Pediatric to Adult Transition of Care in IBD

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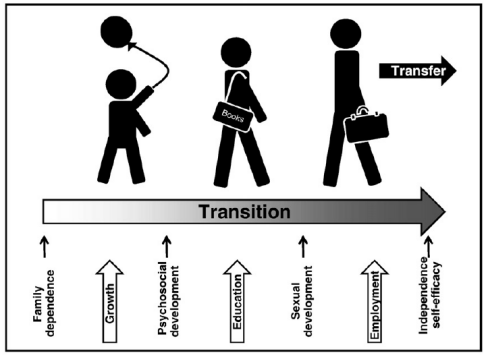

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OAG GAMIFICATION

Bollegala - Game Code:

COCOA

CanMEDS Roles Covered

X	**Medical Expert** (as *Medical Experts*, physicians integrate all of the CanMEDS Roles, applying medical knowledge, clinical skills, and professional values in their provision of high-quality and safe patient-centered care. *Medical Expert* is the central physician Role in the CanMEDS Framework and defines the physician's clinical scope of practice.)
	Communicator (as *Communicators*, physicians form relationships with patients and their families that facilitate the gathering and sharing of essential information for effective health care.)
X	**Collaborator** (as *Collaborators*, physicians work effectively with other health care professionals to provide safe, high-quality, patient-centred care.)
X	**Leader** (as *Leaders*, physicians engage with others to contribute to a vision of a high-quality health care system and take responsibility for the delivery of excellent patient care through their activities as clinicians, administrators, scholars, or teachers.)
X	**Health Advocate** (as *Health Advocates*, physicians contribute their expertise and influence as they work with communities or patient populations to improve health. They work with those they serve to determine and understand needs, speak on behalf of others when required, and support the mobilization of resources to effect change.)
	Scholar (as *Scholars*, physicians demonstrate a lifelong commitment to excellence in practice through continuous learning and by teaching others, evaluating evidence, and contributing to scholarship.)
	Professional (as *Professionals,* physicians are committed to the health and well-being of individual patients and society through ethical practice, high personal standards of behaviour, accountability to the profession and society, physician-led regulation, and maintenance of personal health.)

Disclosures

Company	Speaking Fees	Advisory Board	Research Support
Janssen	x	x	
Pfizer	x	x	x
Takeda	x	x	
Abbvie	x	x	

Objectives

- To review current literature in the transition of young adults from pediatric to adult care in IBD
- To discuss current approaches to improving the quality of care for young adults with pediatric onset IBD
  - The Canadian Guidelines for Pediatric to Adult Transition of care in IBD

Introduction

Childhood Onset Chronic Diseases in Gastroenterology:

- IBD (~20%) - Canada has amongst the highest rates of pediatric onset Crohn's Disease in the world
- Other gastrointestinal diseases: Celiac Disease, Eosinophilic GI Disorders, Liver Disease including Liver Transplant

Transfer of care to an adult gastroenterologist in Ontario usually occurs at age 18

Pediatric healthcare systems are significantly different from adult healthcare systems

- **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*"
  - Transition focuses on patient education and the development of necessary skills to independently and successfully manage chronic disease in a new and unfamiliar setting.

R. W. Blum, D. Dale Garell, C. H. Hodgman et al., "Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine," *Journal of Adolescent Health*, vol. 14, no. 7, pp. 570–576, 1993.

Goals of a Transition Program

- To provide age and developmentally appropriate medical care
- Focus on communication and collaborative decision-making
- Promote continuity of care
- Improve treatment adherence and disease knowledge
- Build confidence in the new adult healthcare team
- Improve or maintain disease control and quality of life
- Encourage independent disease management and self-advocacy within the healthcare system

The Transition Gap

- There is NO established standard of care for transitioning adolescents with IBD in Canadian IBD centers
  - There is no consensus on which transition skills to develop, how to institute a curriculum, how to assess these skills, who would constitute the transition team
  - There is limited funding and access to multi-disciplinary supports, especially in adult IBD care

Characterizing the Standard of Care

Paediatric to Adult Transition of Care in IBD: Understanding the Current Standard of Care Among Canadian Adult Academic Gastroenterologists

Noor Jawaid, MD, FRCPC[1], Thurarshen Jeyalingam, MD, FRCPC[2], Geoffrey Nguyen, MD, PhD, FRCPC, AGAF[2,3], Natasha Bollegala, MD, MSc, FRCPC[2,4]

Journal of the Canadian Association of Gastroenterology, 2019, XX(XX), 1–8

- Aim: To establish the current standard of care across Canada amongst adult GI
- Methods:
  - Transition oriented adult academic gastroenterologists practicing in large urban centers and receiving significant volumes of transition patients were targeted
  - 9 adult GI centers across 6 provinces were sampled
  - 25 anonymous surveys distributed, 17 semi-structured interviews conducted

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Characterizing the Standard of Care

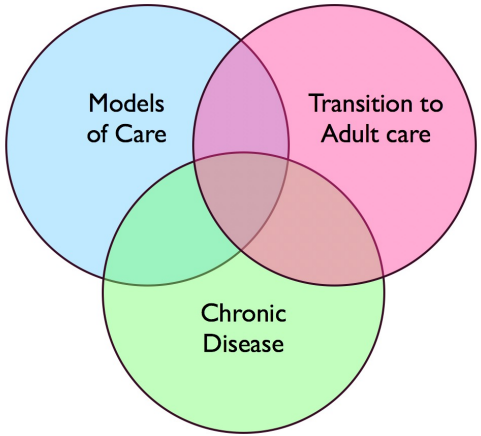
- Results:
  - Most transition patients referred to academic centers
  - Transition practices - transition clinic (n=4) vs direct transfer (n=5)
  - Transfer volume 12-100/year
  - Transfer of information was optimized with a shared EMR and comprehensive referral package
  - Lack of access to a multi-disciplinary team considered a challenge
  - The strongest attributes of a transition program: HCP interest, complete information transfer
  - Areas for quality improvement: increased resource allocation, consensus-based guidance
  - Suggested transition-specific quality indicators: treatment adherence, depression/anxiety scores, disease knowledge

Models of Pediatric-to-Adult Care Transition in Complex Chronic Disease:

A Systematic Review of Transition Interventions

Marani H, Fujioka J, Tabatabavakili S, Bollegala N. Children and youth services review; 2020;118.

- **Aim:** To review models of care in a population of adolescents with pediatric onset chronic diseases as they are transferred to adult health services.
- **Methods:**



1. Transition to Adult Care/
2. Adolescent/ or Young Adult/ or Pediatrics/ or (adolescen* or teen* or juvenile or youth or young person or young persons or young person's or young people or young adult or young adults or emerging adult or p?ediatric*).ti,ab,kf.
3. Adolescent Health Services/
4. Adolescent Medicine/
5. 2 OR 3 OR 4
6. Patient Transfer/
7. Continuity of patient care/
8. Transitional Care/
9. (transition* adj10 (care or service* or center* or centre* or clinic or clinics or facilit* or unit or units or department* or patient* or adult* or healthcare)).ti,ab,kf.
10. (transfer* adj10 (care or service* or center* or centre* or clinic or clinics or facilit* or unit or units or department* or patient* or adult* or healthcare)).ti,ab,kf.
11. Clinical handover/
12. ((Hand-off or handoff or hand off or handover or hand-over or hand over) adj10 (adult*)).ti,ab,kf.
13. 6-12/OR
14. (adult* adj10 (care or service* or center* or centre* or clinic or clinics or facility* or unit or units or hospital* or department* or patient* or medicine or healthcare)).ti,ab.
15. 5 AND 13 AND 14
16. 1 OR 15

Limits
NOT exp animals/ not humans/
NOT autobiography, bibliography, biography, comment, editorial, historical article, letter, news, newspaper article, video-audio media, webcasts

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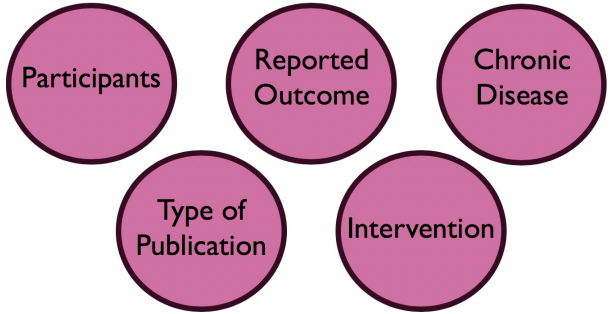
Models of Pediatric-to-Adult Care Transition in Complex Chronic Disease

Database	Time Period	Results
Ovid Medline	1946 to present	3385
Ovid Embase	1947 to July 3, 2018	3442
PubMed, non-medline and publications ahead of print	To July 4, 2018	439
CINAHL		2958
Ovid Cochrane Database of Systematic Reviews & CENTRAL	2005 to June 28, 2018 To June 2018	225
TOTAL		10449



- **Title and Abstract Screening**
  - First reviewer screened 10,499 papers with a low threshold for inclusion
  - Phase I Screening = 305 papers
- **Full-text Review**
  - First and Second reviewer screened 305 papers independently
  - Phase II Screening = **<u>30 papers</u>**

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Systematic Review in Models of Care for Pediatric to Adult Transition

- **Results: Data Extraction Summary (2 independent reviewers)**

Pediatric Onset Chronic Disease	Number of Papers
Type 1 Diabetes	8
Juvenile Idiopathic Arthritis	4
Cystic Fibrosis	3
Inflammatory Bowel Disease	3
Congenital Heart Disease	2
Chronic Kidney Disease	1
Congenital Adrenal Hyperplasia	1
Spina Bifida	1
Sickle Cell Disease	1
Haemophilia	1
HIV	1
Esophageal Atresia	1
Epilepsy	1
General	2

Year of Publication	Number of Papers
1992	1
2004	1
2006	2
2007	1
2008	1
2009	1
2010	1
2012	3
2013	1
2014	2
2015	4
2016	3
2017	4
2018	5

Location of Study	Number of Papers
USA	10
Canada	8
Australia	3
UK	2
Spain	1
Italy	1
Belgium	1
Germany	1
Israel	1
Denmark	1
Netherlands	1

Research Design	Number of Papers
RCT	3
Non-RCT	27

Transition Model	Number of Papers
Transition clinics with multidisciplinary team involving one or multiple appointments	9
Transition program with a facilitator	17
Remote transition programs (self-management online education modules and telephone coaching)	3
Other	1

Models of Pediatric-to-Adult Care Transition in Complex Chronic Disease

Intervention studied	Examples of intervention	Trend observed in outcomes
Transition clinics	Single or multiple appointments with multi-disciplinary healthcare team prior to transfer to adult care Pediatric Specialist, Adult Specialist, Nurse educators, Dieticians, Social Workers, etc.	No discernible trends or patterns
Transition Program Facilitator	Transition Coordinator Nurse-led Transition Social Worker	Improvements in disease-specific outcomes (glycemic control) Improved self-management skills and disease-specific knowledge Improved compliance post-transfer
Online Transition Program	Online self-management educational modules and telephone coaching	Improved compliance post-transfer High satisfaction

Canadian consensus statements on the transition of adolescents and young adults with IBD from pediatric to adult care

Fu N* Bollegala N* et al. JCAG 2022 (online publication, in press)

- **Co-chairs:** Drs. Natasha Bollegala, Nancy Fu, Eric Benchimol
- Supported by Crohn's and Colitis Canada
- **Steering Committee:** 3 Adult GI, 2 Pediatric GI, 1 Pediatric RN
- **Voting Panel:** 4 Adult GI, 5 Pediatric GI, 1 Adult RN, 1 Adult GI Surgeon, 1 Adolescent Medicine, 1 Patient, 1 Parent
- **Process:** Comprehensive literature review, 2 local patient/parent focus groups, 2 IBD RN focus groups, 1 pediatric GI focus group, 1 adult GI focus group, 2 online voting rounds, 1 in-person voting round

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General Statements

Transition Program Structure

Statement 1. All adolescents and young adults (AYA) with pediatric-onset inflammatory bowel disease (IBD) should attend a structured transition program.

Statement 2. A structured transition program should incorporate:

- Delivery of personalized care with a multi-disciplinary approach.
- Collaborative goal setting between the patients, guardians, and healthcare providers.
- Communication strategies that are adaptable to the patient, healthcare provider and local setting.
- A defined post-transfer adult transition phase.
- Evaluation of the program's processes and outcomes and change in response to this evaluation.

Statement 3. Transition programming should be structured according to the local resources and should reflect input from local key stakeholders

Transition of Care

Focuses of Transition Program

Statement 4. A pediatric to adult IBD transition of care program should implement developmentally appropriate strategies for AYAs to assess and address the following skills:

- Health-related knowledge.
- Health-related behaviours.
- Transition-related skills.

Statement 5. A pediatric to adult IBD transition of care program should address IBD-related adolescent issues with AYAs

Statement 6. A pediatric to adult IBD transition of care program should implement strategies for guardians/caregivers to support and encourage the development of independence in AYAs.

Statement 7. HCP training programs should integrate training in transition and create opportunities for related knowledge and skill development

Statement 8. Patients with pediatric onset IBD undergoing transition of care to adult services should have access to a Primary Care Provider.

Care Transfer Overlap

Late Pediatric and Early Adult Transition Phase/Overlap

Statement 10 A pediatric to adult IBD transition of care program should include a transition coordinator/navigator.

Statement 11

a. The timing of care transfer to adult services should be flexible.

b. Strategies should be implemented to optimize communication during the handover process between pediatric and adult IBD healthcare providers.

Statement 12 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.

Statement 13 IBD transition of care networks should be developed and supported to facilitate transition and transfer planning.

Unpublished data: Bollegala N, Fu N, Benchimol E

Adult Phase Transition

Statement 14 The adult team engaged in a structured pediatric to adult IBD transition program should prioritize care delivery to transitioning AYAs

Statement 15

a. The pediatric and adult IBD transition teams should review the processes and structure of adult healthcare with AYAs and guardians/caregivers.

b. The adult IBD transition team should establish expectations and goals with the AYAs and guardians/caregivers.

Unpublished data: Bollegala N, Fu N, Benchimol E

Next Steps

Implementing a Multi-modal Intervention to Improve the Transition of Patients with IBD from Pediatric to Adult Care

- Co-PI: Drs. Natasha Bollegala, Nancy Fu, Melonie Barwick, Eric Benchimol
- Recruitment centers: University of Toronto, University of Ottawa, McMaster University, University of British Columbia
- Integration of a transition agenda within a national QI program - PACE
- Objectives:
  - We will conduct a randomized controlled clinical trial (RCT) to evaluate the clinical and implementation efficacy of an intervention (consisting of 4 core components) to improve the transition from pediatric to adult care in AYAs with Crohn's disease.
  - Hybrid Type 1 effectiveness-implementation trial - To understand the context for effective implementation of the intervention

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Conclusions

Age and developmentally appropriate transition care is recognized as a healthcare priority

- HOWEVER there is a significant gap in the quantity and quality of related research, allocated resources

Coordinating a smooth transition for young adults is a challenge but an early start is KEY and continuing this process into early adulthood is CRITICAL

Identifying local available resources, appreciating the importance of close follow-up, encouraging independence and facilitating open communication between the pediatric and adult teams remain the most practical immediate steps for HCPs

Thank You

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