TRANSITION OF ADOLESCENTS FROM PEDIATRIC TO ADULT CARE

HOW AND WHEN TO DO IT?

Sanja Kolaček

Children's Hospital Zagreb

TRANSFER *vs* TRANSITION

Definitions

Transfer

- Change in health care provider that occurs at a distinct point of time

Transition

- Purposeful, planned movement of adolescents with chronic physical and medical condition from child to adult-centred health care*

** Blum RW et al. J Adolesc Health 1993;48:570-6*

TRANSFER *vs* TRANSITION

What are the general problems?

Features of adolescent age group

- unstable, rapidly changing roles,
- social & geographical flux,
- financial insecurity, often un-insured...

Number of adolescents with chronic diseases

- > 750,000 adolescents with special health needs transfer annually in USA
- increasing survival of patients with chronic diseases

TRANSFER *vs* TRANSITION

What are the specific problems?

Adolescent with chronic disease

- anxiety & depression & social problems more common
- delays in acquisition of developmental milestones & sex maturity
- poor adherence to therapy, neglect of disease.....

Abraham BP, et al. Gastroenterology&Hepatology 2014

TRANSFER *vs* TRANSITION

Course of disease after transfer?

- **Diabetes mellitus type 1**
  - 1/3 have gap of >6 months in med. care following transfer
  - high lost to follow-up, increased hospitalization rate....
- **Liver transplant patients**
  - increased rate of acute rejection, decreased levels of drugs, increased hospitalization
- **Deterioration around transfer also described for CF, Coeliac disease, rheumatoid arthritis, cardiac.....**

TRANSITION vs TRANSFER

Take home message 1

- Adolescent age - difficult
- Increasing number of adolescent patients ready for transfer
- In transfer, chronic disease In adolescent patients often deteriorates

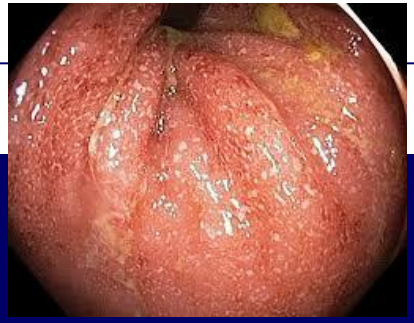
CAN THIS BE IMPROVED!!??

TRANSITION in CHILDREN WITH IBD

to be presented:

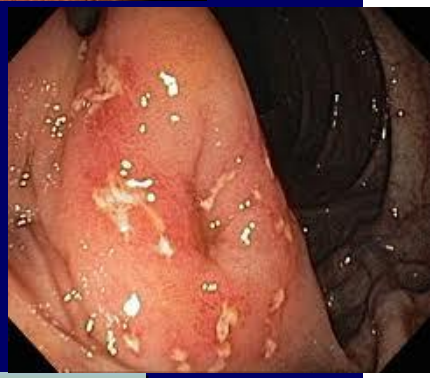
- **Pediatric *versus* adult care**
- **Most common barriers**
- **Transitional care programms**
- **Does it work?**

WHY TRANSITION IN IBD



Children are different

- **Disease:** **more severe & extensive**
  phenotype different
  clinical picture (growth!!)
  efficacy of treatment (EN!!)



Numbers are high and increase

- **Prevalence in USA 100-200/100,000 (**up to 100,000 cases)
  10,000 new cases annually

Summarized in: Bollegala N, Nguyen GC. Gastroenterology Research Practice 2015

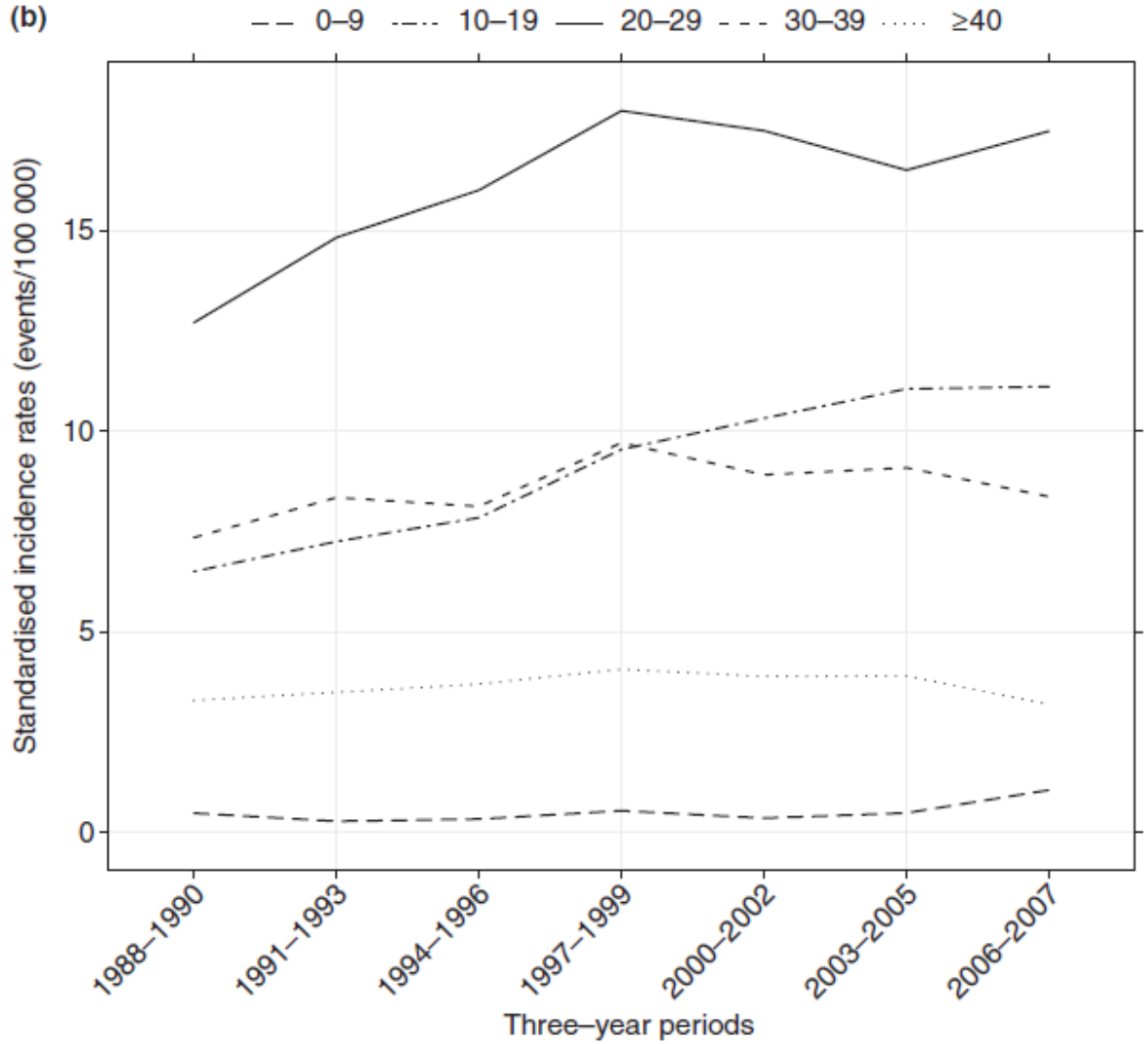


Figure 4 | (a) Evolution of the incidence of Crohn's disease in Northern France from 1988-1990 to 2006-2007 according to 20-year age groups. (b) Evolution of the incidence of Crohn's disease in Northern France from 1988-1990 to 2006-2007 according to 10-year age groups.

Chouragi et al. Aliment Pharmacol Ther. 2011;33:1133-42.

TRANSITION in CHILDREN WITH IBD

to be presented:

- **Pediatric *versus* adult care**
- **Most common barriers**
- **Transitional care programms**
- **Does it work**

FEATURES OF PEDIATRIC *versus* ADULT HEALTH CARE

PEDIATRIC CARE	ADULT CARE
▪ Family oriented ▪ Decisions made by physician and parents ▪ Pasive role of ped. patient ▪ Care objectives: - growth & maturation - ionizing radiation - risk behaviour prevention ▪ Different practice: - endoscopy in general anest. - multidiscip. team approach	▪ Patient oriented / partnership ▪ Decision made by physician and patient ▪ Patient self-responsibility ▪ Care objectives: - fertility & pregnancy - carcinoma prevention - work capacity/mobility.. ▪ Type of practice - shorter appointments - less importance to pain

Trivedi I et al. Curr Gastroenterol Rep 2016;

Barriers in transition ???

Bensen R et al. Transition in Ped Gastro: Results of National Provider Survey JPGN 2016: in press

What are some of the barriers that you perceive of in your current health care system to the transfer of care of a patient to adult care providers? (check all that apply):	%
Parent's/guardian's attachment to pediatric healthcare providers	81%
Patient's attachment to pediatric healthcare providers	74%
Patient emotional /cognitive delay	64%
Provider's attachment to patient or family	56%
Parent's/guardian's attachment to institution or practice	54%
Patient's on-going active medical issues not amenable to transfer	47%
Patient's attachment to institution or practice	46%
Patient non-compliance with transfer	40%
Patient's unstable social situation	38%
Perceived resistance of other involved pediatric practitioners to transition	32%
Lack of qualified adult providers familiar with disease process	31%
Health insurance issues	29%

Barriers in transition???

Bensen R et al. Transition in Ped Gastro: Results of National Provider Survey JPGN 2016: in press

Themes of additional barriers from qualitative analysis: (n=22)	*Illustrative quotes*
Factors within adult care (n=8)	
Wait for appointments (n=2)	"Difficulty in getting follow up date"
Other (n=6)	"Families try transition and it does not go well with major issues in hospitalization, communication, etc."
Factors across systems (n=7)	
Culture differences (n=2)	"Differences in attitude between pediatric and adult providers (more protective and solicitous)"
Reimbursement & insurance (n=2)	"No funding"
Ancillary services (n=2)	"Lack of psychosocial support"
Difficult transfer of health information (n=1)	"Lack of good information exchange programs"
Factors within pediatrics (n=5)	"When other primary services don't transfer care, their referrals for GI issues are still through pediatric system"
Factors related to patients/ parents (n=2)	"Parental resistance for fear of losing their role in patient's care"

BARRIERS IN TRANSTITION

Adult gastroenterologists' point of view

results of nationwide survey in USA

- **73% feel competent with medical care for adolescents**
- **46% felt competent with adolescent development and medical health**
- **51% report receiving inadequate information from pediatric provider**

Hait E et al. J Pediatr Gastroenterol Nutr 2009; 48:61-6

HOW TO ORGANIZE TRANSITION

Goals of transition care

Get the patient ready

- acquirre skills and knowledge of the disease
- capable to become self-responsible

Get the parents ready

- often reluctante, unhappy.....

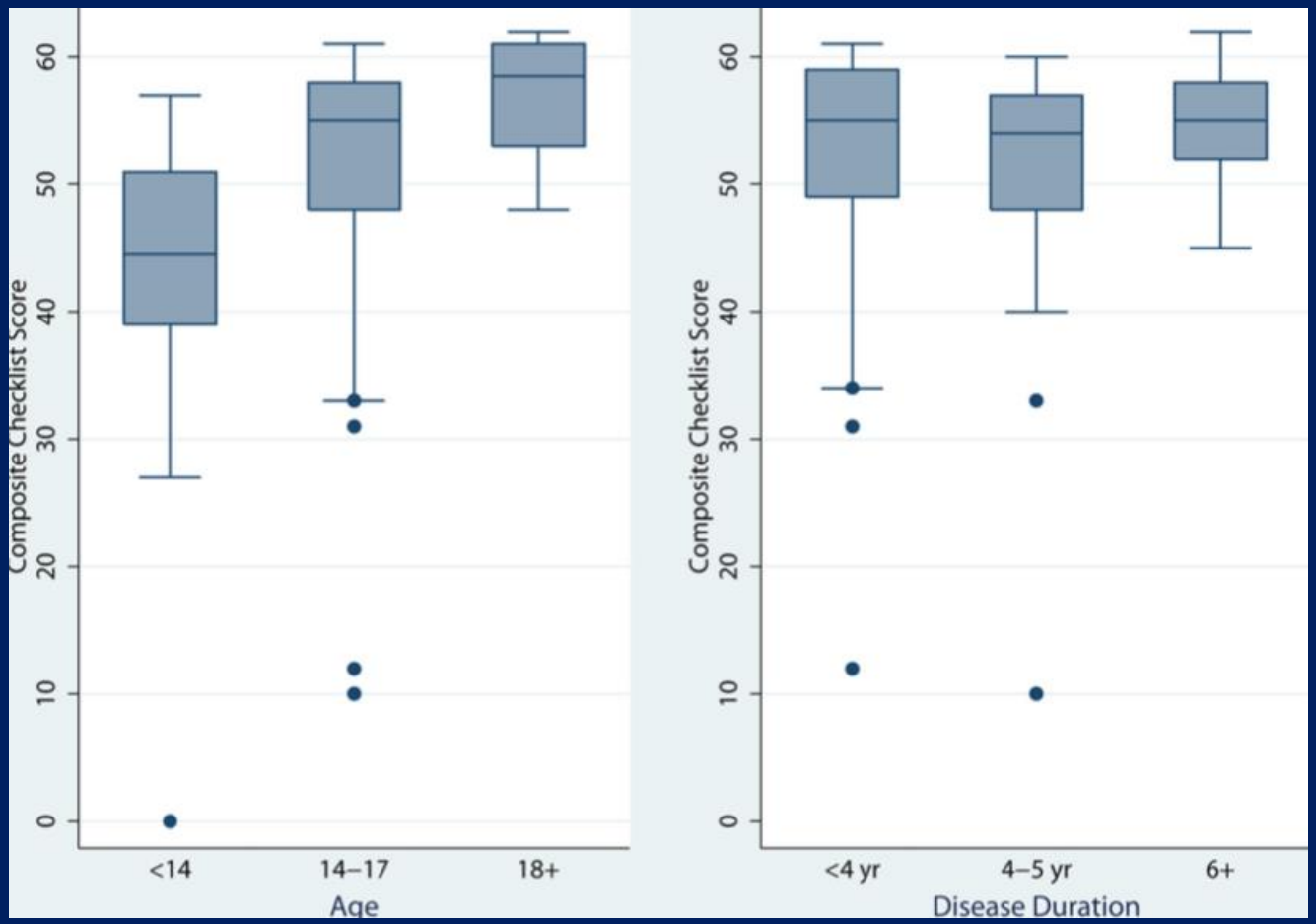
Get the adult gastroenterologist ready

- lack of training and competence for adolecents
- medical documentation not transferred

When is the patient ready???

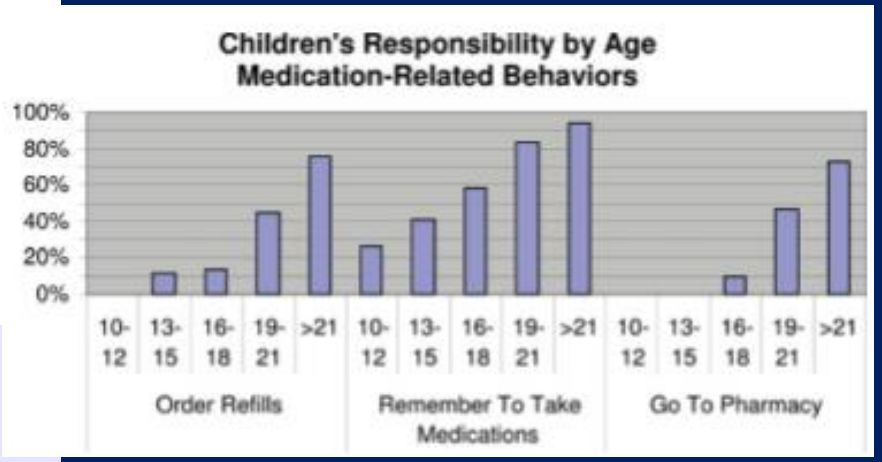
Whitfield EP et al. Transition readiness in patients with IBD.JPGN 2016

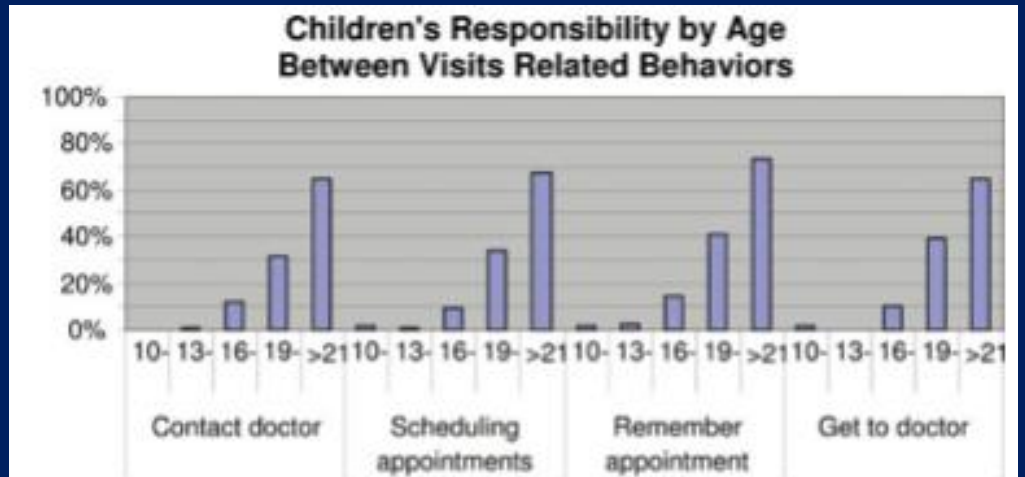
Acquisition of self-management skills in 67 IBD patients, age 10-21



When is the patient ready???

Van Groningen J et al. When independent healthcare behaviour develop in adolescents with IBD. Inflamm Bowel Dis 2012





When is the patient ready???

Van Groningen J et al. When independent healthcare behaviour develop in adolescents with IBD. Inflamm Bowel Dis 2012

Whitfield EP, et al. Transition readiness..:Survey of self managment skills JPGN 2015

Age which makes a difference: 19-21y

> 80% of patients can do without help majority of tasks

However !!!

< 50% order medication refill, set apointments & pick drug from pharmacy, can articulate a problem

ARE THEY EVER READY?
HOW DIFFERENT ARE ADULTS??

When is the patient ready?

HOW DO ADULT PATIENTS PERFORM?

Fishman LN, et al. Examining adult medication knowledge and self-management skills. JPGN 2016, in press

Only 57% reported full independence

- 43% do not pick-up the drug
- 37% do not recall dose frequency
- 35% do not recall dose
- 55% do not know possible side effects

TRANSITION vs TRANSFER

Take home message 2

Various barriers to successful transition

- Attachment to pediatric provider
- Unprepared adult provider
- Patient emotional/congnitive delay

Be aware that adults are not different*

Readiness to transfer needs to be assessed by validated tool

ARE THE TOOLS AVAILABLE!!??

**Kahn SA. Transition Care...:The more we learn, the less we know. JPGN 2016, in press*

TRANSITION ASSESSMENT TOOLS

Educational Resources for Providers

- A Case-Based Monograph Focusing on IBD. Improving Health Supervision in Pediatric and Young Adult Patients With IBD[79]
- Transition in IBD. http://www.ibdtransition.org.uk/

Transition Guidelines for Providers

- Educate, communicate, anticipate—practical recommendations for transitioning adolescents with IBD to adult health care[17]
- Transition of the patient with inflammatory bowel disease from pediatric to adult care: recommendations of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition[18]
- Transitioning the adolescent inflammatory bowel disease patient: guidelines for the adult and pediatric gastroenterologist[20]

Transition Readiness Assessment and Tools

- Transitioning a Patient With IBD From Pediatric to Adult Care[80] (includes a healthcare provider checklist for transitioning a patient with IBD from pediatric to adult care)
- Preparing to Transition From a Pediatric to Adult Care Practitioner: Transitioning to Adulthood With IBD[81] (includes a patient checklist for preparing to transition from a pediatric to an adult care practitioner)
- TRxANSIT Scale and STARx Transition Readiness Questionnaire. http://pediatrics.med.unc.edu/transition/files/

Resources and Tools for Adolescents and Parents

- IBD U (IBD University). http://www.ibdu.org/
- CCFA (Crohn's & Colitis Foundation of America) Campus Connection. http://www.ccfa.org/campus-connection/
- CCFA I'llBDetermined. http://www.ibdetermined.org/
- CCFA GI Buddy (symptom tracker). http://www.ibdetermined.org/Tracker.aspx/
- myIBD (symptom tracker). http://www.sickkids.ca/IBDacademy/IBD-Mobile-App/
- Good 2 Go Transition Program—MyHealth Passport. https://www.sickkids.ca/myhealthpassport/
- American Academy of Pediatrics. How to Help Your Teen Transition to Adult Health Care. http://www.healthychildren.org/English/family-life/health-management/Pages/How-to-Help-Your-Teen-Transition-to-Adult-Health-Care-Video.aspx/

Transition Advocacy and Support for Patients, Parents, and Providers

- Got Transition. http://gottransition.org/
- Society for Adolescent Health and Medicine. Transition to Adult Care. http://www.adolescenthealth.org/Topics-in-Adolescent-Health/Transition-to-Adult-Care.aspx/

Taken from: Abraham BP, et al. Gastroenterology & Hepatology 2014

TRANSITION in CHILDREN WITH IBD

to be presented:

- **Pediatric *versus* adult care**
- **Most common barriers**
- **Transitional care programms**
- **Does it work**

TRANSITIONAL CARE PROGRAMS

Distinct transition clinic

Pediatric + adult clinic fused

Supported with team: nurse, dietitian, psychologist..

Educational programs

Attended by patient + parent for 1-2 years

Alternating service

Alternating visits to pediatric and to adult care provider

First attended jointly patient & parent, than only by patient

Joint pediatric + adult clinic

On the same visit present pediatric and adult gastroenterologist

At the beginning attended by parent + adolescent, later patient

Organized for 3-12 months

TRANSITIONAL CARE PROGRAMS

Do we know which program performs best??

No, we do not!
There are no studies yet!

HOW DID WE ORGANISE TRANSITION CARE?

1. Age: 18-19 years
on finishing secondary school

2. Duration: 3-6 months

3. Schedule

1st visit: pediatrician defines transition
discusses with parent+patient

2nd visit: adult i pediatric care provider
alone (!) discuss medical history

3rd visit: parents + patient + both doctors jointly

4th visit: parents + patient + adult doctor

4. Efficacy assessment: PhD student thesis

DOES TRANSITIONAL CARE WORK?

Cole R et al. Evaluation of outcomes in adolescent IBD...
J Adolescent Health 2015;57:12-7

72 patients: 44 went through transition;
28 NO formal transition process

Observational period: within 2 years after transfer

Disease status at transfer

	Group A	Group B	*p* value
Disease in remission with or without medications	30 (69%)	11 (39%)	.01
Active disease on treatment	13 (29%)	4 (14.5%)	.01
Active disease not on treatment	0	0	—
Active disease needing emergency admission	1 (2%)	13 (46.5%)	.001

DOES TRANSITIONAL CARE WORK?

Cole R et al. Evaluation of outcomes in adolescent IBD...
J Adolescent Health 2015;57:12-7
72 patients: 44 went through transition;
28 NO formal transition process
Observational period: within 2 years after transfer

Reasons for admission within 2 years of transfer

	Group A (n = 44)	Group B (n = 28)	*p* value
Patients needing admission (total)	13 (29%)	17 (69%)	.002
For acute flare up ± emergency surgery	3 (7%)	11 (39%)	.001
For elective/planned surgery	8 (18%)	5 (17%)	NS
For nutritional intervention	1 (2%)	1 (3%)	NS
Drug toxicity, other	1	0	NS

NS = not significant.

SIGENP et al. Transition of gastroenterological patients from paediatric to adult care: A position statement by the Italian Societies of Gastroenterology. Dig Liver Dis 2015

Characteristics of transition for patients with inflammatory bowel disease, celiac disease and chronic liver diseases.

	IBD	CD	CLD
Suggested start age (years)	16	16	16–18
Duration of the transition process (months)	6–12 Specialists should stay in contact and/or schedule web conferences to maintain a uniform follow-up	1 IBD-like transition process to be considered when dealing with complicated cases	6 Specialists should stay in contact and/or schedule web conferences to maintain a uniform follow-up
Number of combined visits (minimum)	1 or 2 depending on the severity of the disease	1	4
Location of visits	Alternating between the paediatric and adult gastroenterological services	Adult gastroenterological service	Transitional clinic
Location of service	Secondary or tertiary referral centres	Secondary or tertiary referral centres	Secondary or tertiary referral centres

IBD, inflammatory bowel disease; CD, celiac disease; CLD, chronic liver diseases.

TRANSITION CARE
Take home messages

- In chronically sick adolescent patients after transfer
  disease tend to significantly deteriorate
- Special transition care is required to prepare patients, parents and adult care providers
- There are several models
  Initial studies show they work
  However, more studies needed

**Kahn SA. Transition Care...:The more we learn, the less we know. JPGN 2016, in press*