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CLINICAL RESEARCH

The medical history of adults with complex congenital heart disease affects their social development and professional activity



L'histoire médicale des patients adultes ayant une cardiopathie congénitale impacte leur développement socioprofessionnel

Clement Karsenty^{a,b,c,*}, Philippe Maury^{b,c},
Nathalie Blot-Souletie^b, Magalie Ladouceur^d,
Bertrand Leobon^e, Valérie Senac^b, Pierre Mondoly^b,
Meyer Elbaz^b, Michel Galinier^b, Yves Dulac^a,
Didier Carrié^b, Philippe Acar^a, Sebastien Hascoet^{a,b,c}

^a Paediatric Cardiology Unit, Children's Hospital, Toulouse University Hospital, Toulouse, France

^b Department of Cardiology, Toulouse University Hospital, Toulouse, France

^c Inserm U1048, Institut des Maladies Métaboliques et Cardiovasculaires (I2MC), Toulouse, France

^d Adult Congenital Heart Disease Unit, Hôpital Européen Georges-Pompidou–Necker, AP–HP, Inserm U970-PARCC, Paris Descartes University, Paris, France

^e Department of Congenital Heart Disease Surgery, Children's Hospital, Toulouse University Hospital, Toulouse, France

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KEYWORDS

Adult congenital heart disease;
Lifestyle;
Education

Summary

Background. – In recent decades, advances in surgery and therapeutic catheterization have steadily increased the life expectancy and prevalence of adults with congenital heart disease (CHD).
Aims. – We assessed medical and psychosocial variables of adults with CHD, according to the disease complexity.

Abbreviations: CHD, congenital heart disease; CHD, congenital heart disease; CI, confidence interval; IQR, interquartile range; NYHA, New York Heart Association; WHO, World Health Organization.

* Corresponding author. Service de Cardiologie Pédiatrique, Hôpital des Enfants, 330, avenue de Grande-Bretagne, 31059 Toulouse cedex 9, France.

E-mail address: clement.karsenty@hotmail.fr (C. Karsenty).

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Methods. – We included, from a single-centre observational cohort study, 135 consecutive adults with CHD (median age of 40 years, interquartile range: 28.0–51.0) followed in our cardiology unit, who answered a questionnaire assessing daily activity and psychosocial functioning. Disease complexity was classified according to the Bethesda conference.

Results. – Cardiac malformation complexity was simple in 61 (45.2%), moderate in 50 (37.0%) and complex in 24 (17.8%) patients. Cardiac surgery had been performed in 86.5% of moderate and complex patients. Complications (such as heart failure, arrhythmia and pulmonary hypertension) were mainly observed in the complex group ($P=0.003$). Physical activity was lower in the complex group (no activity in 58.8%, but sport previously contraindicated in 50% of these; $P=0.03$). Education level tended to be lower in the complex and moderate groups than in the simple group (respectively, 31.2% and 33.3% vs. 45.7% had passed the Baccalaureate; $P=0.47$). The pass rate was lower in patients with complications ($P=0.037$) or more than one cardiac surgery ($P=0.03$). In the complex group, 56.3% of patients were unemployed ($P=0.048$).

Conclusions. – Complexity of heart disease and medical history affect education level and employment of adults with CHD. Academic education of children with a complex defect and career counselling are important to prevent unemployment among adults with CHD.

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MOTS CLÉS

Cardiopathie congénitale de l'adulte ;
Style de vie ;
Éducation

Résumé

Contexte. – Grâce aux progrès médico-chirurgicaux ces dernières décennies, l'espérance de vie et la prévalence des adultes ayant une cardiopathie congénitale (ACC) ont constamment augmenté.

Objectif. – Nous avons évalué les paramètres médicaux et psychosociaux des ACC selon la complexité de la cardiopathie.

Méthodes. – Nous avons inclus consécutivement à partir d'une cohorte observationnelle monocentrique, 135 ACC (40 ± 12 ans) qui ont répondu à un questionnaire évaluant les aspects psychosociaux et de la vie quotidienne. La complexité de la cardiopathie était classée selon la conférence de Bethesda.

Résultats. – La complexité de la cardiopathie était simple pour 61 patients (45,2 %), modérée pour 50 (37,0 %) et complexe pour 24 (17,8 %). Une chirurgie cardiaque a été effectuée pour 86,5 % des patients ayant une cardiopathie complexe ou modérée. Les complications (insuffisance cardiaque [$n=15/24$], arythmie [$n=14/24$], hypertension pulmonaire [$n=6/24$]) ont été principalement observées dans le groupe complexe ($p=0,002$). L'activité physique était moins importante dans le groupe complexe ($p=0,03$, et aucune activité pour 58,8 % mais 33 % avaient été contre indiqués). Les patients des groupes complexe et modéré ont tendance à avoir un niveau d'étude inférieur aux patients du groupe simple (respectivement 31,2 %, 33,3 % versus 45,7 % ont le Baccalauréat ; $p=0,47$). L'obtention du Baccalauréat était plus faible pour les patients ayant au moins une complication ($p=0,038$) et plus d'une chirurgie cardiaque ($p=0,03$). Dans le groupe complexe, 56,3 % des patients étaient au chômage ($p=0,048$).

Conclusion. – La complexité de la cardiopathie et l'histoire médicale des patients impactent le niveau d'éducation et taux d'emploi des ACC. La scolarité de ces enfants et l'orientation professionnelle sont importantes pour prévenir le chômage.

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Background

Improved imaging, catheterization, medical therapy and surgical techniques in recent decades have led to the increased survival of children with congenital heart diseases (CHDs). Around 90% of children with CHD now reach adulthood [1]. By 2010, adults accounted for 66% of the entire CHD population [2]; many of them require further medical care and surgery or catheterization [3] during

adulthood to treat residual lesions or complications, such as heart failure, arrhythmia or pulmonary hypertension [4,5]. Dedicated attention is also required to deal with daily life issues [6]. However, loss of follow-up of adults with CHD is a critical issue, and occurs particularly at the time of transition from paediatric to adult care [7]. Thus programmes for education and for the transition from paediatric to adult medical care have been recommended [8].

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