Self-Efficacy and Physical Activity Level Holds Important Implications for Transfer of Adult Congenital Heart Disease

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Congenital heart disease (CHD) affects close to 1% of live births. Surgical advances and improvement in medical care have significantly reduced early mortality and led to an exponential growth of the adult CHD (ACHD) population. As a result, Japan has approximately 400,000 ACHD patients, 130,000 of whom are estimated to be moderate or severe; this number is estimated to increase by 9,000 annually. However, many patients currently continue treatment with pediatric cardiologists, even after reaching adulthood, which stems from the inadequacy of regional ACHD centers, particularly adult cardiologists’ passive attitudes toward ACHD care, and the lack of a cooperative network between regional ACHD centers and children’s hospitals. Therefore, the number of regional centers offering outpatient and inpatient care is limited by a reluctance to deal with low numbers of patients, a lack of experience with older CHD patients and because transfers from pediatric departments are not standard in Japan.2,3

ACHD patients generally experience similar symptoms regardless of the underlying anatomy. Patient-reported outcomes (PROs)-related symptoms of greatest importance to ACDH patients are increasingly valued in addition to traditional medical parameters. PROs are directly reported by patients, without interference of the attending physician. PROs thus offer unique insight into how patients sense and judge their health and wellbeing. Thus we read with interest the article in this issue of the Journal investigating PROs in ACHD by Ochiai and colleagues4 about the preferences

Figure 1. Comparison of physical activity level between adolescent CHD patients and healthy controls (HC). CHD, congenital heart disease.

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regarding transfer of patients with CHD who attend children’s hospitals as they seek to better understand the variation in transfer practices. They examine 3 important issues in improving the education of patients regarding the opportunities for transfer: in order to develop systematic transition programs between regional ACHD centers and children’s hospitals. (1) Approximately 60% of patients wish to continue to receive ongoing care at their children’s hospital. (2) The physician had not explained about the transfer to approximately 65% of patients. (3) Acquisition by patients of self-management may promote transfer.

In other word, these 3 issues interfere with the physical activity level (PAL) in ACHD patients. PAL has the potential to modify cardiovascular risk factors and promote general health. Almost 70% of ACHD patients did not reach the WHO recommended PAL of 2.5 h/week of physical activity of ≥3 metabolic equivalents (METS). There is a large variation among countries in the proportion of patients who achieve the recommended PAL, from 10% to slightly more than 50%. Given the proportion of patients not reaching the recommended PAL, many patients are at potential risk for developing long-term complications related to low PAL. In ACHD patients, in particular, Bay et al demonstrated low PAL in those who were older, had worse NYHA functional class, and were physically less active. Several patient-related factors are potentially associated with low PAL in patients with ACHD: reduced aerobic capacity, impaired muscle function, restriction recommendations by their cardiologists, parental overprotection, and self-efficacy. Therefore, issues regarding the PAL should be encouraged and discussed in all consultations with ACHD patients. Furthermore, the identified predictors of PAL may help to identify vulnerable patients and thereby allow for targeted interventions.

A recent published study found greater transition readiness in adolescent CHD patients with greater self-efficacy. Among children and adolescents with CHD, the settled conviction of one’s own self-efficacy was shown to correlate with increased PAL, independent of disease complexity. My group has also observed stronger associations between sport participation and PAL. In our study, physical education participation rates in adolescent CHD patients (n=60) were lower than in those of healthy controls (n=20) (Figure 1). Surprisingly, 40% of the adolescent CHD patients reported that physical education was cancelled by a teacher or instructor without a clear explanation (Figure 2). It is an important matter for both children and adolescent CHD patients in deciding to participate in exercise. Transfer from pediatric to adult congenital specialists should occur as the summit of a multiyear process of transition education. Education should include anticipatory guidance regarding residual lesions, potential late sequel implications for vocation and lifestyle issues, as well as contraceptive and pregnancy planning. The importance of lifelong care should be emphasized at a young age, as demonstrated by many patients failing to follow-up with pediatric cardiology before adulthood. As the vitality required for maintaining lifelong and active motivation to participate in exercise improves, so that ability to work at exercising increases. It is most important for ACDH patients to graduate from the protection of parents and shift to specialized ACHD facilities in the future. Needless to say, exercise-specific patient-parent-doctor-teacher education guidance is required ASAP.

References
3. Lear CP, Jefferies JL. The challenges of transfer and transition

Figure 2. Comparison of teacher interference in sport participation between adolescent CHD patients and healthy controls (HC). CHD, congenital heart disease.


