Early introduction of self-educational program for the early adolescents with congenital heart disease in outpatient clinic of the local independent children’s hospital-nursing perspectives

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Background: Although the patient care for the adults with congenital heart disease (ACHD) has been emphasized in centralization of ACHD medical center, the self-educational program of the patients preparing their independence is also mandatory but often passed away. Aim: To investigate the self-assessment status of the ACHD patients by questionnaires and to assess the nursing patient-aid program to help postsurgical children learn their disease to be an independent adult. Methods: The subjects were 415 young children and early adolescents with CHD in outpatient clinic, age ranged 10-34 years; (194<15y, 114:15-18y, 104:18y< ). After they learned their disease by drawing figures and explanations of charged doctors, they filled the questionnaire regarding to their diagnosis, surgical procedure, hemodynamics, medications, social matters and the issues of pregnancy in our hospital which was established 20 year ago. Then their achievement degree was reassessed by the nurses and encourage them to make a plan to learn by themselves. Results: All patients were once informed from the age of 6 years old about their diagnosis and the content of treatment including the surgery and medications with figures in outpatient clinic. At the second visit after having information, more than 70% of the patients could answer their timing of the surgery. Of 415, the correct answer of their diagnosis and treatment of the patients was 62% (18y<); 23% (<15y), 42% (18y): 19%(<15y), respectively. The prevention of infective endocarditis and pregnancy were poorly recognized as 34%, 19% even in 18y<. After the aid of nursing support program, 67% of patients could improve their achievement scores.

In conclusion, self-educational program for CHD children/adolescents is indispensable to train them to be independent in adult, which could be introduced even in the local children’s hospital.