Transition program in pediatric cardiology

Geiser Mages V., Gendre C., Sekarski N., Di Bernardo S., Mivelaz Y., Boulos Ksontini T., Prsa M.
University Hospital, Lausanne, Switzerland

Introduction:
Thanks to advances in diagnosis, medical treatments and surgery, children born with congenital heart disease (CHD) have a good chance to reach adulthood with an excellent quality of life. Several studies have shown the importance of a transition program for adolescents with a chronic disease. Our center covers an area of 2 Mio inhabitants and all CHD patients are followed at our clinic.

Objective:
Creation of a transition program targeting the specific needs of adolescents with CHD in our outpatient clinic.

Method:
Patients with CHD from our clinic between 14 and 18 years old and their parents received each a questionnaire targeting their educational needs and the actual satisfaction of them. At the same time we began a program of thematic workshops for these patients and organized two sessions on the theme“A Healthy Heart”.

Results:
We sent 187 questionnaires to adolescents with CHD aged 14 to 18 years and their parents (374 questionnaires in total). We received 136 answers (61 adolescents and 75 parents). The main topics where adolescents had insufficient knowledge were: signs of gravity (50.8%), physical restrictions (46.1%), adulthood follow-up (71.7%), future risks (45.9%). According to their parents they lack information about their CHD (39.2%), the effect of alcohol and tobacco (61.2%), contraception and pregnancy (67.4%) and adulthood follow-up (72.3%). 77% of the adolescents and 90.7% of their parents found important that the nurses in pediatric cardiology see the patients to give them additional explanations and answer their questions. The two sessions of thematic workshops on the theme“ A Healthy Heart” were followed by 11 adolescents. Nine of them reported to have learned something new and were ready to participate in further workshops.

Conclusion:
The answers to the questionnaires show the need for a personalized educational program for adolescents with CHD including their present condition and their future. The thematic workshops answer to some needs of the adolescents and will be extended and completed with the following themes: “My Cardiopathy”, “Daily life with a Congenital Heart Disease” and “My future”.