

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

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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

Current Services*

Transition Services

- 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)

Confidential

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Experience of transition to adult care for young people with neuromuscular disorders

SECTION 1: TO BE COMPLETED BY THE YOUNG PERSON

1a. First 2 letter of first name _____

1b. First 2 letters of surname _____

1c. Date of survey completed _____
(Enter DD-MM-YYYY)

2a. DOB _____
(Enter DD-MM-YYYY)

2b. Age _____

3a. Diagnosis? _____

3b. Date of Diagnosis _____
(Enter DD-MM-YYYY)

3c. How was the diagnosis made?
 Genetic Testing CK Test Muscle Biopsy Other
Other (Specify) _____

4. Do you CURRENTLY access specialist medical care through:
 A Children's Hospital An Adult Hospital
A Children's Hospital (specify which) _____
(Please go to Question 5)

An Adult Hospital (specify which) _____
(Please go to Question 9)

5. If you answered Children's Hospital above, has your medical team discussed transfer of your care to an adult specialist?
 Yes No Don't know/unsure

IF YOU ANSWERED NO TO THE ABOVE QUESTION (Q5), THANK YOU, YOU DON'T NEED TO ANSWER ANY FURTHER QUESTIONS.

PLEASE COMPLETE THIS SECTION ONLY IF YOU HAVE DISCUSSED TRANSFER OF YOUR MEDICAL CARE TO AN ADULT SPECIALIST BUT HAVE NOT YET TRANSITIONED.

6. What has been discussed/ received so far with regards to your transition to adult health services? Please describe below:

7. Do you have any concerns regarding the transition process?

Yes No Don't know/unsure

Please specify your concern

8. What information would you like to receive/access regarding the transition process? Please specify:

THANK YOU, YOU HAVE COMPLETED THE SURVEY! YOU DON'T NEED TO ANSWER ANY FURTHER QUESTIONS.

PLEASE COMPLETE THIS SECTION IF YOU HAVE TRANSITIONED TO ADULT HEALTH SERVICES

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

Study Participants

CHW

n = 59

Exclusion Criteria:

- > 25 years of age (n=5)
- Not contactable (n=1)
- Deceased (n=3)

n = 50 patients invited

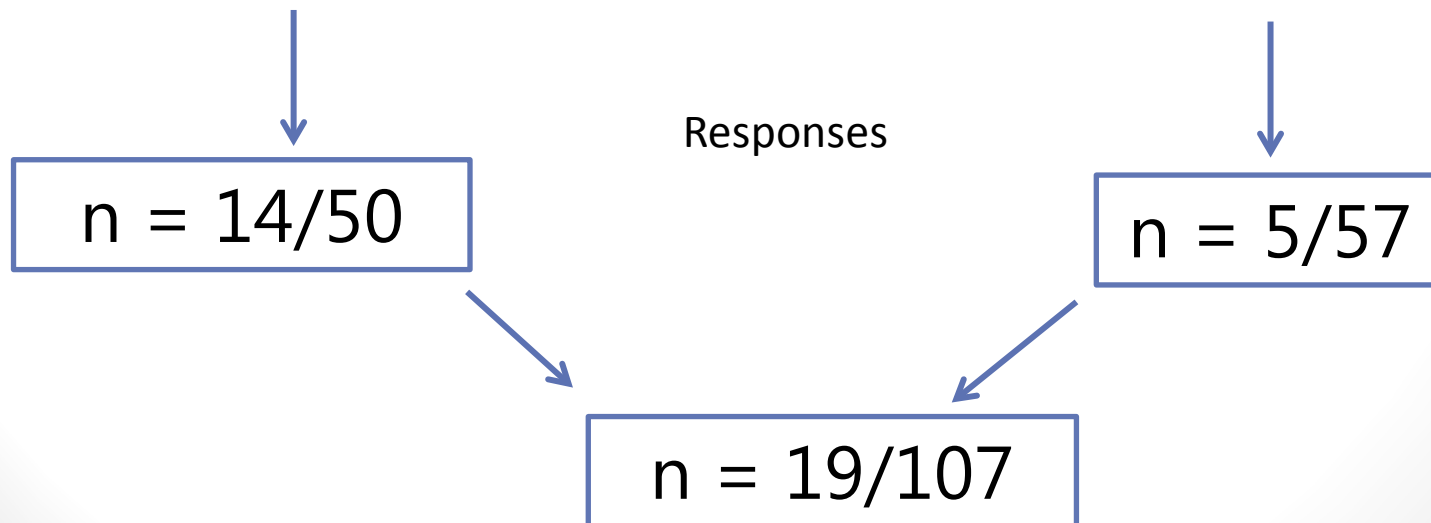
SCH

n = 62

Exclusion Criteria:

- > 25 years of age (n=1)
- Not contactable (n=3)
- Deceased (n=1)

n = 57 patients invited



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

Condition	n (%)
Muscular Dystrophies (congenital muscular dystrophy, Becker's muscular dystrophy, myotonic dystrophy)	12 (63)
Spinal Muscular Atrophy	4 (21)
Other: (Myopathy, Marinesco-Sjögren syndrome, undiagnosed-query x-linked episodic muscle weakness)	3 (16)

Transition

	Median	Range (years)
Age transition first discussed	17	16 – 18
Age transition occurred	18	17 – 20



- 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."

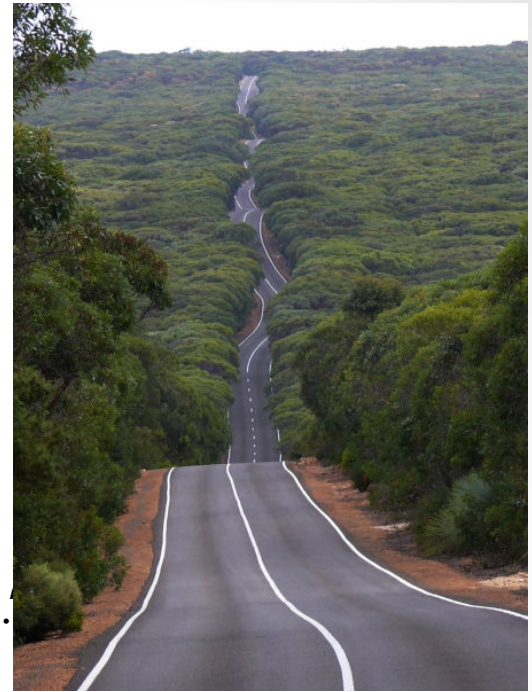
Mum: "They talked to *John* - he didn't understand what they were talking about - I did all the arrangements before. "

"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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Thank You - Questions?

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A screenshot of the APSU website homepage. The header includes the APSU logo (a blue square with 'ap' over 'su'), the text 'The Australian Paediatric Surveillance Unit at the Kids Research Institute', a search bar with a 'GO' button, and social media icons for Twitter and Facebook. A navigation menu contains links for Home, About, Studies, Research, Publications, Rare Diseases, Other surveillance systems, and Contact Us. The main content area features a large image of two young girls with blue and purple paint on their faces, with a 'PARENTS! Read this first!' callout box. Below the image is a 'Welcome to the APSU' section with introductory text. On the right side, there are three news items: 'APSU New Publication' with a link to a paper on Kawasaki disease, 'APSU Report Card Changes' regarding severe complications of influenza, and 'APSU NEWSLETTER' with a link to the March 2015 issue. At the bottom of the right sidebar, there is a 'Congratulations to the BPSU - 30 Years!' message with a link to more information.