Transition: From Pediatric and Adult Care

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Conflict of Interest

• Research Grants
  – FAPESP
  – CNPq
Agenda

• Define transition
• Review how improved survival rates in childhood illnesses have changed how we practice medicine
• Understand the challenges of transition from multiple perspectives
• Present key elements to implementing a transition plan
• Our experience
No Longer Just a Childhood Illness

• ~11.2 million children (15% of all US children) 0-17 years have special health care needs

• Survival rates have increased for children with chronic illnesses
  – >90% survive beyond their 20th birthday
Rheumatic disease: fluctuating course

• Chronic diseases

• Fluctuating course
  – SLE flare rates: 1.4-5%/year
  – JIA: 30-50% active disease
Transition

Pediatric Care ➔ Adult Care
Transition

Pediatric Care → Adult Care

Child and family-centered health care → Patient-centered adult-oriented health care

Society for Adolescent Medicine, 1993
Child and family-centered health care

Patient-centered adult-oriented health care
Transition
Adolescence

- Embarrassed by parents section
- Ability to remember the lyrics to offensive hip hop song...
- Have no idea...
- Cars, cars, cars, cars, and... oh, yeah, girls...
- Girls are suddenly fascinating section
- Ability to listen to extremely loud bass tracks
- School Work (smallest section of the brain)
Adolescence

• Latin word “adolescere” = to grow, to mature
• They are no longer children yet not adults
• It is characterized by rapid physical growth, significant physical, emotional, psychological and spiritual changes.

Tattersall & McDonagh 2010
World Health Organization 2014
World Health Organization 2012
Problems of adolescents are multi-dimensional in nature.
Transition

My Life, My Choice, My Way™
- Check my progress
- Receive services and support
- Organise services and support
- My life, my choice, my way
- Welcome to Care Connect
- Discuss my needs
- Plan my future
“Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health related services of a type or amount beyond that required by children generally.”
Skills needed for transition

Health maintenance skills  +  Life skills

management of the disease/disability and general and sexual health

mobility, home management, time management, relationships, leisure, work and training

Why Transition is Important

• Failure to recognize and plan transition may result in patients dropping out of care

• Poor transition processes are recognized to have a significant negative effect on morbidity and mortality in young adults with chronic health needs
Persistent morbidity into adulthood

- Reduced participation in school and social activities
  - Fatigue
  - Pain
  - Stiffness
- Increased risk for overall adjustment problems and internalising symptoms
- Unfavourable psychosocial outcome

Landgraf et al. Disability and Rehabilitation, 2009; 31(8): 666–674
Life with JIA: from childhood to adulthood

Theme
Living with juvenile idiopathic arthritis involves struggle and adjustment to an insecure everyday life and an unpredictable life course

Categories
Bodily experiences of limitations or freedom
Being acknowledged or set aside in interpersonal relationships
Intrapersonal experiences of insecurity or confidence

Sub-categories
Unpredictable or stable course of disease
Suffering or well-functioning body
A sense of devotedness or abandonment
Experience of being believed or mistrusted
A sense of loneliness or belonging
The disease as loss or value
Struggling against or along with the disease
Loss of self-esteem or perceived positive self-image
**Rheumatological diseases: a more complex transition**

<table>
<thead>
<tr>
<th>Simpler Transition</th>
<th>More Complex Transition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single health condition</td>
<td>Multiple health conditions</td>
</tr>
<tr>
<td>Low risk of future health problems</td>
<td>High risk of future health problems</td>
</tr>
<tr>
<td>No dependence on medical equipment</td>
<td>Reliance on life-sustaining medical equipment</td>
</tr>
<tr>
<td>Rare acute illness, medically stable</td>
<td>Frequent acute episodes, medically unstable</td>
</tr>
<tr>
<td>Few medications</td>
<td>Multiple medications, medication problems</td>
</tr>
<tr>
<td>No cognitive impairments</td>
<td>Profound mental retardation</td>
</tr>
<tr>
<td>No physical impairments</td>
<td>Serious physical impairments</td>
</tr>
<tr>
<td>Mentally healthy</td>
<td>Mentally ill</td>
</tr>
<tr>
<td>No behavioral concerns</td>
<td>Serious behavioral concerns</td>
</tr>
</tbody>
</table>

*SOURCE: Adapted from Kelly et al. (2002)*
What are the challenges?
Patient Challenges: Many transitions at once

• Healthy peers:
  – Graduate, move away, new job
  – New relationships, new opinions about politics and religion
  – Choices about alcohol, tobacco, drugs, sexual activity
  – Focus on independence

• Addition:
  – Unpredictable disease course
  – Disease management
  – Expectation of the future?

Landgraf et al. Disability and Rehabilitation, 2009; 31(8): 666–674
Biological, social and social changes
Variable and unpredictable disease

Transition process to adulthood
Control life

Landgraf et al. Disability and Rehabilitation, 2009; 31(8): 666–674
Family Challenges

• Close ties with pediatric caregivers
• Considered an adult at 18 y.o. → privacy becomes an issue
  – Mistrust
• Lack of confidence in:
  – Young adult’s ability to adequately provide self-care
  – Adult medical team

Landgraf et al. Disability and Rehabilitation, 2009; 31(8): 666–674
Pediatric Care Team Challenges

- Tight bond with patient and family
- Limited contact with adult providers and services
- Lack of trust in adult healthcare system/providers
- Lack of training on how or when to start transition
Adult Care Team Challenges
<table>
<thead>
<tr>
<th>Item</th>
<th>Mean Likert Rating</th>
<th>Category</th>
<th>Wilcoxon Rank&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Internists may not have the training in congenital and childhood chronic illnesses to prepare them to manage them beyond childhood.</td>
<td>2.86</td>
<td>Medical competency</td>
<td>1</td>
</tr>
<tr>
<td>2. It is difficult to care for patients with cerebral palsy or mental retardation if the family does not stay involved.</td>
<td>2.86</td>
<td>Family involvement</td>
<td>1</td>
</tr>
<tr>
<td>3. It can be difficult to meet psychosocial needs of young adults, especially those living with chronic illness.</td>
<td>2.77</td>
<td>Psychosocial needs</td>
<td>1</td>
</tr>
<tr>
<td>4. Some patients may need a super specialist to manage complex problems (e.g., complex congenital heart disease).</td>
<td>2.77</td>
<td>Medical competency</td>
<td>1</td>
</tr>
<tr>
<td>5. Internists often lack training in adolescent medicine, adolescent development, and adolescent behavior.</td>
<td>2.63</td>
<td>Medical competency</td>
<td>1</td>
</tr>
<tr>
<td>6. It is often difficult to face disability and end-of-life issues at an early age and early in the doctor-patient relationship.</td>
<td>2.63</td>
<td>Medical competency, psychosocial needs</td>
<td>1</td>
</tr>
<tr>
<td>7. Managed care/financial considerations limit the time an internist is able to spend with transitioning young patients.</td>
<td>2.57</td>
<td>System issues</td>
<td>1</td>
</tr>
<tr>
<td>8. The families of transitioning patients have high expectations of the amount of time/attention needed for proper care.</td>
<td>2.55</td>
<td>Family involvement</td>
<td>1</td>
</tr>
<tr>
<td>9. Because patients with chronic illness are often less mature than their healthy counterparts, they may have increased adherence problems.</td>
<td>2.49</td>
<td>Maturity</td>
<td>2</td>
</tr>
<tr>
<td>10. Young patients are not always ready to assume decision-making responsibility.</td>
<td>2.47</td>
<td>Maturity</td>
<td>2</td>
</tr>
<tr>
<td>11. While insurance programs may cover sick children, coverage may not exist for young adults.</td>
<td>2.45</td>
<td>System issues</td>
<td>2</td>
</tr>
<tr>
<td>12. Internal medicine practices often lack adequate infrastructure and staff training to deal with these patients.</td>
<td>2.45</td>
<td>System issues</td>
<td>2</td>
</tr>
<tr>
<td>13. It is often challenging to make sure that the young patient does not get lost to follow-up.</td>
<td>2.44</td>
<td>Maturity, system issues</td>
<td>2</td>
</tr>
<tr>
<td>14. Young patients are often ignorant of morbidity/mortality and therefore may lack motivation for preventive care.</td>
<td>2.44</td>
<td>Maturity</td>
<td>2</td>
</tr>
<tr>
<td>15. Internists may be unfamiliar with local and regional services for chronically ill, young adult patients.</td>
<td>2.42</td>
<td>Medical competency</td>
<td>2</td>
</tr>
<tr>
<td>16. Caring for chronically ill young patients can be potentially very time-consuming.</td>
<td>2.42</td>
<td>System issues</td>
<td>2</td>
</tr>
<tr>
<td>17. It is difficult for young adult patients over 18 with chronic illness to obtain insurance because of their preexisting condition.</td>
<td>2.40</td>
<td>System issues</td>
<td>2</td>
</tr>
<tr>
<td>18. Parents are often reluctant to relinquish responsibility for health care/decision-making to young adult patients.</td>
<td>2.39</td>
<td>Family involvement</td>
<td>2</td>
</tr>
<tr>
<td>19. Young patients with chronic illness often have significant dependency needs.</td>
<td>2.37</td>
<td>Maturity</td>
<td>2</td>
</tr>
<tr>
<td>20. It is difficult to meet the expectations of care for chronic incurable problems; often family wants a full evaluation though one has already been completed.</td>
<td>2.37</td>
<td>Family involvement</td>
<td>2</td>
</tr>
<tr>
<td>21. The transition from pediatric caregivers is often poorly coordinated.</td>
<td>2.36</td>
<td>Transition coordination</td>
<td>2</td>
</tr>
<tr>
<td>22. Young patients often neglect to raise issues or ask questions that their parents previously would have asked.</td>
<td>2.35</td>
<td>Maturity</td>
<td>2</td>
</tr>
<tr>
<td>23. Young patients are often closed-minded to different approaches after living with their illness for so long.</td>
<td>2.32</td>
<td>Maturity</td>
<td>2</td>
</tr>
<tr>
<td>24. Parents and caregivers can remain excessively protective and may not understand privacy issues.</td>
<td>2.32</td>
<td>Family involvement</td>
<td>2</td>
</tr>
<tr>
<td>25. It is often difficult to obtain old records.</td>
<td>2.30</td>
<td>Transition coordination</td>
<td>2</td>
</tr>
</tbody>
</table>
Adult Care Team Concerns

- Patient’s maturity
- Systems issues
- Patient’s psychosocial needs
- Family involvement
- My medical Competency
- Transition coordination
Institutional & System Challenges

• Aging out of treatment
• Insurance coverage/funding changes with age:
  – Limited options for personal health insurance
  – Discontinued from parents’ health insurance
  – Change in eligibility requirements: Supplemental Security Income (SSI), Medicaid
  – Poor reimbursement for transition services
Medical Home Interaction for Patients ≥ 12 Years of Age

2a Yes
   STEP 1: Discuss Office Transitions Policy With Youth & Parents

2b No
   Is the Patient 14–15 Years of Age?
   Yes
   STEP 2: Ensure Step 1 Is Complete, Then Initiate a Jointly Developed Transition Plan With Youth & Parents

2c No
   Is the Patient 16–17 Years of Age?
   Yes
   STEP 3: Ensure Steps 1 & 2 Are Complete, Then Review & Update Transitions Plan & Prepare for Adult Care

2d No
   Is the Patient ≥ 18 Years of Age?
   Yes
   STEP 4: Ensure Steps 1, 2, & 3 Are Complete, Then Implement Adult Care Model

4
   Does Patient Have Special Health Care Needs?
   Yes
   ...
   No
   ...

Row 1: Medical Home Interaction
Row 2: Age Ranges
Row 3: Action Steps for Specific Age Ranges
Row 4: Determination of Special Needs
Elements of Health Care Transition

1. Clinic Policies
2. Registry
3. Preparation
4. Planning
5. Transfer of care
6. Transition Completion
1. Clinic Policies

• Pediatrics:
  – When will the transition process begin?
  – When is the transfer expected to happen?

• Adult Medicine:
  – What age will the clinic start seeing patient?
  – Outline of what to expect
2. Registry

- **Pediatrics:**
  - Identify transition-age youth, especially CYSHCN
  - Start by 12-14 y.o.

- **Adult Medicine:**
  - Identify young adults by level of complexity
  - Monitor health care needs
3. Preparation – *Pediatric Team*

- Prepare patients/family for success in adult care system & envision a future:
  - Visits without parents
  - Discuss illness, meds, troubleshooting
  - Self-management skills

- Assess Readiness:
  - Transition Readiness Assessment Questionnaire (TRAQ):
    - 2 domains: self management and self advocacy
    - Identifies areas for more education
**Transition Readiness Assessment Questionnaire 4.1**

**Direction:** We would like to know how you describe your skills in the areas that are important in your care. Your answers will help us provide services and education that will be important in preparing you to transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private. Please check the box ☑️ that you feel best describes you.

<table>
<thead>
<tr>
<th>Skills for Chronic Condition Self-Management</th>
<th>Not needed for my care</th>
<th>No, I do not know how</th>
<th>No, I do not know but I want to learn</th>
<th>No, but I have started doing this</th>
<th>Yes, I always do this when I need to</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you fill a prescription if you need to?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2. Do you know what to do if you are having a bad reaction to your medications?</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>3. Do you pay or arrange payments for your medications?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>4. Do you take medications correctly and on your own?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>5. Do you reorder medications before they run out?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Do you take care of your medical equipment and supplies?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>7. Do you call the suppliers when there is a problem with the equipment?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Do you order medical equipment before they run out?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Do you arrange payment for the medical equipment and supplies?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3. Preparation – *Adult Team*

- Discuss how to use/access services in adult model of care
- Continue to assess and address gaps in knowledge and skills
4. Planning – *Pediatric Team*

- Health Care Transition Action Plan:
  - Checklist of goals/expectations prior to transfer
- Portable Health Summary:
  - Chronological account of patient’s past and current medical problems
- Emergency Plan:
  - Actions to be taken during urgent/emergent events
Welcome to MyHealth Passport, a project of the SickKids Good 2 Go Transition Program. MyHealth Passport is a custom paediatric medical information. It can be used when you go to a new doctor, visit an emergency room or are writing your fi hero.

Start by filling out the information below.

CREATE PASSPORT

MyHealth Passport was conceived and created by SickKids. Special thanks is given to Crescan Internet Solutions.

The Hospital for Sick Children is not responsible for any information entered in this tool.

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4. Planning – Adult Team

• “Get acquainted” visit
  – Up to one year before transfer

• Continue to use and update:
  – HCT Action Plan
  – Portable medical summary
  – Emergency care plan
4. Planning – Team Discussion

- Insurance
- Guardianship
- Community resources
5. Transfer of Care – *What age?*

- For most, between 18-21 y.o.
- Other factors to consider:
  - Is the patient medically stable?
  - Is the illness terminal?
  - Has transition readiness been assessed?
  - What skills are still needed to make a successful transition?
5. Transfer of Care

• Pediatrics:
  – Direct communication with adult PCP and team
  – Transition package:
    • Transfer letter
    • Health summary

• Adult Medicine:
  – Review history and talk to referring physician
  – Introduce patient to clinic
6. Transition Completion

- Pediatric PCP and team remains a resource for adult PCP/team
...So, how are we doing?
…So, how are we doing?

- Different clinic code
  - Space issues: still at the pediatric ward
  - Access to Family planning clinic
  - Planning adult rheumatology fellows permanent rotation

- Admission at
  - Adult ER
  - Adult rheumatology ward
Transition: Bridging the Gap Between Pediatric and Adult Medicine
Questions?