
POSTER ABSTRACT

Adolescent feedback on the Haemophilia Transition Programme between Our Lady's Children's Hospital and St. James's Hospital Dublin Ireland.

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Introduction: Haemophilia is an X-linked congenital bleeding disorder caused by the absence or low level of particular proteins called clotting factors, specifically factor VIII or factor IX in the blood (1). The complexity of the condition can be particularly challenging during adolescence, as the young adult assumes responsibility for managing their condition. In order to improve and standardise the transition pathway for young adults with haemophilia in Ireland, a Transition Programme was established in 2012 between the National Paediatric Coagulation Centre, Our Lady's Children's Hospital (OLCHC) and the National Coagulation Centre (NCC), St. James's Hospital, Ireland.

Targeted population: To determine if the Transition Programme was addressing the needs and preferences of this patient group, a satisfaction survey was distributed to 83 patients in July 2016. The questionnaire comprised of 50 qualitative and quantitative questions and incorporated categories relating to the paediatric and adult service, knowledge of condition, self-management and general health. The questionnaire was approved by the NCC Patient Partnership Panel. The response rate was 23% (N=19)

Highlights: 90% respondents reported that they felt prepared for their move from paediatric to adult services. Respondents expressed satisfaction with staff interactions, describing staff as helpful and pleasant. 53% were not confident that they knew how to access the adult service after 5pm and 33% reported that they required additional information about the adult service. 26% of adolescents reported that they were not confident that they could recognise a bleeding episode. 21% of the adolescents surveyed were unsure about appropriate oral care. Five patients (26%) highlighted the need for access to personalised information about managing their condition and relevant services in the adult treatment centre. A shared action plan was developed as follows:

Develop a Transition information leaflet.

Develop a "Transition Pack" containing information leaflets about the adult services, condition specific information and transition information.

Facilitate group meetings for parents and adolescents.

Distribute a parental satisfaction survey.

Develop a shared electronic nursing care plan.

Develop a patient portal where adolescents can access information about their treatment centre, condition, self-management and relevant education. This will also include an online transition education programme.

Comments on Transferability: The questionnaire utilised can be adapted for evaluating other chronic disease transition programmes and the improvement initiatives could be adopted to develop transition programmes in haemophilia services internationally.

Conclusions: Feedback on the Transition Programme between OLCHC and NCC revealed that the majority of young adults surveyed felt adequately prepared to transfer to the adult service. However; significant knowledge gaps about their condition and a lack of awareness regarding services available were also discovered. The multidisciplinary team in OLCHC and NCC have identified a number of initiatives that will improve adolescent satisfaction and develop the adolescent's condition knowledge and self-management skills.

References:

1- World Federation of Hemophilia. GUIDELINES FOR THE MANAGEMENT OF HEMOPHILIA 2nd edition. c2012. Available from: <http://www1.wfh.org/publications/files/pdf-1472.pdf>.

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