

Factors influencing the participation of adolescents and young adults with congenital heart diseases in a transition education program: a multicenter observational study

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Purpose: The improvements of the surgical and medical care of patients with congenital heart disease have led to a significant improvement in their life expectancy. Every year it's 200 more patients (on 100000 birth) that will reach the adulthood. Our next objective now is to improve their quality of life. Therapeutic education can be a very useful tool to reach this goal. But more than 50% of the patients don't have any medical monitoring after 18 years. The pediatric cardiologist have to prepare their patients to the adulthood to limit the level of "lost of sight", and that is why we created a transition program in our center. The purpose of this program is to help the patients between 13 and 25 years to get every skills that will help him in his "patient" life. The goal of this study was to highlight the factors that convince the cardiologist to include his patient in this program.

Methods: Transversal observational multicenter study lead from November 2015 and January 2017. We included all patients that participate to the transition program as the transition group. We selected at random in consultation, patients that wasn't included in the program as the control group. They had to complete 3 questionnaires (Knowledge, quality of life and physical activity).

Results: 123 patients included, 57 in the transition group and 66 in the control group. Mean age 19,7 years. The factors that influence the inclusion in the transition program in univariate and multivariate analysis were: the severity of the disease (OR:4,1, p=0,03), the presence of piercing (OR: 5,5, p=0,007), a great level of knowledge (OR 0,29; p=0,02) and a young age (OR 0,289; p= 0,025).

Conclusion: this study highlight the factors that influence the cardiologist when they include a patient in a specific transition program. It's a population of patients with more severe diseases, with a lack of knowledge and with behaviors at risk of complication. Our next study will try to assess the effectiveness of the transition education on the quality of life of patients with a congenital heart disease. (Clinical Trials #NCT03005626)