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Patient and parent feedback in relation to a dedicated cardiomyopathy transition clinic

*Green L., Mackay R., Casey C., Daubeney P., Prasad S.
The Royal Brompton Hospital London England*

Introduction

The Inherited Cardiac Conditions Service offers transitional care to young people and their families transitioning from children's to adult services. Incorporated in this is a dedicated cardiomyopathy clinic for young people between the ages of 16 to 20 years. Transitional care aims to provide the necessary skills for self-management and participation in care (Acuna Mora, 2017). The National Institute for Clinical Excellence (2016) recommend that young people should be involved in transition service design, delivery and evaluation.

Method

'Quick feedback sheets' (QFS) were provided to young people and their carers during their attendance to the cardiomyopathy transition clinic in order to obtain feedback and suggestions for practice development. An 'emotional touchpoint' (ETP) was performed to explore a patient's experiences of transition.

Results

The QFS was completed by 14 patients and their parents who attended the transition clinic. Patients commented on members of the multi-disciplinary team as 'helpful' thus contributing to them having a 'positive experience'. The ETP sourced data in relation to experiences of transition. Feelings were expressed including; feeling "nervous" "It's a new stage in life, things may be a little different from before" and a general theme of support was conveyed, "everyone wants the best for me". Themes of inclusion and communication were also present; 'contact with nurse excellent' and 'I feel included in decisions'. Service development areas were identified, patients responded that they would like the opportunity to meet other young people; a 'way to let patients talk with the same condition to offer support and advice' would be appreciated. Another recommendation was that a patient stated 'I would have liked a transition talk earlier before I turned 16'.

Conclusions

Feedback was obtained from patients, and their parents, attending a cardiomyopathy transition clinic. Using the specified tools, themes were identified, thus reinforcing the need for communication and supportive practice during the transition process. It was recognised that transition consultations are required earlier than at the age of 16 years. Service development should be considered to incorporate the enabling of young people to meet others with the same condition to facilitate peer discussion and support.