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The Application of Grown-up Congenital Heart Self-Assessment Questionnaire to Identify and Improve Knowledge Gap and Self-management in Adults with Congenital Heart Diseases

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Introduction

With improved congenital heart management in children, there is substantial survival to adulthood. This resulted in expanding population of grown-up adults with congenital heart diseases worldwide including Hong Kong. Transition of these patients from paediatric services to adult services represents an important aspect of care. One of the tasks in transition is to empower the patient, which can be achieved by improving their knowledge and their own self-management. Studies showed that these patients had inadequate knowledge and perception about their condition and care. This might result in loss of follow-up, delayed seeking medical care and specialist care, and unnecessary restriction in exercise. However, local scenario is largely unknown.

Objectives

To explore patients' knowledge, perception and their self-management using a structured questionnaire in grown-up congenital heart (GUCH) patients.

Methodology

Grown-up patients (18 years or above) first attended Adult Congenital Heart Disease Clinic in Queen Mary Hospital were asked to complete the Grown-up Congenital Heart Self-Assessment Questionnaire (GUCH-SAQ) which is a self-administered questionnaire on the knowledge and perception of their congenital heart disease, and respective self-management. After completion, patients would be educated and counselled accordingly by the attending cardiologist. Patients' responses were assessed according to criteria from management guidelines or cardiologists' assessment.

Result

Sixty-five patients (Male = 35) completed the GUCH-SAQ. Their mean age was 25.8±6.9 years (range: 18.5 – 51 years). The complexity of CHD was mild in 11 (17%), moderate in 39 (60%) and severe in 15 (23%). Fifty-six patients (86%) had cardiac surgery. Forty-one patients (63%) could tell the name of their heart diseases either

fully correct (27.7%) or partially correct (35.3%); 19 (29.3%) patients could not recall and remaining 5 (7.7%) gave the wrong names. Among patients with prior cardiac surgery, only 5 (9%) recalled the surgery fully correct and 10 (18%) partially correct. Concerning disease severity, 22 (34%) patients perceived in concordance with the cardiologists, while 16 (25%) under-estimated and 10 (15%) over-estimated their severity. The remaining 17 (26%) patients could not tell their severity. Fourteen patients (21.5%) reported that they had received information about their heart diseases from doctors only, 27 (41.5%) from parents only, 21 (32%) from both parents and doctors. Patients who received information from doctors reported higher correctness on their perception on diseases severity ($\chi^2 = 13.7$, $df = 2$, $p = 0.001$). Patients could perceive correctly whether they can or cannot participate in vigorous exercise (69%), moderate exercise (90%), and contact sports (71%) respectively. Fifty-four patients (83%) did not know about endocarditis. Twenty-one patients (32%) did not know whether they require antibiotic before invasive dental procedure. Antibiotic prophylaxis was required in 14 patients, among them, 5 (36%) knew correctly, 5 (36%) considered that they didn't require antibiotic, and 4 (28%) did not know if they need antibiotic or not. Among 30 women in the cohort, pregnancy was considered to be low-risk in 5 (17%), moderate-risk in 18 (60%), high-risk in 4 (13%) and contraindicated in 3 (10%). Four (13%) under-estimated and 10 (10%) over-estimated their pregnancy risk. Twenty-two patients (34%) were correct about the recurrence risk of congenital heart disease in their offspring. Seventeen (26%) patients under-estimated, 1 (1.5%) over-estimated and the remaining 25 (38.5%) did not know the recurrence risk. Conclusions: GUCH-SAQ allows systematic assessment of patients' knowledge, perception and their respective self-management. Grown-up patients have deficit in knowledge, perception, and self-management. These call for strategies to increase education and a structured transition care to empower the patients with congenital heart disease.