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REVIEW

Key issues of daily life in adults with congenital heart disease

Questions de la vie quotidienne des patients adultes ayant une cardiopathie congénitale

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Summary Increasing survival rates of patients with congenital heart disease have resulted in a new and growing patient population of adults with operated congenital heart disease. Medical professionals face the specific medical needs of these patients but must also deal with their daily life issues. Adult patients with congenital heart disease report difficulties in several areas of daily life, such as sport, employment, insurability and travel or driving. Moreover, they must have a healthy lifestyle to prevent cardiovascular complications. All these issues can be addressed in a specific educational program. In this review, we discuss the different daily life issues of adults with congenital heart disease and the preventive measures that can be proposed to improve their quality of life.

Abbreviations: ACHD, adult congenital heart disease; CAD, coronary artery disease; CHD, congenital heart disease; TQTH, Reconnaissance Qualité Travailleur Handicapé; VO_2, oxygen uptake.

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MOTS CLÉS
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Style de vie ;
Qualité de vie ;
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Résumé L'augmentation de la survie des patients ayant une cardiopathie congénitale a conduit à l'émergence d'une population sans cesse croissante d'adultes ayant été opérés d'une cardiopathie congénitale. Aujourd'hui, les professionnels de santé font face aux besoins médicaux spécifiques de ces patients, mais doivent également répondre aux questions qui concernent leur vie quotidienne. Ces patients rapportent en effet des difficultés dans plusieurs domaines de la vie quotidienne comme le sport, l'emploi, l'assurabilité, les voyages ou la conduite de véhicule. Par ailleurs, ils doivent maintenir une bonne hygiène de vie pour prévenir les complications cardiovasculaires communes. Toutes ces questions peuvent être abordées dans un programme éducatif spécifique. Dans cette revue, nous discutons ces différentes questions de la vie quotidienne des adultes ayant une cardiopathie congénitale et les mesures préventives pouvant être proposées pour améliorer leur qualité de vie.

Introduction

The improvement in surgical techniques over the last decades has led to a dramatic increase in survival rates of patients with congenital heart disease (CHD). This success has resulted in the emergence of a growing population of adults with operated CHD. Medical professionals are currently managing the specific medical needs of these patients but have to deal concomitantly with their daily life issues. A minority of adults with mild CHD but a majority of those with complex CHD report difficulties in their daily life [1], with an impact on quality of life [2,3]. It is of note that a high proportion of these patients have an inadequate level of knowledge about their disease and their potential in a variety of areas [4,5]. Patients with complex CHD frequently felt that the direct limitation to their participation in sport, employment or education was their heart disease. Knowledge about reproduction issues, 'family planning' and risk related to pregnancy was found to be poor among women with CHD [6]. An additional difficulty is access of these patients to life insurance and loan applications [7]. Together with these issues, adult patients with CHD should have preventive attitudes in supplementary domains to prevent common cardiovascular complications and endocarditis. Acquiring autonomy to tackle all these aspects of daily life with a CHD is a complex process for adolescents and young adults. The development of a specific transition/transfer program with counseling and educational content related to these issues is crucial for this population. Hopefully, developing these programs should lead to a reduction in complications and an improvement in quality of life.

In this review, we will discuss the key daily life issues for patients with adult congenital heart disease (ACHD). These issues are sport and more general physical activities, employment, family planning, risky behaviors, traveling and driving. We will also analyze the proposals that have been made in the literature for managing these difficulties.

Physical activity

Exercise capacity is a major issue in ACHD that has a significant impact on daily activity and quality of life. Additionally, physical activity has a direct link with cardiac status and a variety of risks, such as arrhythmias or syncope. A recent review by Kempny et al. [8] aggregated the available data on exercise capacity in ACHD comparing cardiopulmonary exercise test results in ACHD in their institution with the data published by other centres. This study confirmed that exercise capacity differs significantly across the spectrum of ACHD. The practical clinical consequence of these findings is that improving exercise capacity through aerobic training is probably worthwhile in virtually all ACHD patients. Kempny et al. [8] proposed different occupations according to peak oxygen uptake (VO_2) results derived from their study. These findings could help greatly in choosing/prescribing recreational activities when counseling a patient with ACHD.

Today, it is widely recognized that physical activity has long-term beneficial effects not only on quality of life but also on long-term morbidity and overall mortality [9,10]. As an example, exercise training in chronic heart failure reduces heart failure-related events, including mortality and hospital admission for worsening of heart failure [10,11]. Data remain scarce on the feasibility and efficacy of exercise training programs in ACHD patients [12]. Still, all these programs were safe and they all demonstrated an increase in exercise capacity or an improvement in quality of life [13–17] (Table 1), despite the controversial link between quality of life and exercise capacity. Indeed, self-estimated physical functioning, evaluated using quality of life scales, poorly predicts actual exercise capacity [18]. It is worthwhile noting that even patients with pulmonary hypertension, who have the poorest VO_2, experienced improvement in exercise endurance, symptomatic status and quality of life after carefully designed exercise training [19,20]. The limited compliance of the patients was the main limitation in these studies that prescribed physical training. Indeed, Swan et al. showed that only one third of ACHD patients regularly practiced at least moderate exercise and one third had no physical activity despite their mean age being 26 years [21]. To be efficient on outcomes, these programs have to be developed over a long period of time. To be sustainable, the programs need patient education reinforcement and are therefore necessarily time consuming. Patient education on the short- and long-term benefits of exercise must be part of ACHD management. Recommendations regarding physical training, exercise and sport