Transitioning the Adolescent Patient to an Adult Program: Trials and Tribulations

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Premise
- Children with Pulmonary Hypertension (PH) are now surviving to adulthood
- Over the last decade, high rates of survival due to medical advances in pediatric care
- Gone are the days of 3-5 years life expectancy and little or no options post initial diagnosis
- Medical care continuing from childhood to adulthood

Transfer or Transition?
Transfer and transition – terms used during the care continuum from childhood to adolescence to adulthood
Transfer ≠ Transition

Definition
- **Transition** = The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult orientated health care systems (Blum et al., 1993)
- **Transfer** = Defines an event or a series of events through which adolescents and young adults who have chronic physical and medical conditions move their care from a pediatric to an adult health care environment (Knauth et al., 2006)
Aim During Transition

Health Care Team to execute a smooth transition for the adolescent patient diagnosed with Pulmonary Hypertension, so transfer to adult care is a positive experience.

Pediatric versus Adult Model of Care

<table>
<thead>
<tr>
<th>Pediatric</th>
<th>Adult</th>
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<tbody>
<tr>
<td>Focuses on growth and development</td>
<td>Partnership with patient</td>
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<tr>
<td>Provision of information directed towards parents and guardians</td>
<td>Provision of information directed towards patient</td>
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Goal of Transition

Patient empowered to take responsibility for own health and lifestyle and attain best quality of life

Transition Process: Identify Gaps

Key Players:
- Patient – new responsibility
- Parent(s)/Guardian(s) – not included in communication
- Pediatric provider – sudden discontinuance of care
- Adult provider – complete reevaluation
Transition Process: Understand the Consequences of Gaps

- **Patient** - Improper timing of transfer of care, discontinuity of care, delay of first appointment, lost to follow-up
- **Parent(s)/Guardian(s)** - Emotional stress
- **Pediatric provider** - contact continues with patient and family, incomplete transfer of information
- **Adult provider** - delay treatment and follow-up care

Transition Process: Fill in the Gaps

Begin with a planned PH specific transition process

- **Patient** - assess age and maturity, discuss transition plan (10-14 y.o.), what to expect
- **Parent(s)/Guardian(s)** - support family & not just patient
- **Pediatric provider** - provide uninterrupted health care from pediatric to adult center, transfer current medical status, comply with institution policy, flexibility of transfer policy
- **Adult provider** - care continued by specialized practitioners, availability, location, experience with medications

(Knauth et al, 2006; Foster et al, 2001)

Transition Process: Role of the Pediatric Centre

- **Prepare** at an early age
- **Communicate** accurate information: diagnosis, treatment
- **Educate** regarding risks, if no follow-up care
- **Discuss** psychosocial issues
- **Liaise** with general physician
- **Show** how to access resources
- **Provide** information about Adult PH Centre

Transition Process: Role of Adult Provider

- **Address** patient’s feelings of uncertainty rather than ignore
- **Recognize** the young, have patience in the first couple of visits, inpatient
- **Consider** involvement of family for first few visits
- **Avoid** abrupt transfer to adult services
- **Continue** transition until patient shows readiness
- **Communicate** with pediatric provider and family doctor and continue with current plan of care
- **Follow-up** with canceled and unrescheduled appointments post transfer thereby avoiding lost to follow-up
Issues Addressed During Transition and Continue Post Transfer

- Diagnosis – symptoms, risks, diagnostic procedures
- Non-Cardiac procedures (with or without GA)
- Insurance – changes in coverage
- Psychosocial - anxiety/depression
- End of life issues – advance directives

Issues Addressed During Transition and Continue Post Transfer: Medications

- Dose
- Schedule
- Side effects
- Interactions with other medications
- Pharmacy – ordering medications, over the counter meds

Issues Addressed During Transition and Continue Post Transfer: Sexuality

- Pregnancy – risks
- Contraception
- Physical involvement
- Transmitted diseases
- Medications

Issues Addressed During Transition and Continue Post Transfer: Health

- Nutrition
- Dental Care
Issues Addressed During Transition and Continue Post Transfer: Lifestyle

- Leisure activities
- Exercise
- Travel

Issues Addressed During Transition and Continue Post Transfer: Lifestyle

- School
- Sports
- Employment
- House Chores

Transition Process at the Pediatric Centre: Helpful Aids

- Passport – meds, appointments, doctors’ address and telephone numbers
- Medical Alert Bracelet
- Emergency medical contact information in wallet/purse
- Address and directions to PH clinic, transportation

The Hospital for Sick Children: Transition of PH Patients

PH Transition Workshop:

- very other year
- x4 hours,
- tour
Key Members of Transition Process

- Patient
- Patients’ families
- Pediatric provider
- Adult provider

All are present at the PH Workshop

The Hospital for Sick Children: Good 2 Go Transition Program

- Established in 2006 at The Hospital for Sick Children
- Offer direct assistance with transitioning patients referred to the program
- Provide education and consultation service to other programs who treat high risk, chronically ill patients
- Team includes: Doctors, nurses, social worker, psychologist

The Hospital for Sick Children: PH Transition Workshop Agenda

- 11:00 – 11:15 a.m.........Meet and Greet, Checklist completion
- 11:15 – 11:30 a.m........Welcome overview of day
- 11:30 – 11:50 a.m........Good to Go
- 11:50 – 12:10 p.m.......Adult PH Program
- 12:10 – 12:30 p.m........Introduction of Adult team
- 12:30 – 1:00 p.m.........Break Out Session (Parents in Rm 4704, Teens in 4A)
- 1:00 – 1:30 p.m........Wrap Up, Tour at Toronto General Hospital
- 1:30 – 2:00 p.m........Evaluation, My Health passports
Goodbye and we wish you all the best...

Universty Health Network (UHN): Toronto General Hospital (TGH)

TGH PH Program: Administrative Assistant

TGH PH Program: Main Entrance and Obtaining of Hospital Card
TGH PH Program: 10th Floor

TGH PH Program: West Elevators to 10th Floor & Register with Aku

PH Experts:
Dr. John Granton,
Dr. John Thenganatt, Dr. Jakov Moric

TGH PH Program PH Nurse Co-ordinators:
Mary & Laura & Murray
PH Transition Process and Workshop Day: Challenges

- Patients long travel to hospital
- Finding one day where patients, families, Transition Team, Adult Hospital Caregivers available
- Lack of effect with patients with Trisomy 21 or developmental delay
- Varying length of follow-up in Clinic – some only seen once per year

The Hospital for Sick Children: Currents Needs for Smooth Transition

- Need PH-specific transition tools: checklist, passport, resource documents
- Need PH-specific structured transition process and plan based on adolescents’ stages of development
- Need specific PH evaluation of transition – at pediatric and at adult PH Centre

Conclusion

Transition does not mean transfer.

- Both pediatric and adult provider play an important role in filling out the gaps for a smooth transition and transfer of the patient, from child/adolescent to adult care.
- Future collaboration between the pediatric and adult healthcare provider is necessary to identify further gaps to enhance smooth transition

References

- Adolescent Health Committee (key authors Kaufman, M & Pinzon, J) Transition to adult care for youth with special health care needs. Paediatric Child Health. 2007; 12 (9), 785-788.
- Bennett, DL and Towns, SJ. Smoothing the transition to adult care. The Medical Journal of Australia. 2007; 182 (8) 373-374.
- Hudsmith, LE and Thorne, SA. Transition of care from paediatric to adult services in cardiology. Archives of Disease in Childhood. 2007;92, 927-930.
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