

Transition program for children with congenital heart disease: the importance of patient engagement and partnership

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Introduction: Most children with congenital heart disease (CHD) reach adulthood. In Canada, > 50 % of adults with CDH don't benefit from a close follow up by healthcare providers and > 60 % of children with CHD in Quebec discontinue follow up at adulthood.

Methods: This study aims to build a transition program for children with CDH in partnership with patients and healthcare professionals. Our hypothesis is that patient engagement through this process and peer support between adult patients who went through the transition and adolescents with CDH will help them acquire skills for self-management and lead to better follow up in adulthood. The study includes quantitative and qualitative data collected through focus groups, individual interviews and questionnaires with healthcare professionals, adult with CHD, adolescents with CHD and their parents. The study assesses the potential benefit of peers in supporting patients through their transition, by implementing a co-constructed program in partnership with patients and their families.

Results: Healthcare professionals (n=15) consider patient engagement in transition program to be important. Even if most feel comfortable with engaging patients as partners in transition programs, they have questions regarding their professional/legal responsibilities in such programs and worry about the burden of increased workload. The transition for adult patients (n=6) was smooth even though the majority didn't have any information or discussion with the medical team about the process. Surgical interventions and changes in treatment after transfer were described as more traumatic than the transition itself. Parents of adolescents (n=7) were much more affected by the transition than the adolescents themselves. In this study, the average age of adolescent was 17.8 [17-18 yrs, n=6]; 83 % of the parents mentioned that they had not discussed the transition with healthcare professionals and 100% said they didn't have any information about it. Parents felt helpless and needed support.

Conclusions: Transition is an important issue to address, and implementing a program based on peer support and partnership with patients and their family is a promising path to respond to the needs of children with CHD and their parents and improve the quality of healthcare services.