

Assessing Transition Readiness in Adolescents & Young Adults with IBD:

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

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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

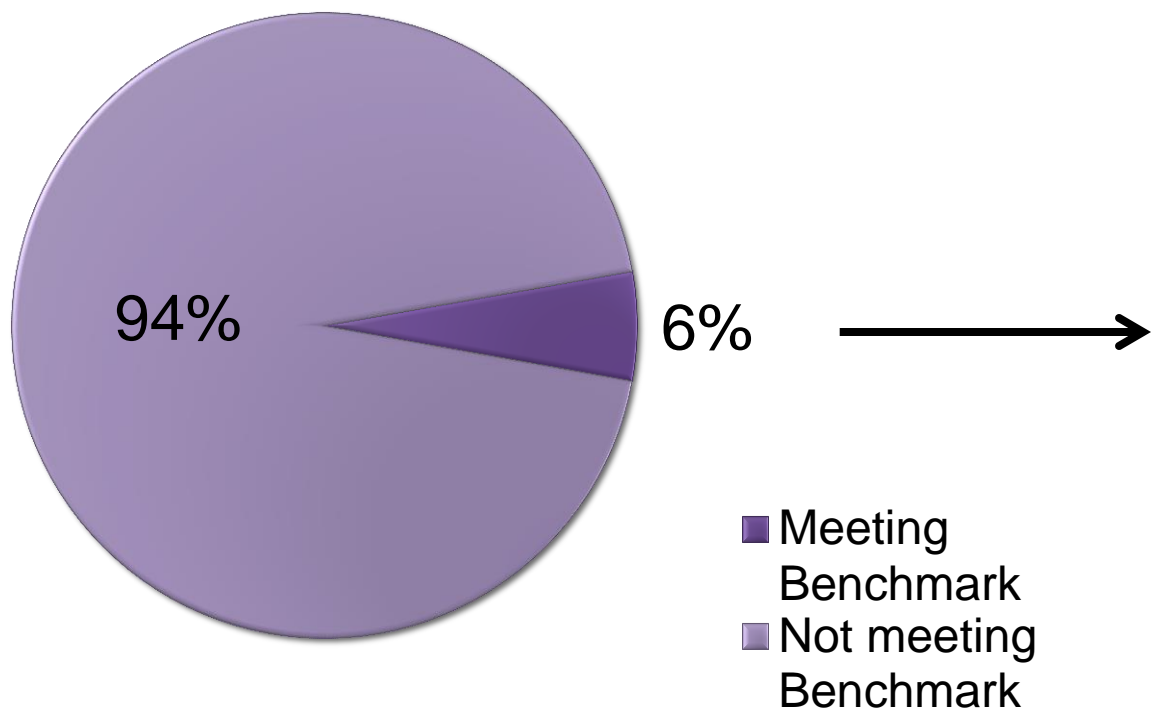
- N = 196
- Age
 - M = 18.06 years
 - SD = 1.86
- 53.1% male
- 75.1% Crohn's Disease
- Disease activity
 - Quiescent = 79.1%
 - Mild = 14.4%
 - Moderate = 6.4%



- Self-efficacy
 - Patient = 8.74 / 10
 - Parent = 8.85 / 10

Results: % pts hitting Benchmark

- Number of patients meeting transition readiness benchmark

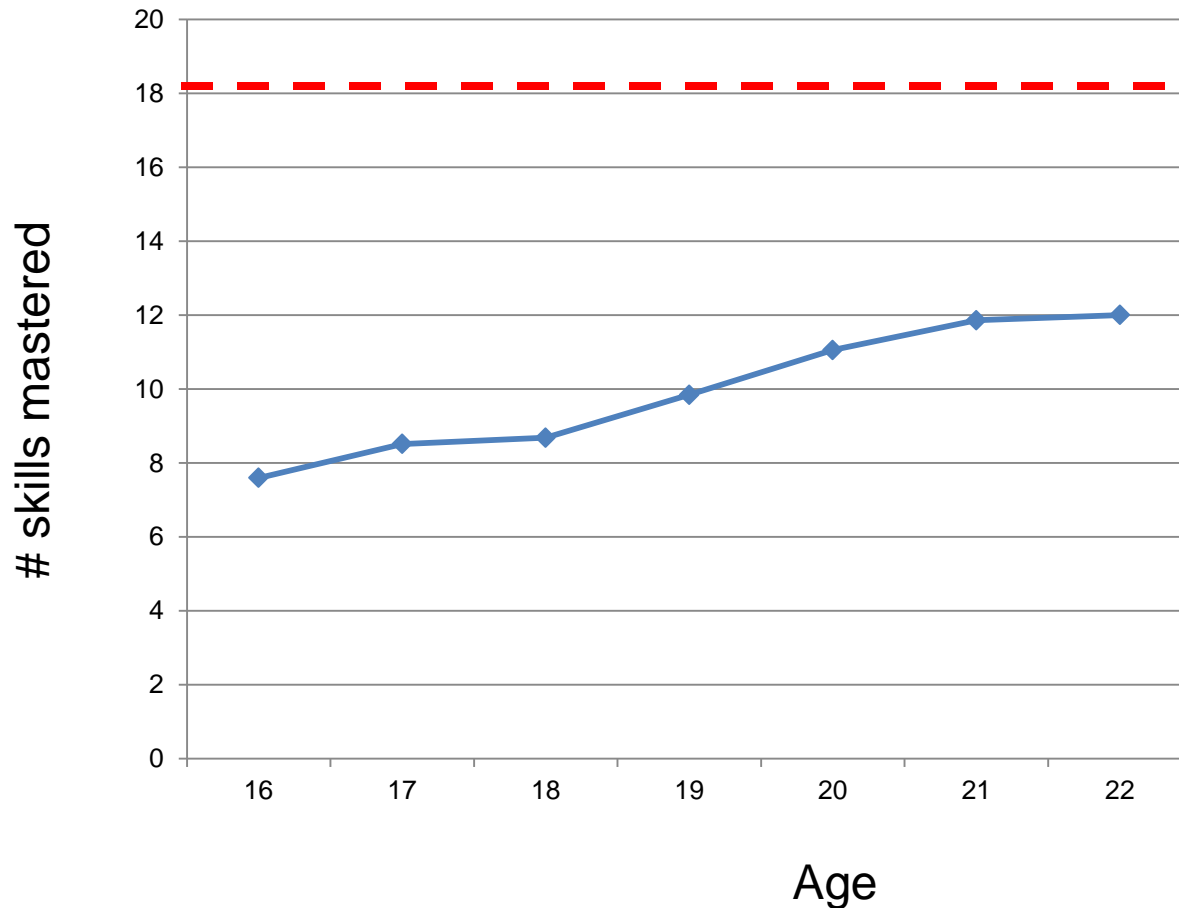


meeting benchmark

| Pt. Age | N | % |
|---------|-------|----|
| < 18 | 3/86 | 3% |
| ≥ 18 | 8/110 | 7% |

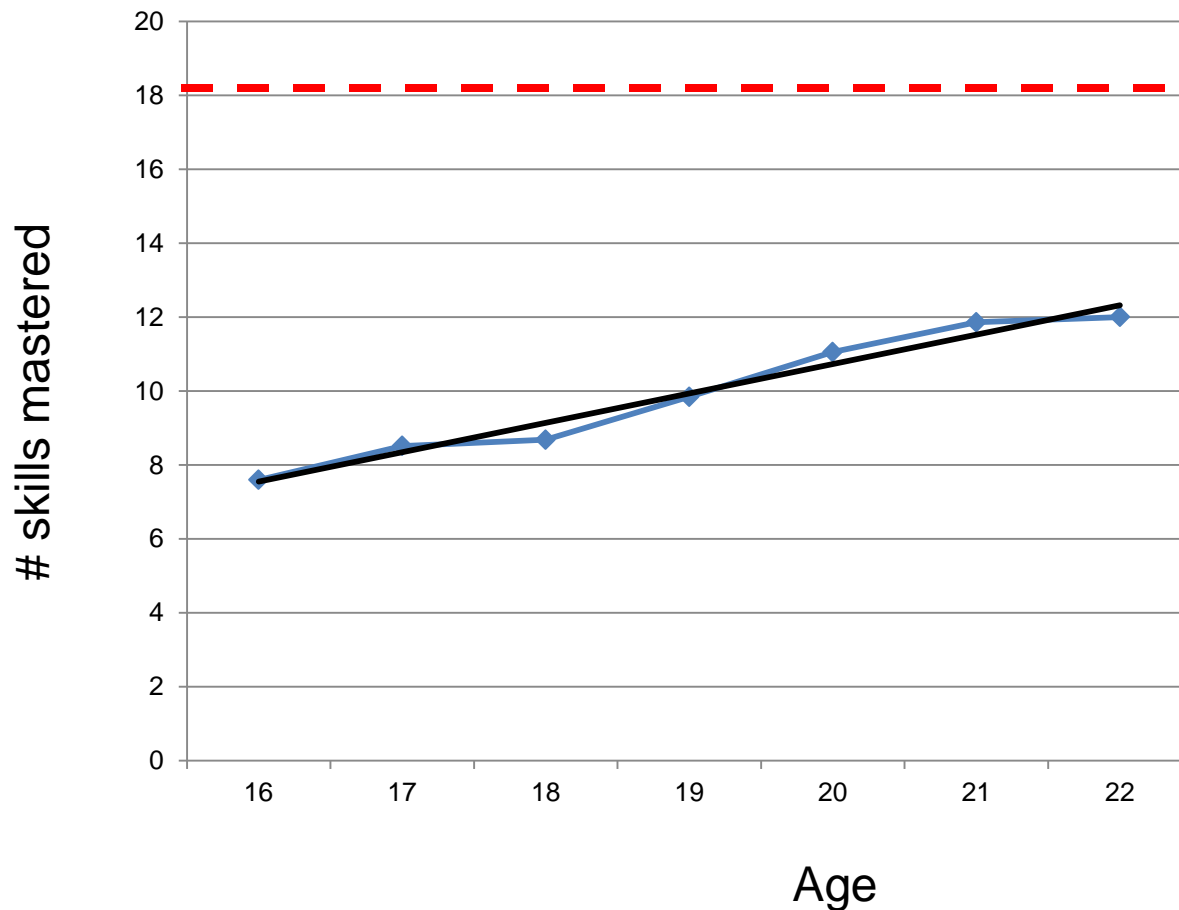
Results: Readiness by Age

Number of transition skills acquired by age



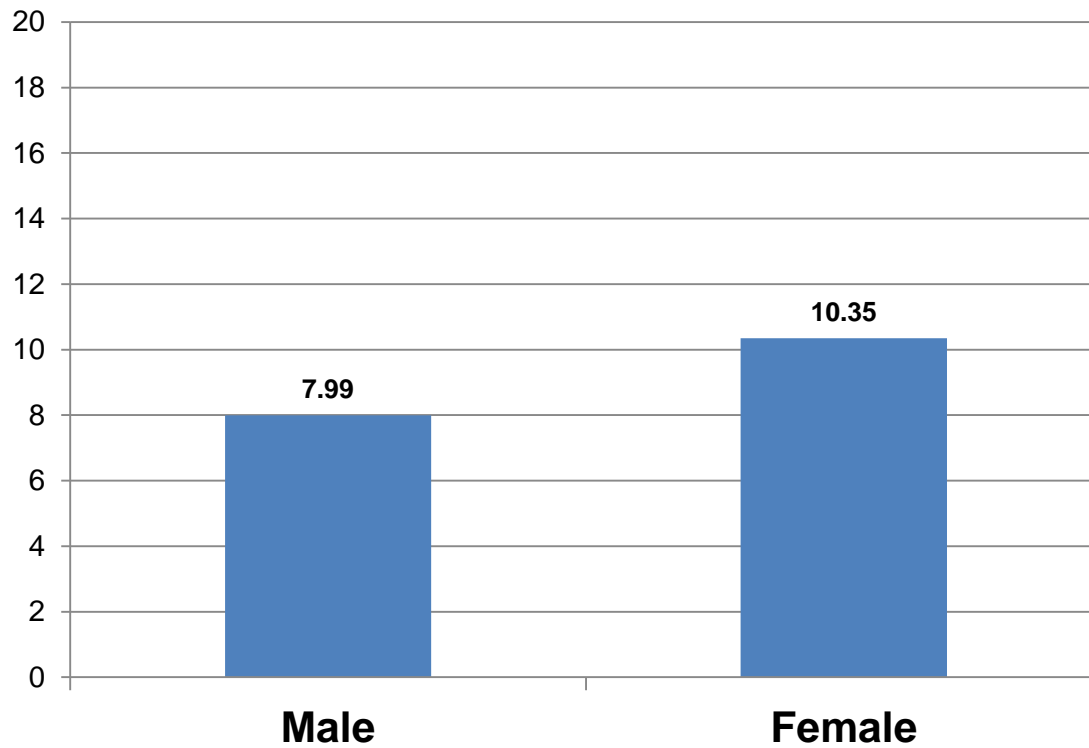
Results: Readiness by Age

Number of transition skills acquired by age



Results: Readiness by Gender

- Gender differences in transition readiness (controlling for age)



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

Results: Readiness, disease activity, self-efficacy

| | 1 | 2 | 3 | 4 |
|------------------------------------|------|--------|-------|---|
| 1. Number of tasks mastered (TRAQ) | - | | | |
| 2. Disease activity (PGA) | -.05 | - | | |
| 3. Self-efficacy (patient) | .14 | -.30** | - | |
| 4. Self-efficacy (parent) | -.02 | -.47** | .50** | - |

** $p < .01$

Transition readiness skill acquisition NOT associated with disease activity or patient/parent-reported self-efficacy.

Results: What patients do well

Skills Patients are Mastering

Answering questions from medical providers

Telling doctor or nurse what you are feeling

Taking medications correctly and independently

Know what to do when having a bad reaction to medication

Filling out medical history form including allergies

Arranging for rides for medical appointments

Keeping home/room clean and cleaning up

Utilizing neighborhood stores and services (e.g., grocery, pharmacy)

Helping to plan/prepare meals

Results: Room for improvement

Areas to Target in Clinical Care

How to apply for health insurance coverage

Knowing what health insurance covers

Seeking financial help with school/work

Calling doctor about unusual changes in health

Calling doctor's office to make an appointment

Following up on referrals for tests or check-ups or labs

Making a list of questions before the doctor's visit

Keeping track of medical and other appointments

Filling a prescription when needed

Reordering medications before they run out

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

| AGE | PATIENT | HEALTH CARE TEAM |
|--------------|---|---|
| 12-14 | <p>EARLY ADOLESCENCE <i>New knowledge and responsibilities</i></p> <ul style="list-style-type: none"> <input type="checkbox"/> I can describe my GI condition <input type="checkbox"/> I can name my medications, the amount and times I take them <input type="checkbox"/> I can describe the common side effects of my medications <input type="checkbox"/> I know my doctors' and nurses' names and roles <input type="checkbox"/> I can use and read a thermometer <input type="checkbox"/> I can answer at least 1 question during my health care visit <input type="checkbox"/> I can manage my regular medical tasks at school <input type="checkbox"/> I can call my doctor's office to make or change an appointment <input type="checkbox"/> I can describe how my GI condition affects me on a daily basis | <ul style="list-style-type: none"> <input type="checkbox"/> Discuss the idea of visiting the office without parents or guardians in the future <input type="checkbox"/> Encourage independence by performing part of the exam with the parents or guardians out of the examining room <input type="checkbox"/> Begin to provide information about drugs, alcohol, sexuality and fitness <input type="checkbox"/> Establish specific self-management goals during office visit |
| 14-17 | <p>MID ADOLESCENCE <i>Building knowledge and practicing independence</i></p> <ul style="list-style-type: none"> <input type="checkbox"/> I know the names and purposes of the tests that are done <input type="checkbox"/> I know what can trigger a flare of my disease <input type="checkbox"/> I know my medical history <input type="checkbox"/> I know if I need to transition to an adult gastroenterologist <input type="checkbox"/> I reorder my medications and call my doctor for refills <input type="checkbox"/> I answer many questions during a health care visit <input type="checkbox"/> I spend most of my time alone with the doctor during visit <input type="checkbox"/> I understand the risk of medical nonadherence <input type="checkbox"/> I understand the impact of drugs and alcohol on my condition <input type="checkbox"/> I understand the impact of my GI condition on my sexuality | <ul style="list-style-type: none"> <input type="checkbox"/> Always focus on the patient instead of the parents or guardians when providing any explanations and <input type="checkbox"/> Allow the patient to select when the parent or guardian is in the room for the exam <input type="checkbox"/> Inform the patient of what the parent or guardian must legally be informed about with regards to the patient condition <input type="checkbox"/> Discuss the importance of preparing the patient for independent status with the parents or guardian and address any anxiety they may have <input type="checkbox"/> Continue to set specific goals which should include: <ul style="list-style-type: none"> • Filling prescriptions and scheduling appointments • Keeping a list of medications and medical team contact information in wallet and backpack <p>DISCUSS IN MORE DEPTH:</p> <ul style="list-style-type: none"> <input type="checkbox"/> The impact of drugs, alcohol and non adherence on their disease <input type="checkbox"/> The impact of their disease on sexuality, fertility <input type="checkbox"/> Future plans for school/work and impact on health care including insurance coverage. <input type="checkbox"/> How eventual transfer of care to an adult gastroenterologist will coordinate with future school or employment plans |

AGE

17+

PATIENT

LATE ADOLESCENCE

Taking charge

- I can describe what medications I should not take because they might interact with the medications I am taking for my health condition
- I am alone with the doctor or choose who is with me during a health care visit
- I can tell someone what new legal rights and responsibilities I gained when I turned 18
- I manage all my medical tasks outside the home (school, work)
- I know how to get more information about IBD
- I can book my own appointments, refill prescriptions and contact medical team
- 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 .
- I carry insurance information (card) with me in my wallet/purse/backpack.

HEALTH CARE TEAM

- Remind patient and family that at age 18 the patient has the right to make his or her own health choices
- Develop specific plans for self-management outside the home (work/school)
- Provide the patient with a medical summary for work, school or transition
- Discuss plans for insurance coverage
- If transitioning to an adult subspecialist, provide a list of potential providers and encourage/facilitate an initial visit.

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**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.

| | No, I do not know how | No, but I want to learn | Yes, I am learning to do this | Yes, I started doing this | Yes, I always do this when I need to |
|---|-----------------------------|-------------------------------|--|---------------------------------|---|
| | 1 | 2 | 3 | 4 | 5 |
| 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? | | | | | |