Univerzita Palackého
v Olomouci

KVALITA ŽIVOTA U DĚTÍ PO OPERACI KRITICKÉ VROZENÉ SRDEČNÍ VADY

Klásková E.

[1]Dětská klinika LF UP a FN Olomouc

XXV. výroční sjezd České kardiologické společnosti; Brno; 7. - 10. května 2017

WHO – HODNOCENÍ KVALITY ŽIVOTA (WHOQOL)

Quality of life is defined as an individual's perception of their position in life in context of the culture and value system in which they and relation to their goals, expectations, standard and concerns.

It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment.

WHOQOL Group, Qual Life Res 1993; 2:153-159.

Neurokognitivní funkce

Prožívání a spokojenost se zdravím

Fyzické zdraví

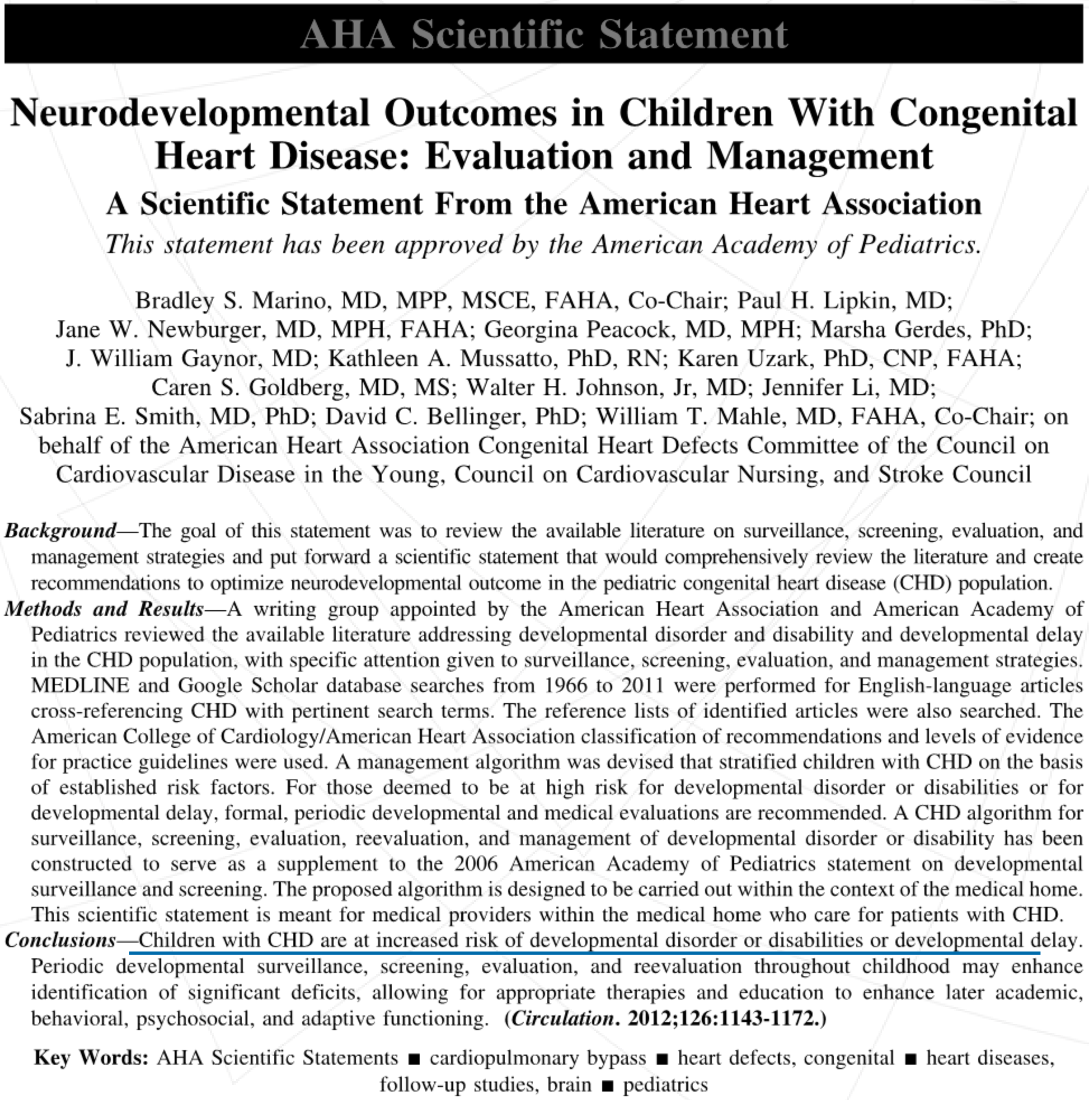
Kvalita života

Úroveň soběstačnosti

Sociální vztahy

Prostředí

NEUROKOGNITIVNÍ FUNKCE



AHA Scientific Statement

Neurodevelopmental Outcomes in Children With Congenital Heart Disease: Evaluation and Management

A Scientific Statement From the American Heart Association

This statement has been approved by the American Academy of Pediatrics.

Bradley S. Marino, MD, MPP, MSCE, FAHA, Co-Chair; Paul H. Lipkin, MD;
Jane W. Newburger, MD, MPH, FAHA; Georgina Peacock, MD, MPH; Marsha Gerdes, PhD;
J. William Gaynor, MD; Kathleen A. Mussatto, PhD, RN; Karen Uzark, PhD, CNP, FAHA;
Caren S. Goldberg, MD, MS; Walter H. Johnson, Jr, MD; Jennifer Li, MD;
Sabrina E. Smith, MD, PhD; David C. Bellinger, PhD; William T. Mahle, MD, FAHA, Co-Chair; on
behalf of the American Heart Association Congenital Heart Defects Committee of the Council on
Cardiovascular Disease in the Young, Council on Cardiovascular Nursing, and Stroke Council

Background—The goal of this statement was to review the available literature on surveillance, screening, evaluation, and management strategies and put forward a scientific statement that would comprehensively review the literature and create recommendations to optimize neurodevelopmental outcome in the pediatric congenital heart disease (CHD) population.

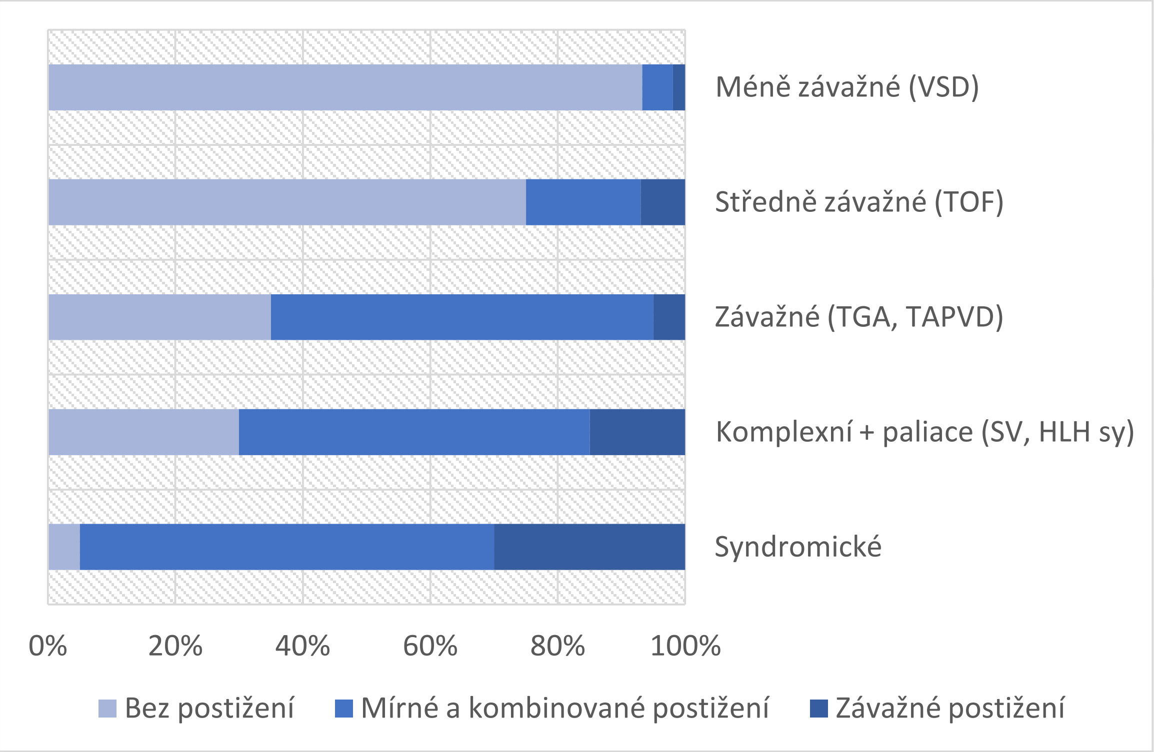
Methods and Results—A writing group appointed by the American Heart Association and American Academy of Pediatrics reviewed the available literature addressing developmental disorder and disability and developmental delay in the CHD population, with specific attention given to surveillance, screening, evaluation, and management strategies. MEDLINE and Google Scholar database searches from 1966 to 2011 were performed for English-language articles cross-referencing CHD with pertinent search terms. The reference lists of identified articles were also searched. The American College of Cardiology/American Heart Association classification of recommendations and levels of evidence for practice guidelines were used. A management algorithm was devised that stratified children with CHD on the basis of established risk factors. For those deemed to be at high risk for developmental disorder or disabilities or for developmental delay, formal, periodic developmental and medical evaluations are recommended. A CHD algorithm for surveillance, screening, evaluation, reevaluation, and management of developmental disorder or disability has been constructed to serve as a supplement to the 2006 American Academy of Pediatrics statement on developmental surveillance and screening. The proposed algorithm is designed to be carried out within the context of the medical home. This scientific statement is meant for medical providers within the medical home who care for patients with CHD.

Conclusions—Children with CHD are at increased risk of developmental disorder or disabilities or developmental delay. Periodic developmental surveillance, screening, evaluation, and reevaluation throughout childhood may enhance identification of significant deficits, allowing for appropriate therapies and education to enhance later academic, behavioral, psychosocial, and adaptive functioning. **(*Circulation*. 2012;126:1143-1172.)**

Key Words: AHA Scientific Statements ■ cardiopulmonary bypass ■ heart defects, congenital ■ heart diseases, follow-up studies, brain ■ pediatrics

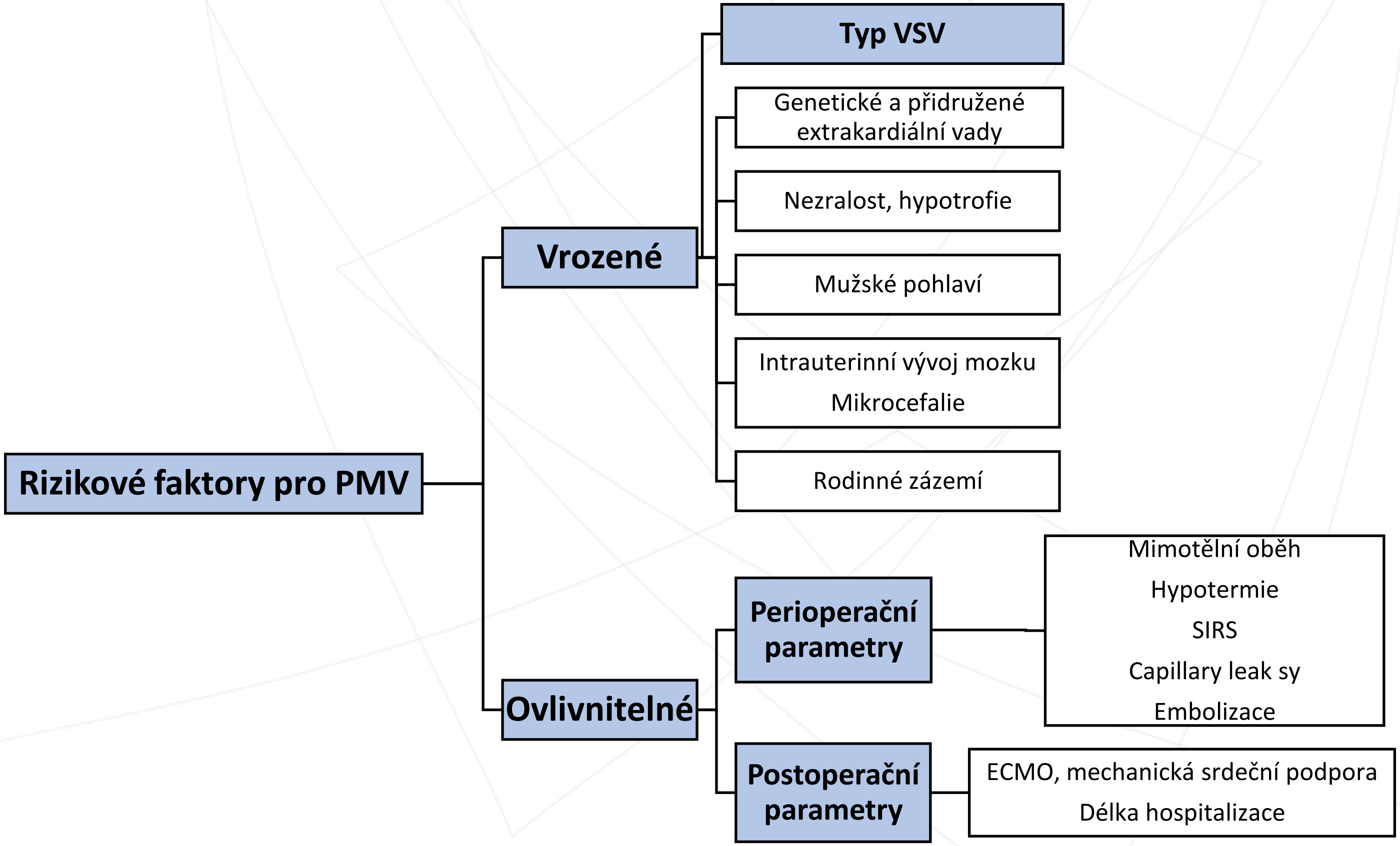
Marino B.S. et al., Circulation 2012; 126:1143-1172

POSTIŽENÍ NEUROKOGNITIVNÍ FUNKCÍ U DĚTÍ A MLADÝCH DOSPĚLÝCH PO OPERACI VSV



Upraveno podle Wernovsky G., Cardiol Young 2006; 16 (Suppl. 1):92-104

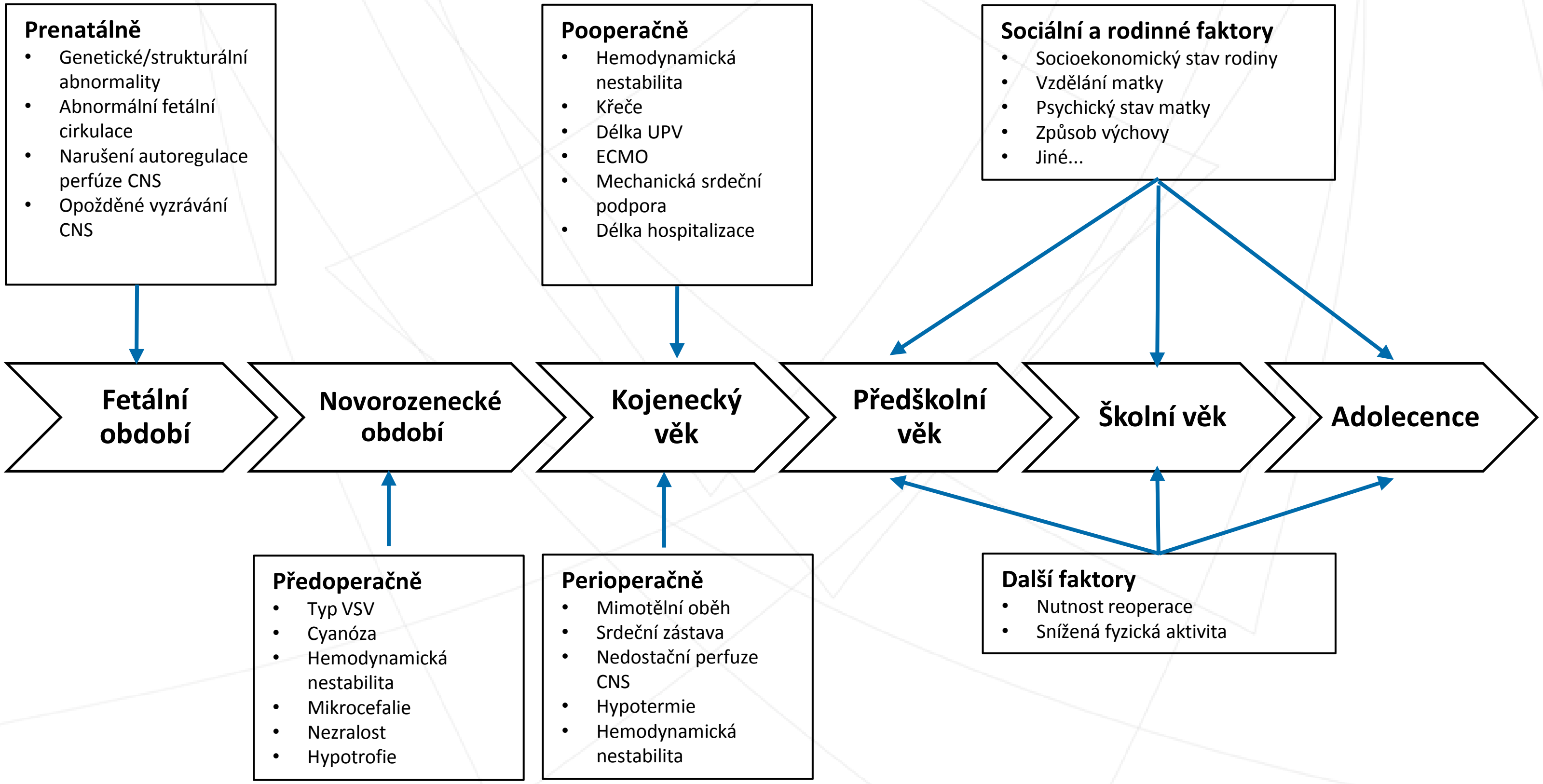
FAKTORY OVLIVŇUJÍCÍ PSYCHOMOTORICKÝ VÝVOJ U KOJENCŮ PO KARDIOCHIRURGICKÉM VÝKONU



- **Rizikové faktory pro PMV**
  - **Vrozené**
    - **Typ VSV**
    - Genetické a přidružené extrakardiální vady
    - Nezralost, hypotrofie
    - Mužské pohlaví
    - Intrauterinní vývoj mozku
Mikrocefalie
    - Rodinné zázemí
  - **Ovlivnitelné**
    - **Perioperační parametry**
      - Mimotělní oběh
      - Hypotermie
      - SIRS
      - Capillary leak sy
      - Embolizace
    - **Postoperační parametry**
      - ECMO, mechanická srdeční podpora
      - Délka hospitalizace

Upraveno dle Hövels-Gürich, Front Pediatr 2016; doi: 10.3389/fped.2016.00137

FAKTORY OVLIVŇUJÍCÍ VÝVOJ MOZKU



Prenatálně
- Genetické/strukturální abnormality
- Abnormální fetální cirkulace
- Narušení autoregulace perfúze CNS
- Opožděné vyzrávání CNS

Pooperačně
- Hemodynamická nestabilita
- Křeče
- Délka UPV
- ECMO
- Mechanická srdeční podpora
- Délka hospitalizace

Sociální a rodinné faktory
- Socioekonomický stav rodiny
- Vzdělání matky
- Psychický stav matky
- Způsob výchovy
- Jiné...

Fetální období

Novorozenecké období

Kojenecký věk

Předškolní věk

Školní věk

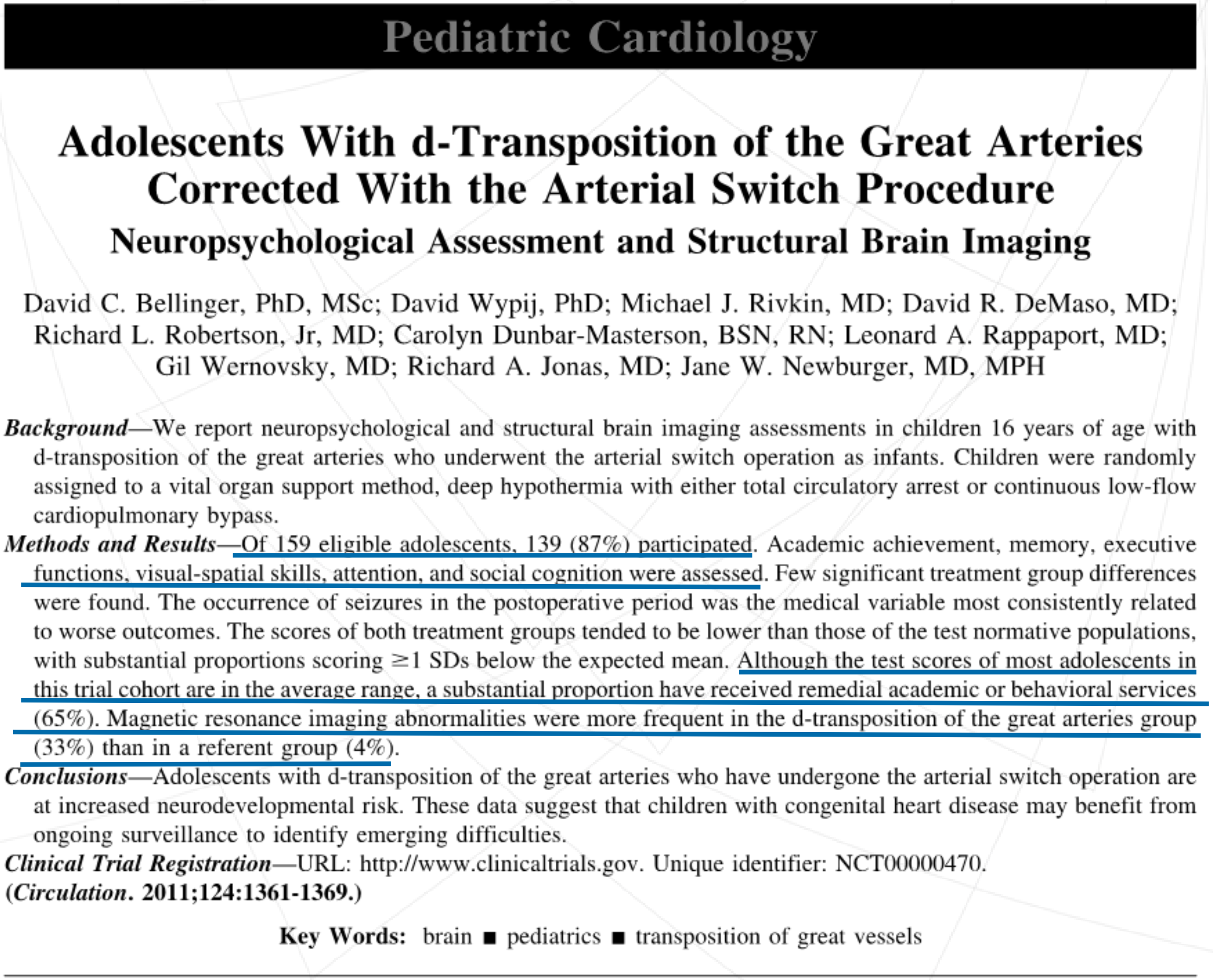
Adolecence

Předoperačně
- Typ VSV
- Cyanóza
- Hemodynamická nestabilita
- Mikrocefalie
- Nezralost
- Hypotrofie

Perioperačně
- Mimotělní oběh
- Srdeční zástava
- Nedostační perfuze CNS
- Hypotermie
- Hemodynamická nestabilita

Další faktory
- Nutnost reoperace
- Snížená fyzická aktivita

Upraveno dle Hövels-Gürich, Front Pediatr 2016; doi: 10.3389/fped.2016.00137



Pediatric Cardiology

Adolescents With d-Transposition of the Great Arteries Corrected With the Arterial Switch Procedure

Neuropsychological Assessment and Structural Brain Imaging

David C. Bellinger, PhD, MSc; David Wypij, PhD; Michael J. Rivkin, MD; David R. DeMaso, MD;
Richard L. Robertson, Jr, MD; Carolyn Dunbar-Masterson, BSN, RN; Leonard A. Rappaport, MD;
Gil Wernovsky, MD; Richard A. Jonas, MD; Jane W. Newburger, MD, MPH

Background—We report neuropsychological and structural brain imaging assessments in children 16 years of age with d-transposition of the great arteries who underwent the arterial switch operation as infants. Children were randomly assigned to a vital organ support method, deep hypothermia with either total circulatory arrest or continuous low-flow cardiopulmonary bypass.

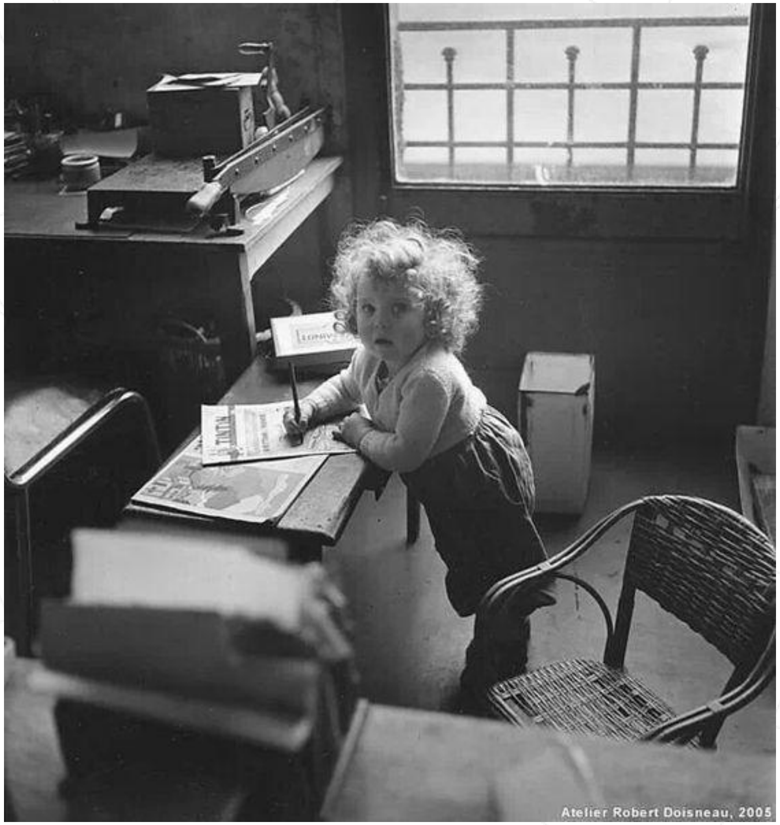
Methods and Results—Of 159 eligible adolescents, 139 (87%) participated. Academic achievement, memory, executive functions, visual-spatial skills, attention, and social cognition were assessed. Few significant treatment group differences were found. The occurrence of seizures in the postoperative period was the medical variable most consistently related to worse outcomes. The scores of both treatment groups tended to be lower than those of the test normative populations, with substantial proportions scoring ≥ 1 SDs below the expected mean. Although the test scores of most adolescents in this trial cohort are in the average range, a substantial proportion have received remedial academic or behavioral services (65%). Magnetic resonance imaging abnormalities were more frequent in the d-transposition of the great arteries group (33%) than in a referent group (4%).

Conclusions—Adolescents with d-transposition of the great arteries who have undergone the arterial switch operation are at increased neurodevelopmental risk. These data suggest that children with congenital heart disease may benefit from ongoing surveillance to identify emerging difficulties.

Clinical Trial Registration—URL: http://www.clinicaltrials.gov. Unique identifier: NCT00000470.
(*Circulation*. 2011;124:1361-1369.)

Key Words: brain ■ pediatrics ■ transposition of great vessels

ŠKOLNÍ VÝSLEDKY



ŠKOLNÍ VÝSLEDKY

Pediatr Cardiol
DOI 10.1007/s00246-013-0781-6

ORIGINAL ARTICLE

Academic Proficiency in Children After Early Congenital Heart Disease Surgery

**Sarah B. Mulkey · Christopher J. Swearingen · Maria S. Melguizo ·
Rachel N. Reeves · Jacob A. Rowell · Neal Gibson · Greg Holland ·
Adnan T. Bhutta · Jeffrey R. Kaiser**

- 256 dětí, které prodělaly kardiochirurgický výkon v prvním roce života
- 26 % vyžadovalo speciální vzdělávací program (OR 3,01)
  - OR pro mentální retardaci – 4,96
  - OR pro kombinované postižení – 10,66

Mulkey S.B. et al., Pediatr Cardiol 2014; 35:344-352.

Inattention, Hyperactivity, and School Performance in a Population of School-Age Children With Complex Congenital Heart Disease

Amanda J. Shillingford, MD[a], Marianne M. Glanzman, MD[b], Richard F. Ittenbach, PhD[c], Robert R. Clancy, MD[d], J. William Gaynor, MD[e], Gil Wernovsky, MD[a]

Divisions of [a]Cardiology, [b]Child Development and Rehabilitation, [c]Biostatistics and Data Management Core, [e]Cardiothoracic Surgery, and [d]Neurology, Children's Hospital of Philadelphia, Philadelphia, Pennsylvania

The authors have indicated they have no financial relationships relevant to this article to disclose.

What's Known on This Subject

Children with complex congenital heart disease are known to have neurodevelopmental impairment, particularly related to visual-spatial skills, fine motor skills, and language development. New evidence suggests that the congenital heart disease group is also at risk for behavioral problems.

What This Study Adds

We are the first to use standardized questionnaire data from both parents and teachers to identify a high prevalence of children with congenital heart disease who are at risk for clinically significant problems with inattention and hyperactivity.

ABSTRACT

INTRODUCTION. There is a growing interest in characterizing the neurodevelopmental outcomes of school-age survivors of cardiac surgery. The purpose of this study was to examine a population of 5- to 10-year-old children who underwent newborn cardiac surgery for complex congenital heart disease to characterize and assess risk factors for problems with inattention and hyperactivity, as well as the use of remedial school services.

PATIENTS AND METHODS. This study was a cross-sectional analysis of patients who underwent newborn cardiac surgery and were enrolled in a neuroprotection trial conducted at our institution between 1992 and 1997. Parents and teachers completed questionnaires for the school-age child to elicit information pertaining to the child's general health and academic performance. The severity of hyperactivity and inattention were assessed by using 2 standardized questionnaires (Attention-Deficit/Hyperactivity Disorder Rating Scale-IV and Behavior Assessment System for Children). In addition to calculating descriptive estimates of their occurrence, single-covariate logistic regression models were specified and tested by using 3 different outcomes (inattention, hyperactivity, and use of remedial school services) and 14 different covariates representing preoperative, intraoperative, and postoperative factors.

RESULTS. Data were obtained from parents and/or teachers for 109 children. Fifty-three (49%) were receiving some form of remedial academic services, and 15% were assigned to a special-education classroom. The number of children receiving clinically significant scores for inattention and hyperactivity on the Behavior Assessment System for Children was 3 to 4 times higher than observed in the general population. On the Attention-Deficit/Hyperactivity Disorder Rating Scale-IV, 30% of the parents reported high-risk scores for inattention and 29% reported high-risk scores for hyperactivity. No perioperative factors were statistically associated with adverse outcomes.

www.pediatrics.org/cgi/doi/10.1542/peds.2007-1066

doi:10.1542/peds.2007-1066

Key Words
congenital heart disease, ADHD, congenital heart disease outcomes, school performance, deep hypothermic circulatory arrest

Abbreviations
CHD—congenital heart disease
CPB—cardiopulmonary bypass
DHCA—deep hypothermic circulatory arrest
BASC—Behavior Assessment System for Children
ADHD-IV—Attention-Deficit/Hyperactivity Disorder Rating Scale-IV
ADHD—attention-deficit/hyperactivity disorder

Accepted for publication Sep 5, 2007

Address correspondence to Amanda J. Shillingford, MD, Division of Cardiology, Children's Hospital of Philadelphia, 34th Street and Civic Center Boulevard, Philadelphia, PA 19104. E-mail: shillingford@email.chop.edu

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

Shilingford A.J. et al., Pediatrics 2008; 121:e759-e767

Specifické potřeby žáků po operaci komplexní VSV

ADHD-IV rating scale podle rodičů a pedagogů

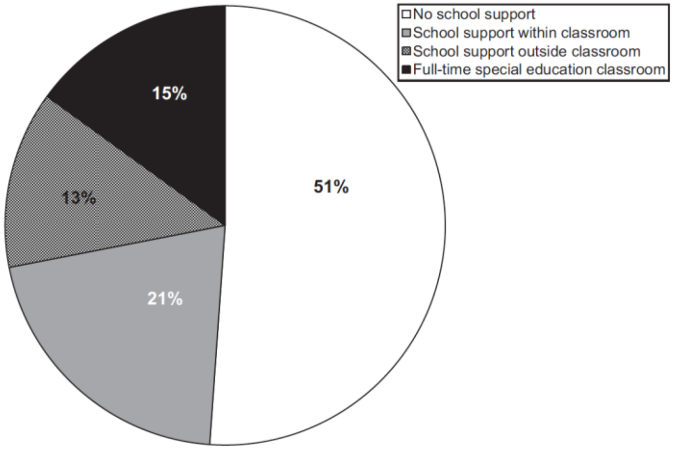
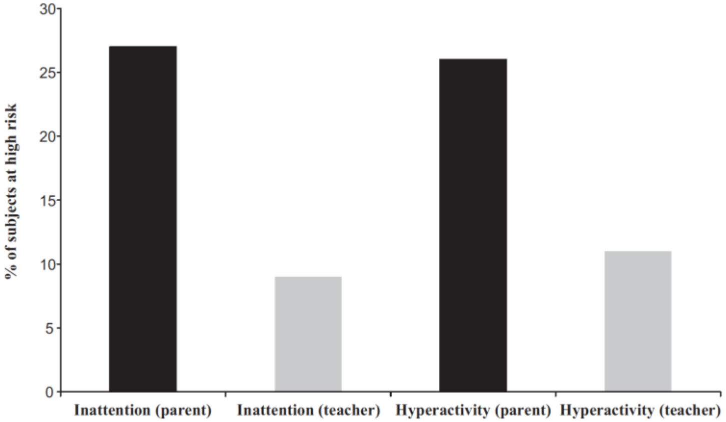


FIGURE 3
Distribution of the type of remedial school services that the children in this cohort used.



Shilingford A.J. et al., Pediatrics 2008; 121:e759-e767

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PORUCHY CHOVÁNÍ A PSYCHOSOCIÁLNÍ PROBLÉMY

BMC Pediatrics

BioMed Central

Research article

Open Access

Psychological adjustment and quality of life in children and adolescents following open-heart surgery for congenital heart disease: a systematic review

Beatrice Latal[1], Susanne Helfricht[1], Joachim E Fischer[2], Urs Bauersfeld[3] and Markus A Landolt*[4]

Address: [1]University Children's Hospital Zurich, Child Development Centre, Steinwiesstrasse 75, 8032 Zurich, Switzerland, [2]Heidelberg University, Mannheim Medical Faculty, Institute of Public Health, Social and Preventive Medicine, 68072 Mannheim, Germany, [3]University Children's Hospital Zurich, Department of Pediatric Cardiology, Steinwiesstrasse 75, 8032 Zurich, Switzerland and [4]University Children's Hospital Zurich, Department of Psychosomatics and Psychiatry, Steinwiesstrasse 75, 8032 Zurich, Switzerland

Email: Beatrice Latal - bea.latal@kispi.uzh.ch; Susanne Helfricht - susanne.helfricht@gmx.net; Joachim E Fischer - jfischer@medma.uni-heidelberg.de; Urs Bauersfeld - urs.bauersfeld@kispi.uzh.ch; Markus A Landolt* - markus.landolt@kispi.uzh.ch

* Corresponding author

Latal B. et al., BMC Pediatrics 2009; 9:6

PORUCHY CHOVÁNÍ A PSYCHOSOCIÁLNÍ PROBLÉMY

Metaanalýza – randomizované kontrolované studie mezi lety 1990-2008, věk pacientů 2-17 let, odstup od operace nejméně 2 roky

Potíže udávané rodiči nebo učiteli

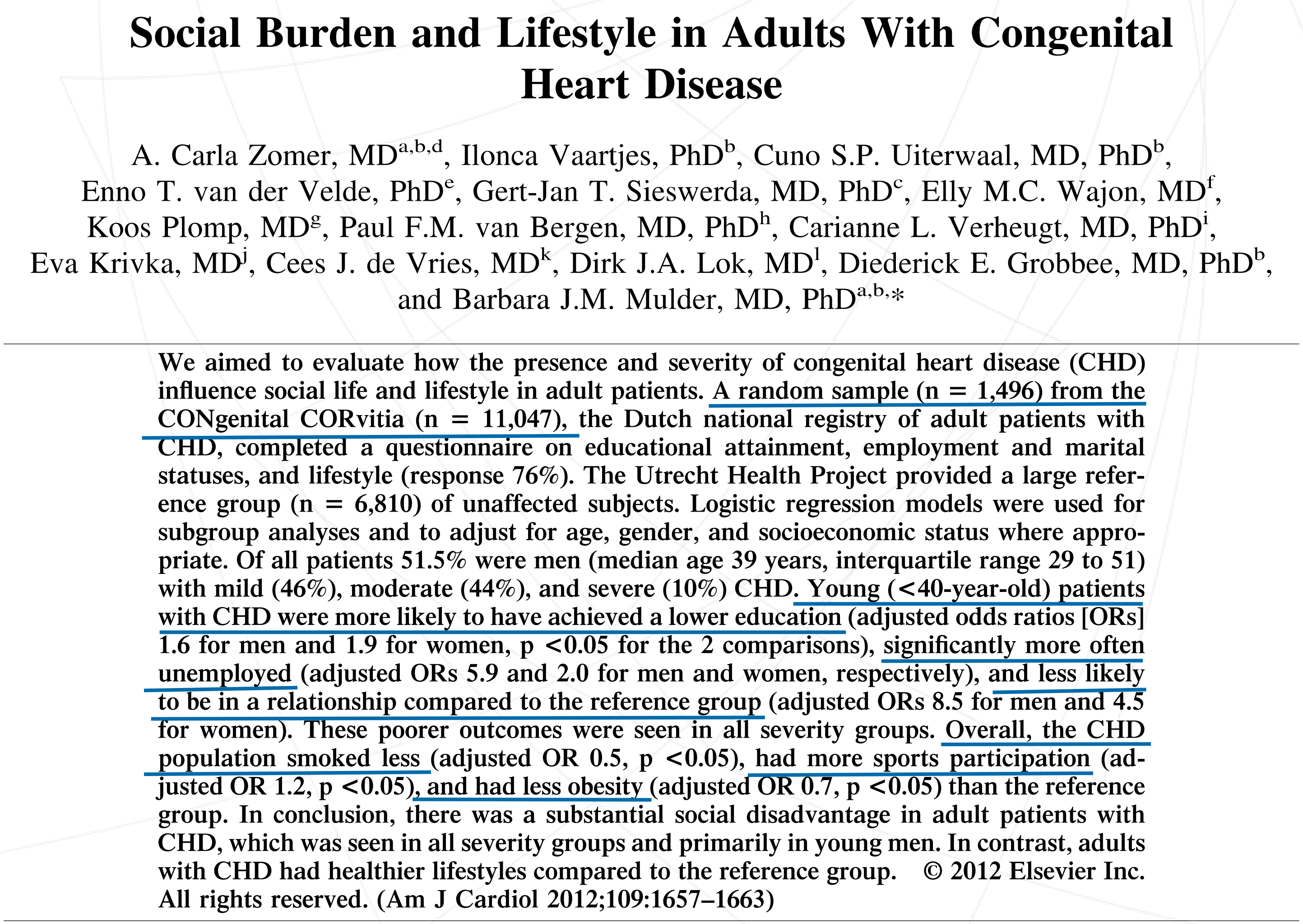
- Psychiatrické poruchy u dětí **po operaci TGA a cyanotických VSV** – 19 - 46%
- Zhoršené vnímaní u matek s vysokou mírou úzkosti, se sníženými výchovnými dovednostmi, u samoživitelek

Sebe-vnímání dětí po operaci VSV

- 3 studie bez signifikantních rozdílů v míře strachu, úzkosti a sebehodnocení
- 1 studie – zvýšený výskyt deprese u školních dětí

Latal B. et al., BMC Pediatrics 2009; 9:6

ÚROVEŇ SOBĚSTAČNOSTI A SOCIÁLNÍ VZTAHY



Social Burden and Lifestyle in Adults With Congenital Heart Disease

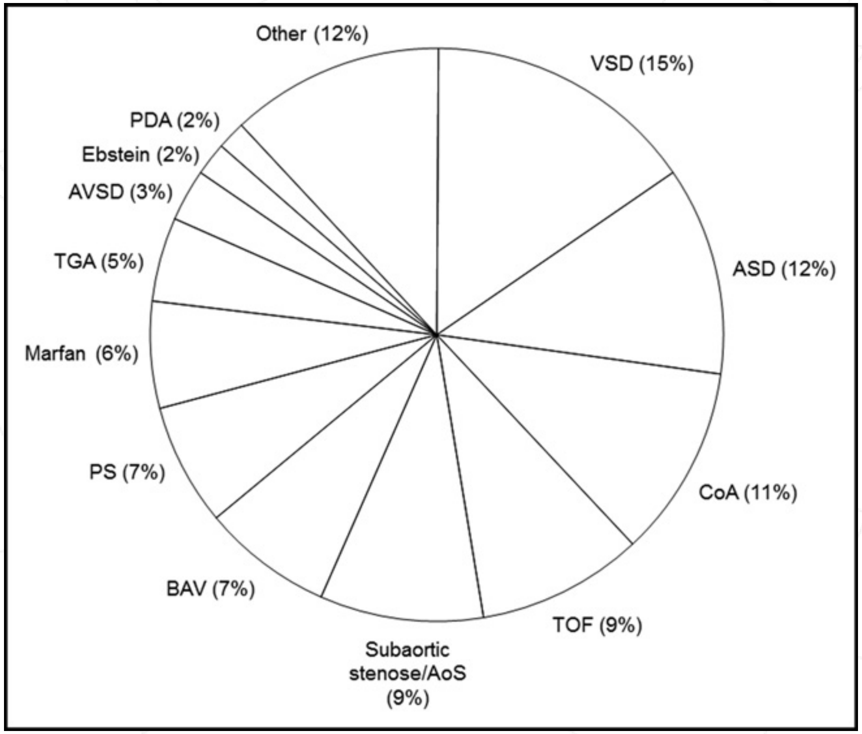
A. Carla Zomer, MD[a,b,d], Ilonca Vaartjes, PhD[b], Cuno S.P. Uiterwaal, MD, PhD[b], Enno T. van der Velde, PhD[e], Gert-Jan T. Sieswerda, MD, PhD[c], Elly M.C. Wajon, MD[f], Koos Plomp, MD[g], Paul F.M. van Bergen, MD, PhD[h], Carianne L. Verheugt, MD, PhD[i], Eva Krivka, MD[j], Cees J. de Vries, MD[k], Dirk J.A. Lok, MD[l], Diederick E. Grobbee, MD, PhD[b], and Barbara J.M. Mulder, MD, PhD[a,b,*]

We aimed to evaluate how the presence and severity of congenital heart disease (CHD) influence social life and lifestyle in adult patients. A random sample ($n = 1,496$) from the CONgenital CORvitia ($n = 11,047$), the Dutch national registry of adult patients with CHD, completed a questionnaire on educational attainment, employment and marital statuses, and lifestyle (response 76%). The Utrecht Health Project provided a large reference group ($n = 6,810$) of unaffected subjects. Logistic regression models were used for subgroup analyses and to adjust for age, gender, and socioeconomic status where appropriate. Of all patients 51.5% were men (median age 39 years, interquartile range 29 to 51) with mild (46%), moderate (44%), and severe (10%) CHD. Young ($<$40-year-old) patients with CHD were more likely to have achieved a lower education (adjusted odds ratios [ORs] 1.6 for men and 1.9 for women, $p < 0.05$ for the 2 comparisons), significantly more often unemployed (adjusted ORs 5.9 and 2.0 for men and women, respectively), and less likely to be in a relationship compared to the reference group (adjusted ORs 8.5 for men and 4.5 for women). These poorer outcomes were seen in all severity groups. Overall, the CHD population smoked less (adjusted OR 0.5, $p < 0.05$), had more sports participation (adjusted OR 1.2, $p < 0.05$), and had less obesity (adjusted OR 0.7, $p < 0.05$) than the reference group. In conclusion, there was a substantial social disadvantage in adult patients with CHD, which was seen in all severity groups and primarily in young men. In contrast, adults with CHD had healthier lifestyles compared to the reference group. **© 2012 Elsevier Inc. All rights reserved.** **(Am J Cardiol 2012;109:1657–1663)**

Zomer C. et al., Am J Cardiol 2012; 109:1657-1663

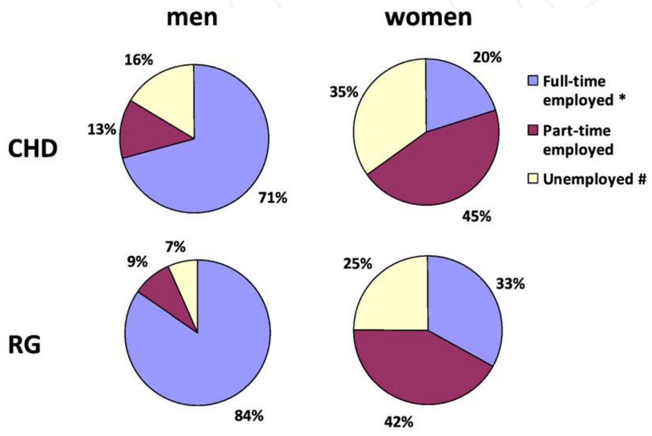
DUTCH NATIONAL REGISTRY CONGenital CORvitia (CONCOR)

1496 dospělých pacientů s VSV, median věku 39 let (29-51 let)



Zomer C. et al., Am J Cardiol 2012; 109:1657-1663; Sluman M.A. et al., Int J Cardiol 2014; 172:230-230

DUTCH NATIONAL REGISTRY CONGenital CORvitia (CONCOR)



Abbreviations: CHD = Congenital Heart Disease, RG = reference group.

Definitions:

* Full-time employed: paid job for > 35 hours per week. Part-time employed: paid job for 12 to 35 hours per week. # Unemployed: no job, job seeking / disabled, volunteer work or paid job < 12 hours per week.

Nezaměstnanost ve srovnání s běžnou populací*

- Ženy – 1,4krát vyšší než v běžné populaci
- Muži – 2krát vyšší než v běžné populaci

*Korigováno vzhledem k věku a závažnosti VSV

Sluman M.A. et al., Int J Cardiol 2014; 172:230-230

ÚROVEŇ SOBĚSTAČNOSTI A SOCIÁLNÍ VZTAHY

1. **Největší socioekonomické rozdíly ve srovnání s běžnou populací jsou přítomny u pacientů po operaci VSV ve věku < 40 let**
   - Vyšší podíl závažných VSV
   - Nižší stupeň dosaženého vzdělání
   - Možná diskriminace dospělých s VSV při získávání zaměstnání
   - Snížené ambice a motivace při získávání zaměstnávání, vyšší závislost na původní rodině
2. **Ve vyšší věkové skupině > 40 let jsou rozdíly méně výrazné**
   - Menší podíl nejzávažnějších VSV v této populaci
   - Více stabilizovaný životní styl
3. **Muži po operaci VSV mají jsou více ohroženi nezaměstnaností než ženy ve srovnání s běžnou populací**

Zomer C. et al., Am J Cardiol 2012; 109:1657-1663

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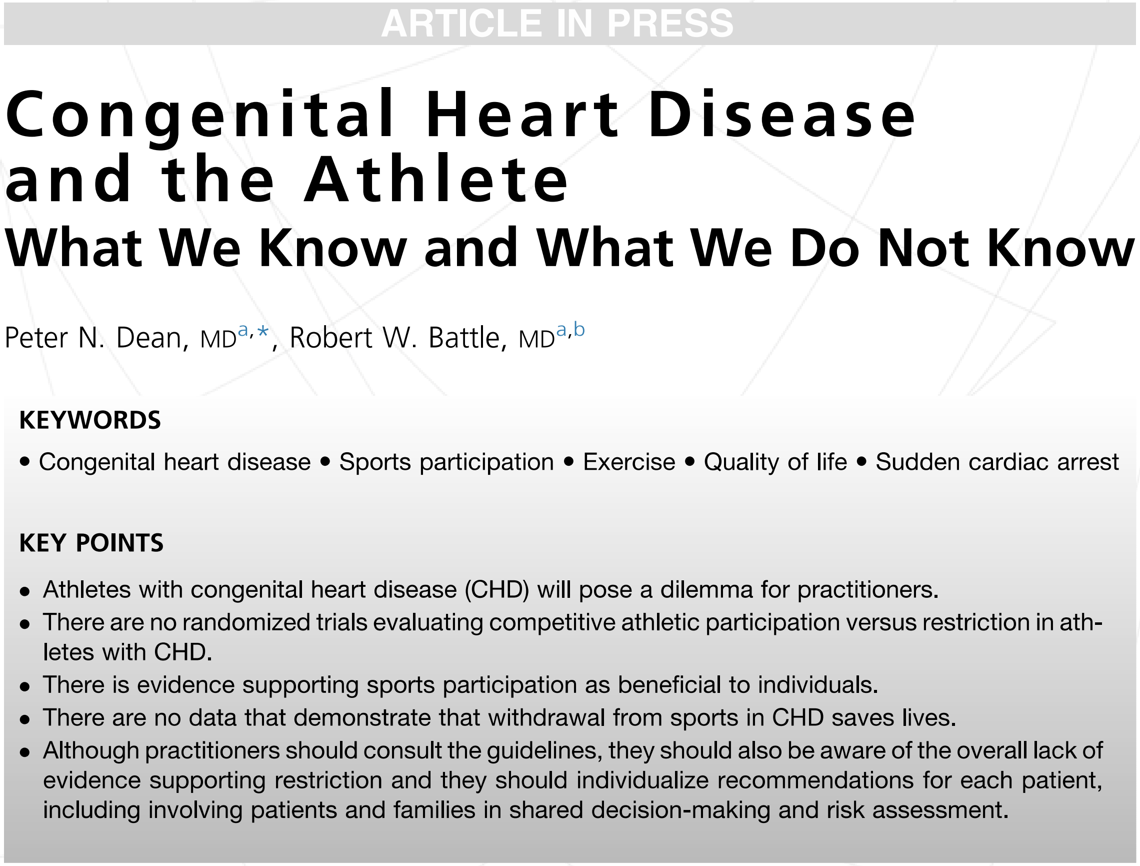
FYZICKÁ AKTIVITA A KVALITA ŽIVOTA



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Congenital Heart Disease and the Athlete

What We Know and What We Do Not Know

Peter N. Dean, MD[a,*], Robert W. Battle, MD[a,b]

KEYWORDS

- Congenital heart disease • Sports participation • Exercise • Quality of life • Sudden cardiac arrest

KEY POINTS

- Athletes with congenital heart disease (CHD) will pose a dilemma for practitioners.
- There are no randomized trials evaluating competitive athletic participation versus restriction in athletes with CHD.
- There is evidence supporting sports participation as beneficial to individuals.
- There are no data that demonstrate that withdrawal from sports in CHD saves lives.
- Although practitioners should consult the guidelines, they should also be aware of the overall lack of evidence supporting restriction and they should individualize recommendations for each patient, including involving patients and families in shared decision-making and risk assessment.

Dean P.N. et al., Cardiol Clin 2016; 34:579-589

VLIV PRAVIDELNÉ FYZICKÉ AKTIVITY NA KVALITU ŽIVOTA DĚTÍ S VSV

STÁVAJÍCÍ DOPORUČENÍ VYCHÁZEJÍ PŘEVÁŽNĚ Z „EXPERT OPINION“ A NE Z EBM

Pacienti s VSV mají zvýšené riziko náhlé srdeční smrti

Nebylo prokázáno, že rutinní zákaz sportu u pacientů s VSV je prevencí náhlé srdeční smrti a příznivě ovlivňuje přirozený vývoj VSV

Dean P.N. et al., Cardiol Clin 2016; 34:579-589; Dean PN et al., Congenit Heart Dis 2015; 10:169-179

VLIV PRAVIDELNÉ FYZICKÉ AKTIVITY NA KVALITU ŽIVOTA DĚTÍ S VSV

Pravidelná fyzická aktivita u pacientů po operaci VSV

- Vede ke zvýšení kvality života ve srovnání s nesportující populací.
- Podporuje rozvoj zdravého sebevědomí a sociálního začlenění dítěte.
- Zvyšuje šanci na dosažení vyššího stupně vzdělání.
- Snižuje míru **depresivity.**
- Zvyšuje aerobní kapacitu a snižuje *body mass index.*

Dean P.N. et al., Cardiol Clin 2016; 34:579-589; Dean PN et al., Congenit Heart Dis 2015; 10:169-179

VLIV PRAVIDELNÉ FYZICKÉ AKTIVITY NA KVALITU ŽIVOTA DĚTÍ S VSV

Negativní důsledky zákazu sportovní aktivity pro pacienta po operaci VSV

- **Pocit falešného bezpečí -** pacienti se zákazem sportu vykonávají množství neorganizovaných sportovních aktivit ve volném čase
- Pouze 10% náhlých srdečních úmrtí nastává při fyzické aktivitě (69 % v klidu, 11 % ve spánku)[2]
- Šance na přežití srdeční zástavy je až 3x vyšší při organizované sportovní aktivitě než při nekontrolované fyzické aktivitě[3]

[1]Dean P.N. et al., Cardiol Clin 2016; 34:579-589; [2]Koyak Z et al., Circulation 2012; 126:1944-1954; Marijon E et al., Am Heart J 2015; 170:339-345.e1.

PROŽÍVÁNÍ A SPOKOJENOST SE ZDRAVÍM

Are cyanosed adults with congenital cardiac malformations depressed?

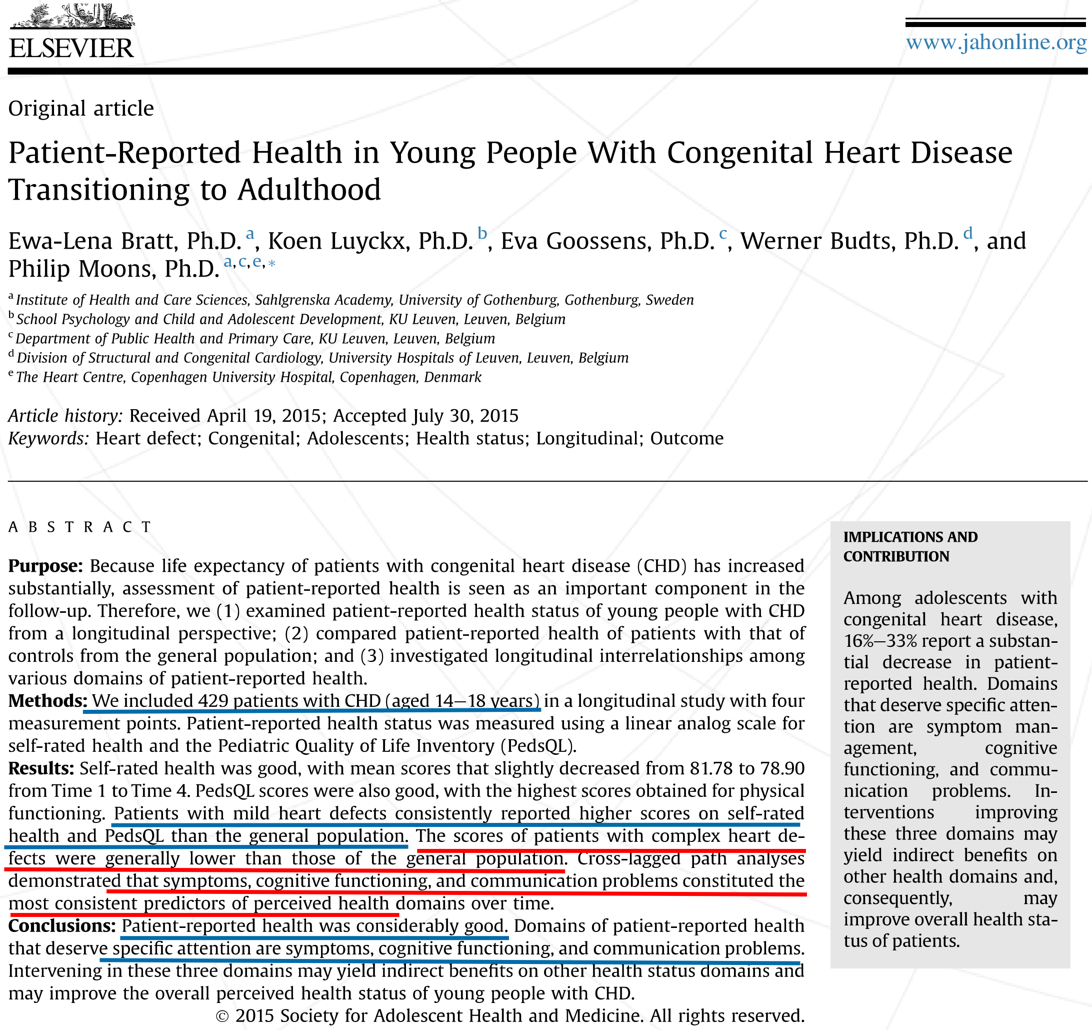
Jana Popelová, Zdeněk Slavík[*], Jan Škovránek[†]

Department of Medicine, 2nd School of Medicine at Charles University, University Hospital Motol, Prague, Czech Republic; [*]Paediatric Surgical Unit, Harefield Hospital, Harefield, United Kingdom; [†]Kardiocentrum, University Hospital Motol, Prague, Czech Republic

Abstract *Objective:* To assess the incidence of depression, and the ability to interact socially, in adult patients with chronic cyanosis and congenital cardiac malformations. *Design:* Prospective study of consecutive patients. *Setting:* Single institution, tertiary referral centre. *Patients:* Between 1993 and 2000, we assessed 76 patients with congenital cardiac malformations and persistent cyanosis, having a median age of 36.5 years, with a range from 19 to 64 years, at the time of referral. Female patients accounted for just under half (48.6%) of the sample. Just under two-fifths of the cohort (39.5%) had functionally univentricular cardiac anatomy, while 14.8% had tetralogy of Fallot with pulmonary atresia and aorto-pulmonary collateral arteries, and 17% had the Eisenmenger syndrome. During the period of follow-up, 17 (22.4%) of the patients died. *Assessment:* We used clinical interviews and non-invasive assessment, employing Zung's questionnaire which provides a scale for the self-rating of depression. On this scale, a score above 50 points is indicative of depression. *Results:* Of the survivors, 32 (54%) completed the self-rating questionnaires. Of these, 20 responders (63%) considered that they lead full lives, including sexual activities, while 26 (81%) had never harboured suicidal thoughts. Depression was diagnosed in 11 responders (34%), with a mean score of 66.9, standard deviation of 8.7, and a range from 53 to 89. The remaining 21 patients (66%) were without signs of depression, scoring a mean of 41.5, with standard deviation of 5.5, and a range from 35 to 46. Depression was associated with older age (40.5 years versus 33.5 years, $p = 0.01$), worse functional state in the classification of the New York Heart Association (2.95 versus 2.48, $p = 0.03$), and unemployment ($p < 0.0001$), but independent from the severity of cyanosis, the level of the haematocrit, the saturation of oxygen, or previous surgical treatment. *Conclusions:* To our knowledge, this is the first evidence suggesting a relatively high incidence of depression in adults with congenital cardiac malformations and persistent cyanosis. Larger, multi-centric studies will be needed to confirm or refute these findings.

Keywords: Congenital heart defects; psychosocial aspects; Zung's self-rating depression scale

Popelová J. et al., Cardiol Young 2001; 11:379-384



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Original article

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

Ewa-Lena Bratt, Ph.D. [a], Koen Luyckx, Ph.D. [b], Eva Goossens, Ph.D. [c], Werner Budts, Ph.D. [d], and Philip Moons, Ph.D. [a,c,e,*]

[a] *Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden*
[b] *School Psychology and Child and Adolescent Development, KU Leuven, Leuven, Belgium*
[c] *Department of Public Health and Primary Care, KU Leuven, Leuven, Belgium*
[d] *Division of Structural and Congenital Cardiology, University Hospitals of Leuven, Leuven, Belgium*
[e] *The Heart Centre, Copenhagen University Hospital, Copenhagen, Denmark*

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

ABSTRACT

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.

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.

Bratt E.L. et al., J Adolesc Health 2015; 57:658-665

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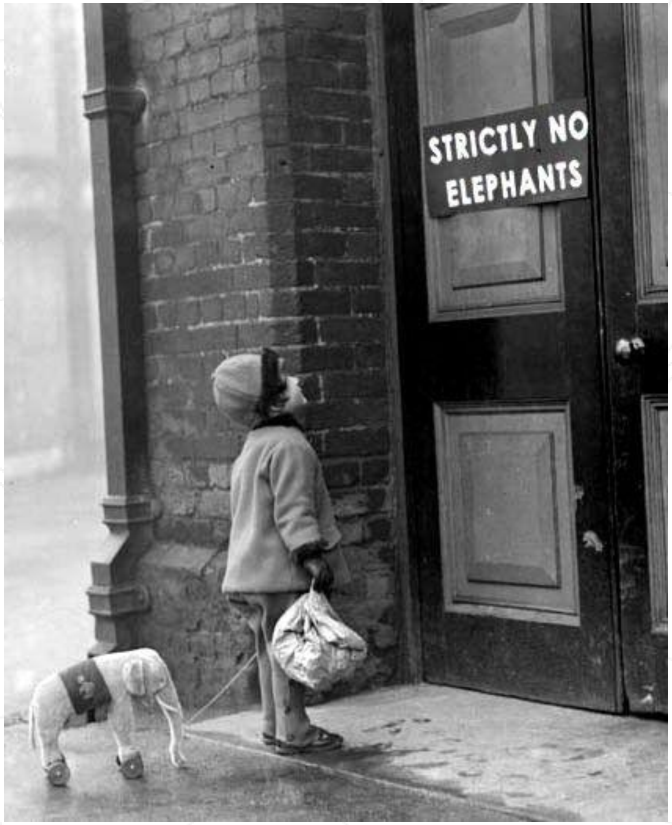
ZÁVĚR



ZÁVĚR

- Kvalita života většiny pacientů po operaci VSV je srovnatelná s běžnou populací.
- Subjektivní vnímání kvality života je obecně nižší u rodičů než u pacientů samotných.
- Rizikovými faktory pro sníženou kvalitu života jsou cyanotické a komplexní VSV, neurokognitivní dysfunkce, nižší socioekonomické zázemí a zvýšená anxieta, zejména u matky.
- Děti po operaci VSV vyžadují celoživotní péči multidisciplinárního týmu, který kromě kardiologické péče nabízí psychosociální podporu a péči rehabilitační.

DĚKUJI VÁM ZA POZORNOST