

Development and implementation of a formal transition pathway for adolescents and young adults on home parenteral support in a UK intestinal failure unit.

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Abstract text

Background

Advances in the management of chronic intestinal failure (IF) over the recent years have resulted in more children on home parenteral support (HPS) surviving into adulthood¹. A UK-wide survey of IF transition services in 2015 highlighted the complexity of this patient cohort, the lack of clinical standards and the need for structured services to support adolescents and young adults (AYAs) through a vulnerable period of their lives². Despite this, there are no reports of IF transition models in the UK.

Aim

We aimed to develop a structured transition pathway for AYAs on HPS to support transfer to adult services.

Methodology

Paediatric and adult multidisciplinary IF teams developed a clinical pathway, led and implemented by the nursing team. Dedicated transition clinics were attended by both teams. The paediatric team identified clinically stable children suitable for transition and HPS independence training in conjunction with homecare. Care proformas including clinical data and social history were developed to standardise consultations. Educational documents covering assessment and transition readiness tools for principle stakeholders (AYAs, parent/guardians, clinical teams) were developed in collaboration with the patient support group PINNT. Clinical outcomes were collected from electronic patient records and patient- and clinician-satisfaction surveys were completed during and after the transition clinics for each AYA.

Results

The transition pathway commenced in 2019. Dedicated annual transition clinics were run for the first three years, with six-monthly clinics thereafter. Standardised proformas were completed for each consultation and transition readiness assessed using validated tools at each visit. To date, 15 AYAs have been seen in total. The mean age at transition commencement was 12.9 years. Three AYAs were female (20%). The most common IF aetiology was SBS (7/15, 46.6%). Five AYAs fully completed transition and successfully transferred care to adult services (four self-caring). The median HPS duration at transfer was 16.5 years (interquartile range 9-16.5 years). No episodes of

catheter-related bloodstream infection, catheter thrombosis or IF related hospital admission occurred during or following transition (>1yr) in any patient. Attendance rates were high, with only one clinic appointment missed (1/11 appointments, 9%). All 15 AYAs and all IF team members reported 'very positive' experiences throughout the transition clinics.

Conclusion

A standardised transition pathway involving multidisciplinary paediatric and adult IF teams for AYAs on HPS is feasible and safe in the UK, and supports successful transfer to adult IF services. National guidance to standardise practice across accredited UK IF units is justified.

References

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