Transitioning Care from Pediatric to Adult Gastroenterologists

Colleen LeBlanc, MD

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Disclosures

- none

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Objectives

- Understand what is transitioning and the background issues that go into transitioning
- Learn ways pediatric GIs can prepare patients for a successful transition, specifically in IBD
- Review the different models of coordinating transition care in IBD

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What is Transitioning

- Transition is the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems
  - Characterized by uninterrupted, coordinated, comprehensive care with attention to the clinical, psychosocial and educational/vocational needs of adolescent and young adult patients

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Blum, 1993; Fu, 2022

Transitioning vs Transfer

- Transition should be a gradual process that allows the adolescent or young adult to acquire the skills and knowledge they need to assume full responsibility of their health care
- Verses thinking of it as a transfer which is a one time event

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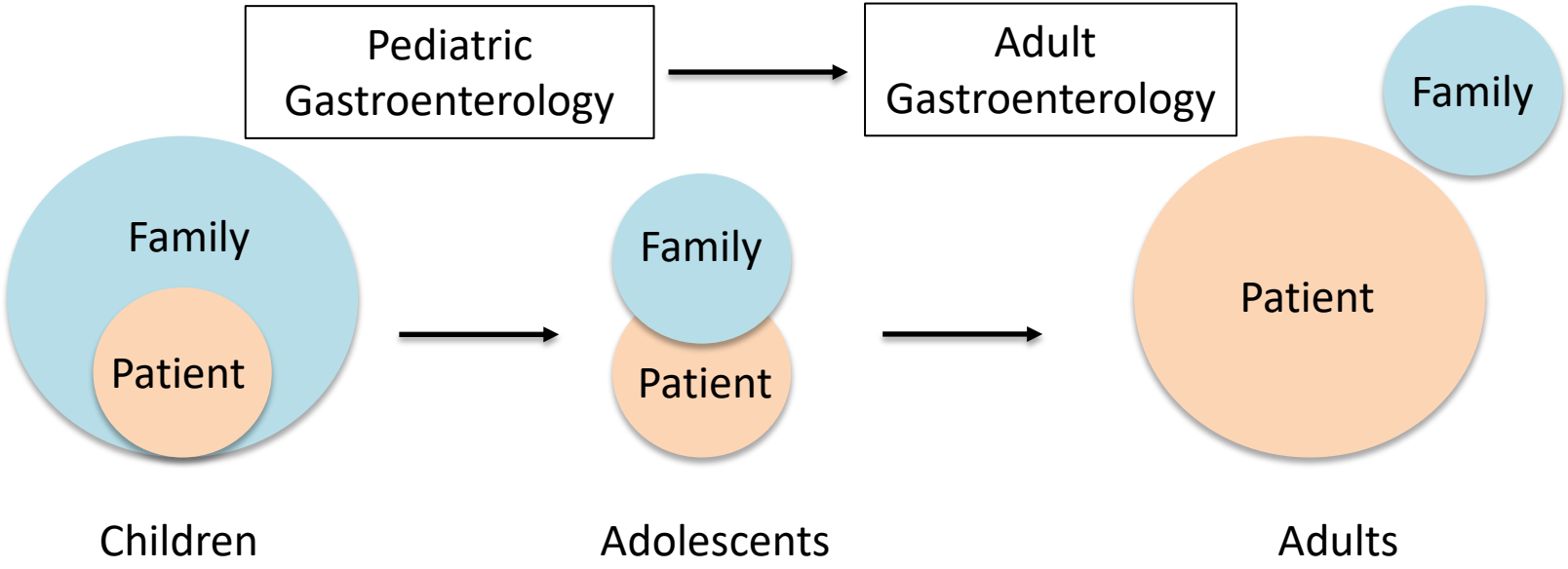
There are 2 transitions happening at the same time



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Why is transitioning important?

- Failed transition and transfer is associated with:
  - Increased emergency department visits
  - Hospitalization
  - Medication escalation
  - Surgery
  - Overall poor patient adherence and attitude

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Fu, 2022

Emotional Issues with Transitioning

- Ped GIs “baby” their patients
- Adult GIs can be more “strict”
- Parents not ready to “let go”
- Childrens Hospitals vs Adult Hospitals

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Logistic Issues with Transitioning

- Is there an adult provider that:
  1. Is willing to see my patient/their condition?
  2. Is convenient for my patient to get to?
  3. Will they take my patients insurance?
- When is the right time to transition?

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What's the Diagnosis

- Will the child require transition to a larger academic center with subspecialists (IBD, liver transplant, short gut/TPN, genetic disorders like VACTERL, chronic tube feedings)

- Will a private outpatient practice be adequate

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IBD transitioning

- 1.5 million Americans with IBD
  - 30% of CD and 20% UC patients have disease onset before age 20
  - Estimated prevalence in pediatrics in the US is 10,000 new cases annually

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Afzali, 2017

Pediatric vs Adult IBD

- Pediatric patients with IBD normally present with more severe disease phenotype
  - Pancolitis in UC, extensive ileocolonic involvement in CD, perianal disease, stricturing disease, malnutrition, growth failure
  - Mental health disorders and low self-esteem are more common in pediatric IBD then other chronic pediatric health conditions

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Afzali, 2017

Preparing for transition

- No ideal IBD transition model has been identified
- Checklists have been developed to help guide and start the process and assess readiness at each encounter

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But what do Adult GI's want

- 2009 survey of Adult GI providers felt that pediatric IBD patients had deficiencies in their knowledge of disease, medical history and medications
- They also felt that there needed to be improved communication from the patient's previous pediatric provider
- They also felt less competent in their own knowledge of adolescent development and mental health issues even though most felt these are very important to overall care

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Hait, 2009

What are NASPGHAN's recs?

1. See the adolescent patient alone in clinic to build independence
2. Introduce the idea of transition early on
3. Select an experienced adult GI provider as the next physician
4. Provide all appropriate records to that adult provider

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Baldassano, 2002

Canadian Consensus Statements on Transitioning

- Released more recently in 2022
- 15 total consensus statements, but 9 with strong recommendations

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Canadian Consensus Statements on Transitioning

1. All AYA with pediatric-onset IBD should attend a structured transition program.

2. Transition programming should be structured according to the local resources and should reflect input from local key stakeholders.

3. A pediatric to adult IBD transition of care program should implement strategies for parents/guardians to support and encourage the development of independence in AYAs.

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Canadian Consensus Statements on Transitioning

4. HCP training programs should integrate training in transition and create opportunities for related knowledge and skill development.

5. Patients with pediatric onset IBD undergoing transition of care to adult services should have access to a primary care provider.

6. The timing of care transfer to adult services should be flexible. Strategies should be implemented to optimize communication during the handover process between pediatric and adult IBD health care providers.

Canadian Consensus Statements on Transitioning

7. Transfer of care documents should be prepared by the pediatric team. These should include a transfer letter summarizing the individualized transition plan and a concise review of the patient's medical history. Relevant supporting records should be included.

8. The adult team engaged in a structured pediatric to adult IBD transition program should prioritize care delivery to transitioning AYAs.

9. The pediatric and adult IBD transition teams should review the processes and structure of adult health care with AYAs and parents/guardians. The adult IBD transition team should establish expectations and goals with the AYAs and parents/guardians.

Fu, 2022

NASPGHAN Transition Checklist

AGE	PATIENT	HEALTH CARE TEAM
12-14	**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	☐ 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

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AGE	PATIENT	HEALTH CARE TEAM

14-17

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

- ☐ Always focus on the patient instead of the parents or guardians when providing any explanations and
- ☐ Allow the patient to select when the parent or guardian is in the room for the exam
- ☐ Inform the patient of what the parent or guardian must legally be informed about with regards to the patient condition
- ☐ Discuss the importance of preparing the patient for independent status with the parents or guardian and address any anxiety they may have
- ☐ Continue to set specific goals which should include:
  - Filling prescriptions and scheduling appointments
  - Keeping a list of medications and medical team contact information in wallet and backpack

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

AGE	PATIENT	HEALTH CARE TEAM

17+

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.

- ☐ 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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Provider Self-management Tool

Patient Name:		MRN:	Date:
Age:	Insurance:	Transition to:	
Plans after High School: (=/>15 years)			

Transition to Self-Management Scale for Adolescents and Young Adults with IBD

Your Disease:	Yes	Some	No
1. Can you tell me what your diagnosis is?	1	.5	0
2. Can you tell me what part of your body is affected?	1	.5	0
3. Can you tell me what symptoms you watch for every day?	1	.5	0
Sum all scores for this section			
Sum of scores possible			

Your Medications:	>90% right	51-90% right	<50% right
1. Can you tell me the names of your medicines?	1	.5	0
2. Can you tell me the doses of your medicines?	1	.5	0
3. Can you tell me how many times each day you take your medicines?	1	.5	0
4. Can you tell me what your medicines are for?	1	.5	0
5. Can you tell me safety information about your medicines?	1	.5	0
Sum all scores for this section			
Sum of scores possible			

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Adapted from *UNC TRxANSITION Scale*

Nutrition:	Yes	Some	No
1. Do you know how to read nutrition labels to see if a food or drink is a healthy choice?	1	.5	0
2. Do you have any vitamin or food/ drink supplements you are supposed to take each day?	1	.5	0
3. If so, do you know what these supplements are for?	1	.5	0
4. What should you change about your diet if you are having a flare?	1	.5	0
Sum all scores for this section:			
Sum of scores possible			

Keeping up with it all:	Yes	Some	No
1. Have you missed a full day of medicine in the past two weeks?	0	.5	1
2. Do you have trouble remembering at least some of your medicines every day?	0	.5	1
3. Does someone have to remind you to take your medicines?	0	.5	1
4. Do you keep up with when your medicines need to be refilled?	1	.5	0
5. Do you pick up your own prescriptions?	1	.5	0
6. Do you come to your scheduled doctor appointments?	1	.5	0
7. If you can't come to an appointment, do you call in advance to cancel and reschedule?	1	.5	0
8. Do you keep up with your own insurance card?	1	.5	0
9. Do you call your doctor's office when you have a question about your health?	1	.5	0
Sum all scores for this section			
Sum of scores possible			

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Safety:	I know/ Yes	I know a little	I don't know/ No
1. Do you know what might happen to your disease if you were to become pregnant ? (females only)	1	.5	0
2. Do you know how your medications could affect an unborn baby if you: - Were to become pregnant, or - Were to get someone pregnant?	1	.5	0
3. Do you know how to keep from becoming/getting someone pregnant?	1	.5	0
4. What do you do to keep yourself safe from sexually transmitted diseases and do you practice what you know?	1	.5	0
5. Do you use alcohol or recreational drugs in an unsafe way?	0	na	1
6. Do you know what can happen to you if you use alcohol or recreational drugs because of your disease and/or the medications you take for your disease?	1	.5	0
Sum all scores for this section			
Sum of scores possible			

Goal score for next visit:_____

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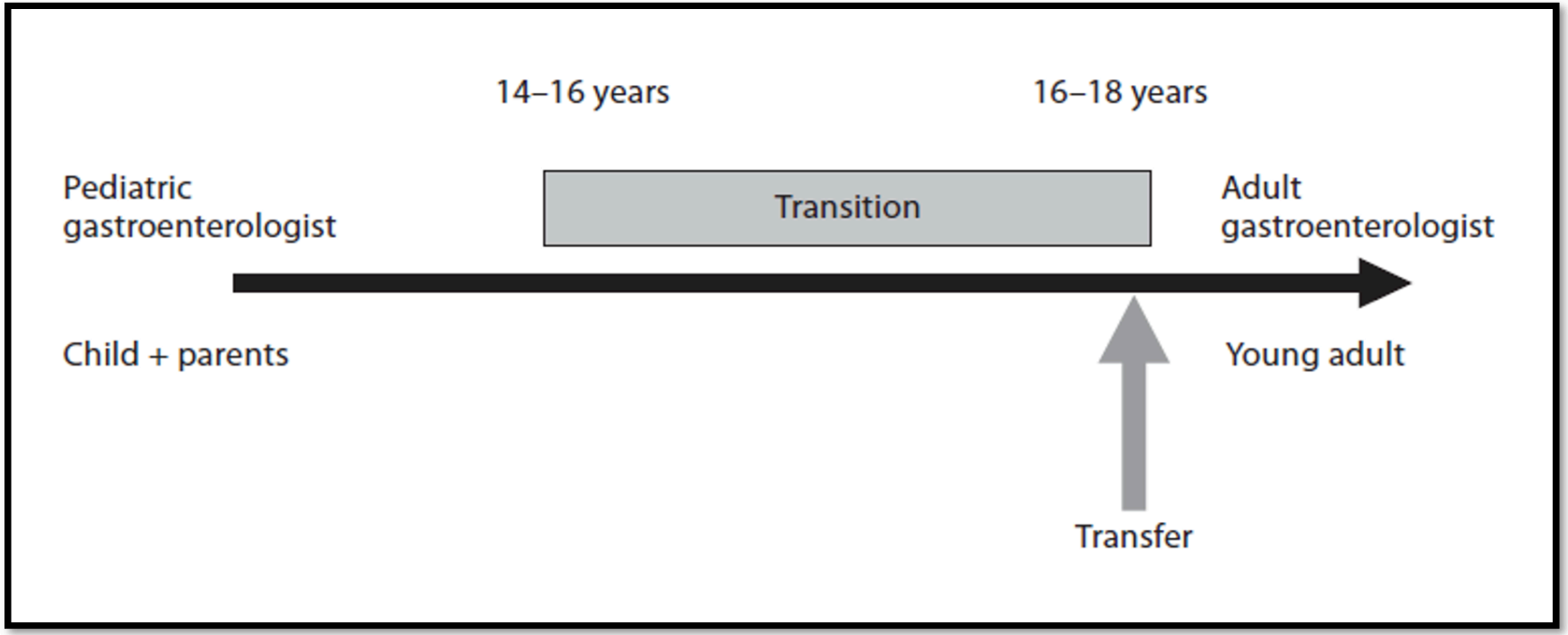
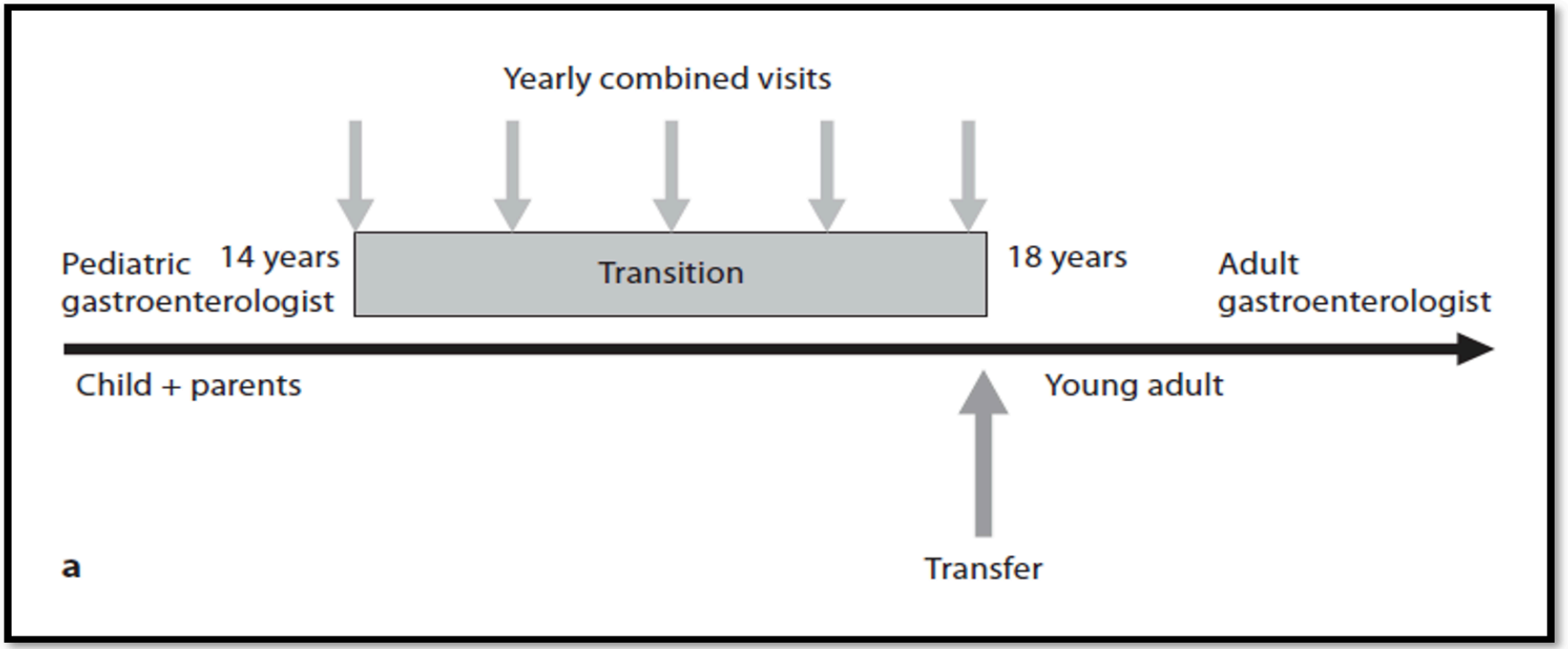
Transition Models



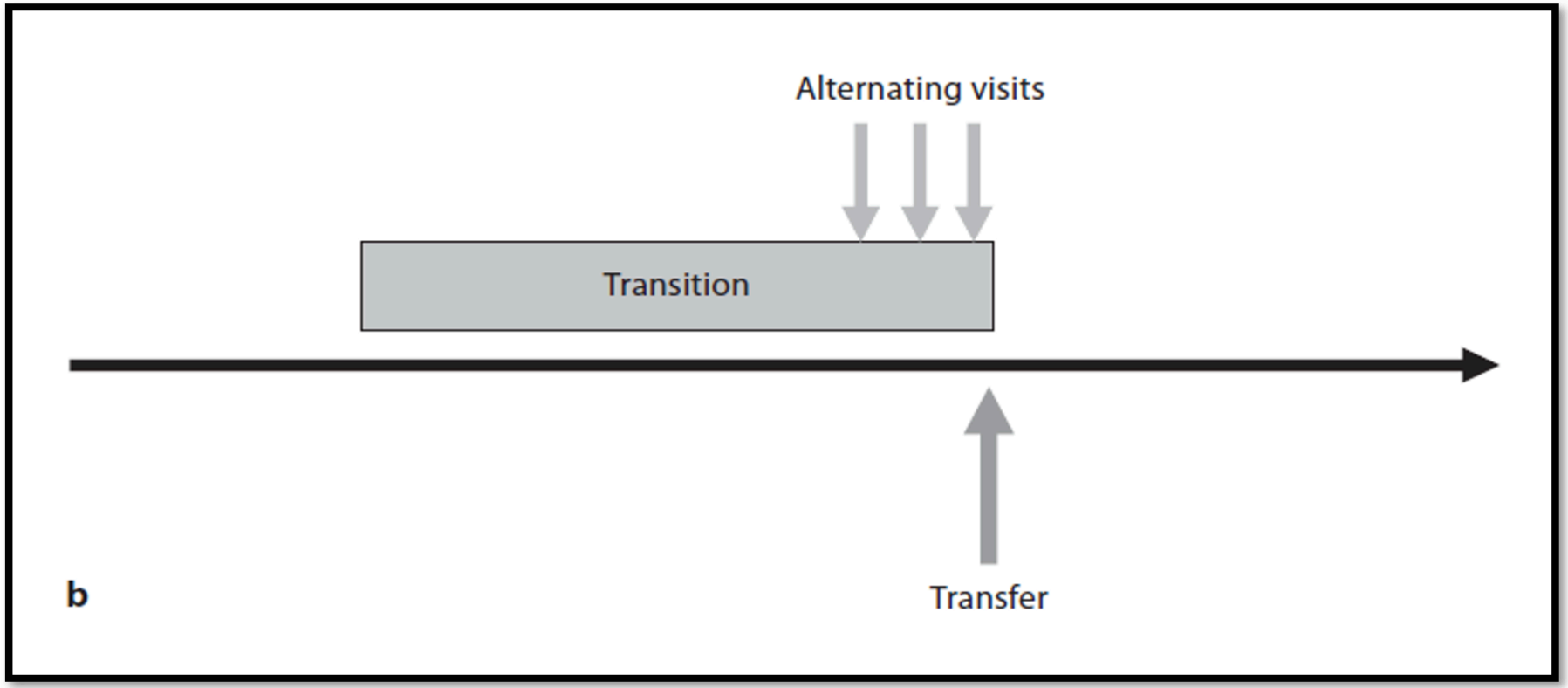
Escher, 2009

Transition Models



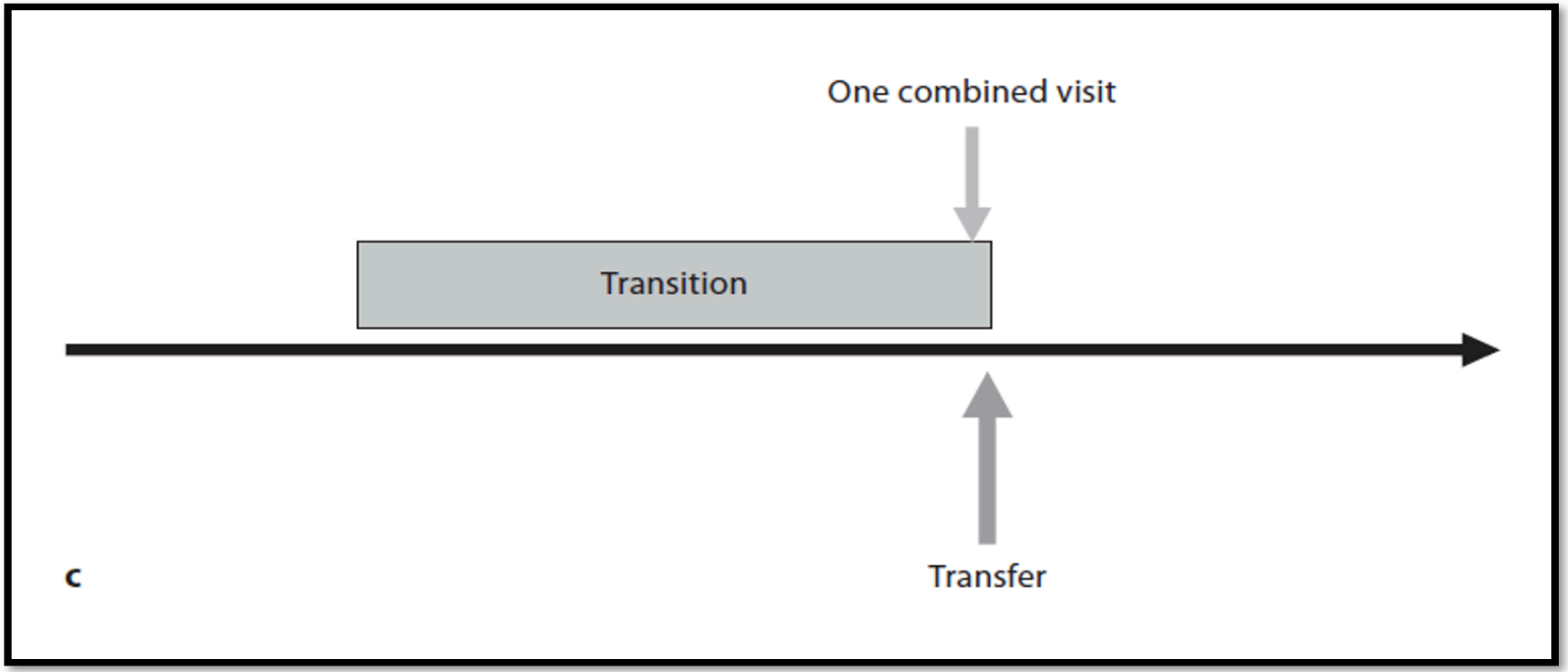
Escher, 2009

Transition Models



Escher, 2009

Transition Models

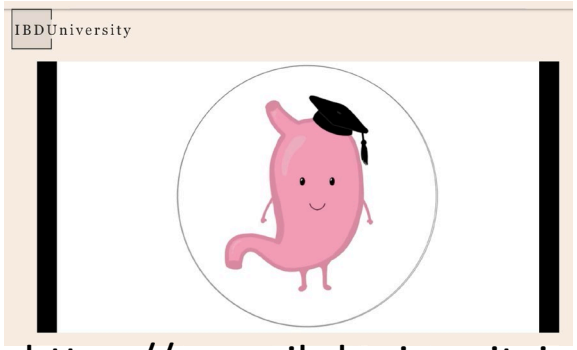


Escher, 2009

Doc4me

got transition®

https://www.gottransition.org/



https://www.ibduniversityinc.org/

SMART

SMART - IBD

My IBD Care

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Final Thoughts

- Transitioning is a gradual process
- Patients (and parents) need to be well prepared for their final transfer of care
- Developing a network of colleagues for transitioning is important for success

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