TRANSITION OF ADOLESCENTS FROM PEDIATRIC TO ADULT CARE

HOW AND WHEN TO DO IT?

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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.....

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 programs
- 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.
TRANSITION in CHILDREN WITH IBD

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- Pediatric versus adult care
- Most common barriers
- Transitional care programs
- Does it work
### FEATURES OF PEDIATRIC versus ADULT HEALTH CARE

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

*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

<table>
<thead>
<tr>
<th>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):</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent’s/guardian’s attachment to pediatric healthcare providers</td>
<td>81%</td>
</tr>
<tr>
<td>Patient’s attachment to pediatric healthcare providers</td>
<td>74%</td>
</tr>
<tr>
<td>Patient emotional /cognitive delay</td>
<td>64%</td>
</tr>
<tr>
<td>Provider’s attachment to patient or family</td>
<td>56%</td>
</tr>
<tr>
<td>Parent’s/guardian’s attachment to institution or practice</td>
<td>54%</td>
</tr>
<tr>
<td>Patient’s on-going active medical issues not amenable to transfer</td>
<td>47%</td>
</tr>
<tr>
<td>Patient’s attachment to institution or practice</td>
<td>46%</td>
</tr>
<tr>
<td>Patient non-compliance with transfer</td>
<td>40%</td>
</tr>
<tr>
<td>Patient’s unstable social situation</td>
<td>38%</td>
</tr>
<tr>
<td>Perceived resistance of other involved pediatric practitioners to transition</td>
<td>32%</td>
</tr>
<tr>
<td>Lack of qualified adult providers familiar with disease process</td>
<td>31%</td>
</tr>
<tr>
<td>Health insurance issues</td>
<td>29%</td>
</tr>
</tbody>
</table>
### Barriers in transition???

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

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

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

HOW TO ORGANIZE TRANSITION

Goals of transition care

Get the patient ready
- acquire skills and knowledge of the disease
- capable to become self-responsible

Get the parents ready
- often reluctant, unhappy.....

Get the adult gastroenterologist ready
- lack of training and competence for adolescents
- medical documentation not transferred
When is the patient ready???

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

Age which makes a difference: 19-21y
> 80% of patients can do without help majority of tasks

However !!!
< 50% order medication refill, set appointments & 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/cognitive 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
- 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
- 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
- Transitioning the adolescent inflammatory bowel disease patient: guidelines for the adult and pediatric gastroenterologist

## Transition Readiness Assessment and Tools
- Transitioning a Patient With IBD From Pediatric to Adult Care (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 (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 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/

## Transition Advocacy and Support for Patients, Parents, and Providers

*Taken from: Abraham BP, et al. Gastroenterology & Hepatology 2014*
TRANSITION in CHILDREN WITH IBD

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- 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
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?


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

Observational period: within 2 years after transfer

<table>
<thead>
<tr>
<th>Disease status at transfer</th>
<th>Group A</th>
<th>Group B</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease in remission with or without medications</td>
<td>30 (69%)</td>
<td>11 (39%)</td>
<td>.01</td>
</tr>
<tr>
<td>Active disease on treatment</td>
<td>13 (29%)</td>
<td>4 (14.5%)</td>
<td>.01</td>
</tr>
<tr>
<td>Active disease not on treatment</td>
<td>0</td>
<td>0</td>
<td>—</td>
</tr>
<tr>
<td>Active disease needing emergency admission</td>
<td>1 (2%)</td>
<td>13 (46.5%)</td>
<td>.001</td>
</tr>
</tbody>
</table>
**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

<table>
<thead>
<tr>
<th>Reasons for admission within 2 years of transfer</th>
<th>Group A (n = 44)</th>
<th>Group B (n = 28)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients needing admission (total)</td>
<td>13 (29%)</td>
<td>17 (69%)</td>
<td>.002</td>
</tr>
<tr>
<td>For acute flare up ± emergency surgery</td>
<td>3 (7%)</td>
<td>11 (39%)</td>
<td>.001</td>
</tr>
<tr>
<td>For elective/planned surgery</td>
<td>8 (18%)</td>
<td>5 (17%)</td>
<td>NS</td>
</tr>
<tr>
<td>For nutritional intervention</td>
<td>1 (2%)</td>
<td>1 (3%)</td>
<td>NS</td>
</tr>
<tr>
<td>Drug toxicity, other</td>
<td>1</td>
<td>0</td>
<td>NS</td>
</tr>
</tbody>
</table>

NS = not significant.
### Characteristics of transition for patients with inflammatory bowel disease, celiac disease and chronic liver diseases.

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

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*