

Evaluation of the Queensland Paediatric Neuromuscular transition model.

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Background:

Patients with a diagnosis of neuromuscular disease must navigate a complex web of state and community services through the transition from child and family-centred to adult-oriented healthcare. This study examined barriers to successful transition from the patients and caregiver perspective as well as the clinician perspective.

Methods:

Adolescents with a primary diagnosis of a neuromuscular condition who were 16 years and over in Queensland were eligible to be included in the study. Surveys were collected over a 6-month period and descriptive statistics were used to summaries and characterise survey responses.

Results:

A total of 40 young people or their carers completed the patient survey with a response rate of 42% and 19 clinicians with a response rate of 54%. There was a high degree of anxiety reported about transition with almost 50% of patients and families surveyed reporting concerns about moving across to the adult hospital system. The main barriers to effective transition identified by clinicians were limited time (84%) and clinic space (58%) as well as a lack of an identified transition coordinator (79%). This study has informed a checklist to guide the transition of neuromuscular patients from paediatric to adult care.

Conclusions:

A new model has been developed to enable a slow, personalised transition that is led by a multidisciplinary team to ensure the continuity of high-level care from paediatric to adult healthcare services and the achievement of the highest possible quality of life for these patients.

Disclosure of Interest Statement: RL has no disclosures to report. KM & AC have received honoraria from Biogen, Novartis and Roche for participation in scientific advisory boards and honoraria from Biogen paid to their institution for participation in educational activities, all unrelated to the content of this manuscript.