
<th></th>
<th>No, I do not know how</th>
<th>No, but I want to learn</th>
<th>Yes, I am learning to do this</th>
<th>Yes, I started doing this</th>
<th>Yes, I always do this when I need to</th>
</tr>
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<tr>
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<td>1</td>
<td>2</td>
<td>3</td>
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<td>5</td>
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</table>

**Managing Medications**
1. Do you fill a prescription if you need to?
2. Do you know what to do if you are having a bad reaction to your medications?
3. Do you take medications correctly and on your own?
4. Do you reorder medications before they run out?

**Appointment Keeping**
5. Do you call the doctor’s office to make an appointment?
6. Do you follow-up on any referral for tests or check-ups or labs?
7. Do you arrange for your ride to medical appointments?
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?
9. Do you apply for health insurance if you lose your current coverage?
10. Do you know what your health insurance covers?
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?

**Tracking Health Issues**
12. Do you fill out the medical history form, including a list of your allergies?
13. Do you keep a calendar or list of medical and other appointments?
14. Do you make a list of questions before the doctor’s visit?
15. Do you get financial help with school or work?

**Talking with Providers**
16. Do you tell the doctor or nurse what you are feeling?
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?

**Managing Daily Activities**
18. Do you help plan or prepare meals/food?