Moving from paediatric to adult health services: transition experiences of young people with neuromuscular disorders

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Introduction

- 2013 - Transition Forum for Young People with rare chronic disease
  - Australian Paediatric Surveillance Unit (APSU) and Rare Voices Australia, Smile Foundation, The University of Sydney, Transition Care Network Agency for Clinical Innovation, NSW Health

- Published article “Challenges of Transition to adult services for patients with Rare Diseases”.

- 2014 – Started Transition Project
  - Transition experiences of patients with neuromuscular disorders
  - Small grant from the ACI

Cochrane Review:
Transition of care for adolescents from paediatric services to adult health services. Cochrane Review, Campbell et al. 2016 (only 4 studies that included evaluation of interventions to improve transition)

Background

- Neuromuscular disorders (NMDs):
  - heterogeneous group of genetic disorders
  - rare chronic
  - progressive muscle weakness and atrophy
  - require complex care from many different specialists and allied health professionals

- Impact on mobility, physical activity, quality of life, mortality
Background

- Young people often find it difficult to navigate the adult health system:
  - They don’t know what to expect
  - Feel anxious and stressed
  - Parents become excluded
  - Coordination of multiple services difficult
  - Some disengage from the health system during and after transition

- Transition into an adult health service by 18 years of age is expected
The NSW Agency for Clinical Innovation Transition Care Network provides a state-wide based service to assist young people transitioning to adult health services (x 3 transition care coordinators).

In 2012, TRAPEZE (www.trapeze.org.au) was established as a specialist adolescent chronic care service of the Sydney Children’s Hospital Network and provides an integrated care approach to transition.

*Services and clinics available in Sydney*
Current Services*

Adult Clinic Services NMDs

- 2 x Adult NMD Clinics (Royal North Shore Hospital & Concord Hospital)
- 1 x Nerve and Muscle Clinic at Prince of Wales Hospital, Randwick
- 1 x Adult Genetics Clinic and one Neurologist at Westmead Hospital (but no specialist NMD service)

*Services and clinics available in Sydney
Study Aims

1. To describe the transition experiences of young people living with neuromuscular disorders from the Sydney Children's Hospital Network (The Children's Hospital Westmead & Sydney Children's Hospital Randwick)

2. To identify enablers, gaps and needs in health services for young people with chronic complex disorders transitioning to adult health services
Survey Design

- Survey consisted of 35 questions, covering topics;
  - Age at transition to adult care
  - Self-assessment of ‘readiness’ for transfer
  - Preparation provided to young person (e.g. letter, meeting, joint consultation)
  - Young persons experiences (adult health care setting vs. children’s health care setting)
Methods

- Survey offered on-line (REDCap)* or as paper copy or telephone interview (Jan – Nov, 2014)

- Participants were sent out an information pack, which included:
  - information sheet (participant and parent/caregiver)
  - consent form
  - copy of the survey

- Surveys could be completed by the young person or by the parent/caregiver

- Included all patients with NMD transitioning during 2008 – 2014

*Research electronic data capture (REDCap)
Study Participants

**CHW**
- n = 59
- Exclusion Criteria:
  - > 25 years of age (n=5)
  - Not contactable (n=1)
  - Deceased (n=3)
- n = 50 patients invited

**SCH**
- n = 62
- Exclusion Criteria:
  - > 25 years of age (n=1)
  - Not contactable (n=3)
  - Deceased (n=1)
- n = 57 patients invited

Responses:
- CHW: n = 14/50
- SCH: n = 5/57
- Total: n = 19/107
Results

- Response rate: n= 19/107 (18%)
  Engaging young people in medical research is a well-recognised problem (Steinbeck et al. 2012)

- 9 (47%) completed by participants
- 10 (53%) completed by parents/caregiver

- 16 (84%) male; 3 (16%) females

<table>
<thead>
<tr>
<th>Condition</th>
<th>n (%)</th>
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<tbody>
<tr>
<td>Muscular Dystrophies (congenital muscular dystrophy, Becker's muscular dystrophy, myotonic dystrophy)</td>
<td>12 (63)</td>
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<tr>
<td>Spinal Muscular Atrophy</td>
<td>4 (21)</td>
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<tr>
<td>Other: (Myopathy, Marinesco-Sjögren syndrome, undiagnosed-query x-linked episodic muscle weakness)</td>
<td>3 (16)</td>
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### Transition

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<th>Median</th>
<th>Range (years)</th>
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<tr>
<td>Age transition first discussed</td>
<td>17</td>
<td>16 – 18</td>
</tr>
<tr>
<td>Age transition occurred</td>
<td>18</td>
<td>17 – 20</td>
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- **Readiness for transition:**
  - READY: 6 (32%)
  - NOT READY: 9 (47%)
  - NOT SURE: 2 (11%)
Transition Preparation

- 65% had never been to the adult hospital before the 1st appointment
- 59% had met the adult specialist before the 1st appointment

How was transition done?

65% Received some formal preparation
47% Moved through Transition Clinic
47% Talk with their Paediatric specialist
53% Referral Letter Dr to Dr
35% Referral letter received by patient

- 8 (47%) felt that preparation was not adequate
Transition not so smooth

“Too much change too soon.”
“Not confident in communicating with adult specialist.”
Mum: “They talked to John - he didn't understand what they were talking about - I did all the arrangements before."

“Should only be moved if there is somewhere for them to go. Promises made at children's hospital but not kept.

“Lack of parking, consulting room too small as we could not all sit in the room together. Door had to be left open as staff could not fit in the room with the wheelchair.”

“The transition for the neuro dept is ok, I don't have much problem. But the transition for other services like eyes clinic, endocrinology were very poorly done.”

“Had 1 meeting to organise transition but after that nothing seemed to happen. No one to help us co-ordinate to see adult doctors. Seemed to get lost in the system. “
General Practitioner (GP)

- GP knowledgeable about their condition/health (70%)
- GPs were generally aware of which medications they were prescribed (82%)
- GPs provided advice about healthy lifestyle choices (59%), and vaccinations (65%), however, they seldom discussed sexual health (17%) or mental health issues (23%)
- Just over a third (35%) reported that their GPs communicated regularly with their medical specialists
Transition/Care Coordinator

- Who would you recognise as the coordinator of your overall medical care?

65% Parents

24% Health Professionals

(Neurologist, GP, Clinical Nurse Consultant, Occupational therapist)
Summary

- There are few studies of transition

- Our results are similar to those published by others
  - Lack of preparation for transition
  - About half not ready
  - Adult clinic too far
  - Difficulty navigating the adult health system
  - Lack of coordination / integration
  - Young people are difficult to engage in research

- UK study of transition experiences of young men with DMD (Abbott, Carpenter, & Bushby, 2012). (38/121 (31%) postal survey; 40/102 (40%) face-to-face interviews)

- Canadian study evaluating transition program for patients with Osteogenesis Imperfecta (Dogba, Rauch, Wong et al, 2014) (6 patients/4 parents; 15 staff)
Future Directions

- Trapeze: Launched new website in 2015 (www.trapeze.org.au)
  - Resources for patients, parents and health professionals
  - Checklists for patients and clinicians
  - Tips & Resources
  - Transition plans

- Transition Mate Phone App in development (Kate Steinbeck’s group)

- Future evaluation studies needed to assess if transition experiences of young people with NMDs have improved.
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Welcome to the APSU

The Australian Paediatric Surveillance Unit (APSU) is a national resource established in 1993 to facilitate active surveillance of uncommon rare childhood diseases, complications of common diseases or adverse effects of treatment. The APSU has a valued relationship with the Paediatrics and Child Health Division of the Royal Australian College of Physicians that has been established over many years between the parties.

We are also closely affiliated with the University of Sydney, discipline of Paediatrics and Child Health and the Sydney Children’s Hospital Network.

Thank You - Questions?