Pediatric liver disease: Transition to adult care

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Outline

• Challenges of transition
• Patient perspectives
• Practitioner perspectives
• Strategies
• Resources
Definitions

• **Transfer**
  – Dictating patient summary & making appointment with adult specialist at set age

• **Transition**
  – Purposeful, planned, gradual
  – Process of preparing patient (& family) for move to adult-oriented health care
    – New location, new practitioner(s), new model of care
How many pediatric patients?

- **North America:**
  - $\leq 15\%$ of youth have chronic health condition causing some limitation in life

- **British Columbia:**
  - 11\% of youth aged 15-24 years
    - Some disability due to physical or mental health condition (89\% mild)

Current practice at BCCH

- Patients transition at age 17-18
  - Coincides with high school graduation
- Sometimes older if complex (oncology, cardiac)
- New patients only <17 years old
- BCCH emergency room ≥ 18 yrs = problematic
Patient G.T.: 18 years old

- Transplanted for OTC deficiency (metabolic disorder)
- Mild intellectual disability, ADHD, moderate hearing loss
- Public high school, specialized program → graduating
- **Meds**: Tacrolimus, Ursodiol, Keppra, Clonidine
- **Providers**: Hepatology, Neurology, Psychiatry, Audiology, Pediatrician, Social work
  - No family doctor
Patient G.T.: 18 years old

**Medical issues**
- Appointments
- Medications: side effects, drug interactions, filling, dosing schedule
- Long-term risks: infections, cancer
- Coordination

**Life issues**
- Education / employment
- Independent living
- Finances
- Sexuality / relationships
- Transportation
- Insurance coverage
Outcomes without transition

- After transfer to adult care:
  - 50% of young patients attend first visit
  - 38% attend second visit
"Providing transition care to adolescent renal transplant recipients is at least cost neutral and may provide a cost benefit to the healthcare system... Anticipate that with reports such as ours, healthcare providers will be obliged to make transition care a priority."

Practitioner perspectives

• How are teenage patients upon transition?
  • 79% “suboptimal preparation”
  • Deficient knowledge of medical condition & treatment
  • Lack of adherence
  • Unprepared to navigate adult health care system
  • Lack of self-care skills

• Other concerns:
  • Overuse of ER, prolonged gaps in care

Patient knowledge gaps

- 78 teenage IBD patients
  - 22% knew location of disease
  - 55% knew when diagnosed
  - ~35% knew pharmacy, insurance provider
- 294 IBD patients >10 yrs old
  - 95% named medication
  - 54% knew dose & timing
  - 32% knew single adverse effect of medication

<table>
<thead>
<tr>
<th>Aspect</th>
<th>MDs reporting aspect is a problem</th>
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<tbody>
<tr>
<td>Knowledge of meds (name, dose, side effects)</td>
<td>69%</td>
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<tr>
<td>Knowledge of medical history</td>
<td>55%</td>
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<tr>
<td>Receiving summary from pediatrics before 1st visit</td>
<td>51%</td>
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<td>Knowledge of impact of smoking, drugs, EtOH</td>
<td>51%</td>
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<tr>
<td>Able to discuss impact of disease on life, activities</td>
<td>48%</td>
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<tr>
<td>Concept of disease &amp; its basic nature</td>
<td>42%</td>
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<tr>
<td>Initiating contact if problem arises</td>
<td>41%</td>
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<tr>
<td>Filling prescriptions</td>
<td>40%</td>
</tr>
<tr>
<td>Active participation in office visit</td>
<td>39%</td>
</tr>
<tr>
<td>Researching illness outside office visit</td>
<td>21%</td>
</tr>
<tr>
<td>Procedures under conscious sedation</td>
<td>12%</td>
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</tbody>
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Why so challenging?

• What else is going on at age 18?
  • Issues of self-image, identity, independence, sexuality, self-worth
  • High school graduation → University? Job?
  • Leaving home? New city?
  • Changing peer, family relationships
Two different cultures

Pediatric health care
- Family centred
- Developmentally oriented
- Parent involvement
- Consent
- Multidisciplinary
- Multiple transitions at age 18

Adult health care
- Person centred
- Autonomy vs. dependency
- Requires consumer skills
- Access to information
- Single MD
- Cohort: older adults & long-term complications
  (18 yr olds = ~2% of patients)
System challenges

- Limited communication b/n pediatric, adult & community providers
- No common electronic health record
- Hard to condense pediatric medical knowledge & care requirements
- Lack of system support for collaborative care across disciplines
Patient perspectives

• What are transition patients looking for in a provider?
  • Knowledgeable about illness
  • Supportive & trustworthy
  • Treat patient with informality
  • Express interest in aspects of patient’s life other than illness
  • Give patient choices and sense of control

Patient perspectives

- Transition patients desire independence
  - Sense of control over health
  - Acquiring health care-related skills (e.g., booking appointments)
  - Want to be “taken seriously”

- Barriers:
  - Don’t necessarily understand what independence entails
  - Overprotective parents +/- health care providers

Patient perspectives: After transition

• **Positive**
  • Efficient staff
  • Feeling like adults; ↑ control over decision-making

• **Negative**
  • Older & sicker patients → fearful about own future
  • Providers less knowledgeable about medical condition
  • Lack of sensitivity & empathy
  • Not enough time with MD
  • Care ≠ encompass all needs of patient

Patient recommendations

- Joint visits with providers from peds & adult care
  - Transition clinic
- Visits to adult care environment before transfer
  - Reduce fears
  - Form relationships with providers
- Initially after transfer:
  - Longer visits
  - More frequent visits

Health outcomes after transition

• Liver transplant
  • ↑ in-range IS levels, ↓ episodes rejection, ↓ liver biopsies, ↓ hospitalizations
• Diabetes
  • ↓ Hgb A1C, better clinic attendance
• Rheumatoid arthritis
  • ↑ QOL

Strategies for improving transition
Mandate:
To ensure successful planning, preparation, and transfer of youth with chronic health conditions and/or disabilities (CHC/Ds) from pediatric care to the adult care system, with attachment to primary care and specialist services.
Core principles

- Preparation starts early in childhood
- Increasing levels of responsibility & information
- Teach skills of negotiation & communication
  - Navigate adult care system
- Include teens with cognitive disabilities
Role of family physician

Identified Roles

- Care coordination and referral
- Provision of primary care
- Surveillance and monitoring
- Health promotion and protection
- Patient advocacy for complex patients, especially for the physically / mental challenged & those in dysfunctional families

Need to:
1. Make explicit referral criteria and pathways
2. Maintain and facilitate attachment
3. Support family physicians in providing a medical home
ON TRAC
Transition Timeline

Youth with CHC/Ds 12-24yrs

Youth 12-14yrs
Transition Clinical Pathway (TCP)
Confirm Family Physician

Youth 15-16yrs
Readiness skills & knowledge

Youth 17-18yrs
Identify Adult Specialist(s)
Medical Transfer Summary (MTS)

Youth 19-24yrs
Adult Care
Adult TCP
Transition Care Management Plans (TCMPs)

Youth/Family Readiness

Transfer Documents

Attachment Protocol
First Adult visit(s) within 6 months
First Adult letter back to BCCH
1-2 visits to FP/yr receiving reports
## Transition checklist: Age 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
Transition checklist: Age 12-14

- 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
Transition checklist: Age 14-17

**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
Transition checklist: Age 14-17

- Discuss impact of drugs, alcohol & nonadherence
- Impact of disease on sexuality & fertility
- Plans for education, employment → insurance implications
Transition checklist: ≥ 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.
Transition checklist: ≥ 17

**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.
Youth strategy: Just Trac It!

- Mobile health intervention
- Use existing Notes, calendar and Contact apps to manage information.
- Pilot study in BCCH clinics
  Summer 2013
- http://ontracbc.ca/justtracit/

Come to clinic – **TURN YOUR PHONE ON!**
1) Please take a moment to turn your phones on.
2) Go to www.ontracbc.ca
3) Save using icon at base of phone and “Add to Home Screen”.
Using your phone

• Photograph medication bottles
• Contact list:
  • Doctors
  • Pharmacy
  • Lab
Conclusions

• Transition, not transfer
• Multiple factors influence success
• Multiple participants: patient, family, pediatric centre, adult centre, community
• Worth the effort
Resources

• ON TRAC (BC Children’s Hospital)
  • Toolbox, clinical practice guidelines
  • www.ontracbc.ca

• Good To Go (SickKids, Toronto)
  • Patient & family resources
  • www.sickkids.ca/good2go
  • www.sickkids.on.ca/myhealthpassport