Journal of Adolescent Health xxx (2015) 1–8

ELSEVIER

JOURNAL OF ADOLESCENT HEALTH

www.jahonline.org

Original article

# Patient-Reported Health in Young People With Congenital Heart Disease Transitioning to Adulthood

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*Article history:* Received April 19, 2015; Accepted July 30, 2015
*Keywords:* Heart defect; Congenital; Adolescents; Health status; Longitudinal; Outcome

A B S T R A C T

**Purpose:** Because life expectancy of patients with congenital heart disease (CHD) has increased substantially, assessment of patient-reported health is seen as an important component in the follow-up. Therefore, we (1) examined patient-reported health status of young people with CHD from a longitudinal perspective; (2) compared patient-reported health of patients with that of controls from the general population; and (3) investigated longitudinal interrelationships among various domains of patient-reported health.
**Methods:** We included 429 patients with CHD (aged 14–18 years) in a longitudinal study with four measurement points. Patient-reported health status was measured using a linear analog scale for self-rated health and the Pediatric Quality of Life Inventory (PedsQL).
**Results:** Self-rated health was good, with mean scores that slightly decreased from 81.78 to 78.90 from Time 1 to Time 4. PedsQL scores were also good, with the highest scores obtained for physical functioning. Patients with mild heart defects consistently reported higher scores on self-rated health and PedsQL than the general population. The scores of patients with complex heart defects were generally lower than those of the general population. Cross-lagged path analyses demonstrated that symptoms, cognitive functioning, and communication problems constituted the most consistent predictors of perceived health domains over time.
**Conclusions:** Patient-reported health was considerably good. Domains of patient-reported health that deserve specific attention are symptoms, cognitive functioning, and communication problems. Intervening in these three domains may yield indirect benefits on other health status domains and may improve the overall perceived health status of young people with CHD.
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**IMPLICATIONS AND CONTRIBUTION**

Among adolescents with congenital heart disease, 16%–33% report a substantial decrease in patient-reported health. Domains that deserve specific attention are symptom management, cognitive functioning, and communication problems. Interventions improving these three domains may yield indirect benefits on other health domains and, consequently, may improve overall health status of patients.

In 2013, the American Heart Association published a scientific statement emphasizing the importance of patient-reported health assessment for clinical decision-making and health surveillance [1]. Patient-reported health status is seen as a critical measure of cardiovascular health [1] and as an important component of patient-centered care [2]. Patient-reported health

**Conflicts of Interest:** None of the authors have any relationship with industry or financial associations that might pose a conflict of interest in connection with the submitted article.

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http://dx.doi.org/10.1016/j.jadohealth.2015.07.021

status reflects the impact of disease on functioning as reported by the patient and is defined as the range of disease manifestations in the individual patient, including symptoms and functional limitations [1]. Although clinicians generally focus on the diagnosis and evaluation of signs and symptoms, patients pay attention to the complete range of effects of disease on their health status [1].

An increasingly growing population of patients in the cardiac field represents persons with congenital heart disease (CHD). CHDs are the most common congenital defects [3], and today, >90% of children with CHD survive into adulthood as a result of improvements in diagnosis and treatment [4,5]. Survival with CHD is often not equivalent to being cured, and many patients are therefore in need of lifelong medical follow-up [6]. The assessment of patient-reported health should be an important component of this follow-up.

Numerous studies on patient-reported health in persons with CHD have been published over the past decades. However, to the best of our knowledge, all studies have used cross-sectional designs, which preclude drawing conclusions about changes over time. Moreover, cross-sectional studies permit investigation of associations between variables but do not allow for assessing the directionality of effects. Such knowledge could provide essential information when designing future interventions to be implemented in transition programs. Indeed, together with preventing interruptions of care, transition programs aim to enhance and maintain good health status and yield optimal quality of life [7,8]. Therefore, these factors have been used as outcome measures in studying the effectiveness of transition programs [9]. However, to know if patient-reported health would be a relevant outcome in transition effectiveness studies in CHD, researchers need baseline data and information about the natural development of patient-reported health, as well as information about possible moderators of this development.

The aims of the present study were to (1) examine patient-reported health status of young people with CHD from a longitudinal perspective; (2) compare patient-reported health of young people with CHD to that of peers from the general population; and (3) investigate the longitudinal interrelationships among the various domains of patient-reported health.

## Methods

### *Study population and procedure*

This study was part of Information technology Devices and Education program for Transitioning Adolescents with Congenital Heart disease (i-DETACH), a longitudinal study on the transition of adolescents with CHD to adulthood including four measurement points (Time 1–Time 4); the measurement interval was 9 months. Hence, we had a 27-month follow-up. Inclusion criteria were as follows: confirmed CHD, defined as structural abnormalities of the heart and/or intrathoracic great vessels that are functionally significant [10]; aged 14–18 years at the start of the study; last cardiac consult ≤5 years ago at our tertiary care center; Dutch speaking; and valid contact details available. Exclusion criteria were cognitive or physical limitations that prevented patients from filling out questionnaires, prior heart transplantation, and absence of consent to participate from patients or their parents. Overall, 498 patients met these inclusion criteria. Eligible patients received by post a package with questionnaires, which they were to return by post after completion. A detailed description of the procedure used in this study has been published previously [11].

Of the 498 eligible patients, a total of 429 (86%) participated at Time 1, 398 at Time 2, 366 at Time 3, and 337 at Time 4. Overall, 304 (71%) subjects participated in all subsequent measurement waves. We performed Little's Missing Completely at Random Test (MCAR) [12] to compare participants with and without complete data. Because missing values were at random, we used the expectation-maximization algorithm to estimate missing values of patient-reported health variables; thus, all analyses were performed on the entire sample of 429 participants. Demographic and clinical characteristics of the sample are detailed in Table 1. Supplementary Table 1 describes for each heart defect the number of patients who did or did not undergo cardiac surgery and the distribution of their heart defect complexity.

For each patient at Time 1, a control subject from the general population was sought. Controls were recruited at secondary schools, colleges, and universities. After data collection, controls were matched to patients (1:1 matching) for sex and age. Overall, 403 patients could be matched to controls, but complete data on the linear analog scale (LAS) and Pediatric Quality of Life Inventory (PedsQL) generic domains were available for 398 controls. Hence, direct comparison of patients and controls was

**Table 1**
Demographic and clinical characteristics of 429 young people with CHD at inclusion

| | n (%) |
|---|---|
| Male subjects | 229 (53.4) |
| Median age (years) | 16.3 (Q1 = 15.3; Q3 = 17.3) |
| Educational level (n = 413) | |
| General secondary/university/university college | 194 (47.0) |
| Technical secondary | 135 (32.7) |
| Vocational secondary/special education[a] | 84 (20.3) |
| Primary CHD diagnosis | |
| Hypoplastic left heart syndrome | 2 (.5) |
| Univentricular physiology | 4 (.9) |
| Tetralogy of Fallot | 11 (2.6) |
| Double outflow right ventricle | 12 (2.8) |
| Double inlet left ventricle | 1 (.2) |
| Truncus arteriosus | 1 (.2) |
| TGA | 26 (6.1) |
| Congenitally corrected TGA | 5 (1.2) |
| Coarctation of the aorta | 43 (10.0) |
| Atrioventricular septal defect | 6 (1.4) |
| Atrial septal defect type I | 4 (.9) |
| Ebstein malformation | 2 (.5) |
| Pulmonary valve abnormality | 38 (8.9) |
| Aortic valve abnormality | 69 (16.0) |
| Aortic abnormality | 9 (2.1) |
| Left ventricle outflow tract obstruction | 5 (1.2) |
| Atrial septal defect type II | 56 (13.1) |
| Ventricular septal defect | 78 (18.1) |
| Mitral valve abnormality | 37 (8.6) |
| Pulmonary vein abnormality | 9 (2.1) |
| Other | 11 (2.6) |
| Complexity of heart defect | |
| Simple | 174 (40.6) |
| Moderate | 204 (47.6) |
| Complex | 51 (11.9) |
| Underwent prior heart surgery for congenital heart disease | 200 (46.6) |
| Pulmonary arterial hypertension | 20 (4.7) |

CHD = congenital heart disease; TGA = transposition of great arteries.
[a] Vocational secondary education is education within vocational schools that prepares people for a specific trade. Special education is education provided by dedicated schools for people with learning disabilities and/or mental retardation.

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