BMH MEDICAL JOURNAL

BMH Medical Journal 2015;2(1):14-19 **Review Article**

Behaviour Problems in Children with Congenital Heart Disease

Beena Johnson, MBBS, DCH, MD, PhD

Baby Memorial Hospital, Kozhikode, Kerala, India. PIN: 673004

Address for Correspondence: Dr. Beena Johnson, MBBS, DCH, MD, PhD, Department of Child Guidance, Baby Memorial Hospital, Kozhikode, Kerala, India. Email: jiacam@gmail.com

Abstract

As more children survive with congenital heart diseases, management of their behavioural problems are becoming increasingly important. In this article we aim to review the current status of knowledge on this aspect. Children with congenital heart diseases have more behavioural problems compared to children without chronic illnesses. Behavioural problems in children can be classified into externalizing behaviours and internalizing behaviours. Externalizing behaviours are marked by defiance, impulsivity, hyperactivity, disruptiveness, aggression and antisocial features. Internalizing behaviours are evidenced by withdrawal, dysphoria and anxiety. Boys with congenital heart diseases have more externalizing problems compared to girls. Preoperative hypoxia as well as peri and postoperative cardiocirculatory insufficiency can lead to internalizing and externalizing behavioral problems in future. High treatment intensity and palliative interventions are associated with poor behavioral outcomes. Children who underwent open heart surgery at very young age are prone to develop attention-deficit hyperactivity disorder on reaching school age. A comprehensive approach in this field is essential, so that effective early interventions and guidance can be planned.

Key Words: Behavioural problems, Children, Congenital heart diseases

Introduction

Children with chronic physical illnesses are vulnerable for behavioural problems [1-4]. In the Ontario Child Health Study, Cadman et al [5] did an epidemiologic survey of 3294 children and adolescents between 4 and 16 years of age in the general community. They compared children having chronic medical illnesses with those children free of such problems. Results showed that children with chronic physical disorders had greater than threefold risk for psychological disorders and social adjustment problems. Janus and Goldberg [6] from Canada, examined the behavioural adjustment of children with chronic illnesses. This study revealed more behavioural problems in children with congenital heart diseases. Behavioural problems in children can be classified into externalizing behaviours and internalizing behaviours. Externalizing behaviours are marked by defiance, impulsivity, hyperactivity, disruptiveness, aggression and antisocial features. Internalizing behaviours are evidenced by withdrawal, dysphoria and anxiety [7]. Children with behaviour disorders are at increased risk for major depression, bipolar disorder and substance abuse in future. Hence better understanding and early management of behaviour problems in children with

congenital heart disease has important public health implications.

Behavioural problems in Children with Congenital Heart Disease

Research has shown that children with congenital heart disease have more behavioural and emotional problems compared to children from the general population [8-11]. Irrespective of the severity of the heart disease, the congenital heart disease patients exhibited more behavioural problems [8,11].

Kramer HH, et al [12] from the Department of Paediatric Cardiology, University of Dusseldorf, Germany, compared 128 children with congenital heart diseases (CHD) and 89 healthy controls and it was found that the cardiac patients had increased feeling of inferiority and anxiety as well as behaviour problems.

In the study conducted at Children's Clinic, University Hospital, Oslo, Norway, Fredriksen PM et al [8] reported that children with congenital cardiac diseases had significantly more behavioural problems than did a reference population and boys scored higher compared to girls. Analysis using Child Behaviour Check-List showed a significant impact of physical capacity on the score representing total problems, as well as scores for externalising and internalising behaviour.

Fredriksen PM et al [13] also found that boys scored significantly higher than girls in total problem score and externalizing scores with more social problems, attention problems, delinquent behaviour and aggressive behaviour. No gender difference was found regarding internalizing problem score. No effect was found related to different diagnoses.

Yang et al [14] studied the neuropsychological and behavioural states of thirty nine Chinese children with acyanotic congenital heart disease, of the age group five to fourteen years. They identified greater behavioural disturbance in children with acyanotic congenital heart disease, compared to controls matched for age, educational level and social class.

Cyanotic Congenital Heart Disease versus Acyanotic Congenital Heart Disease

Gupta S et al [15] from Alberta Children's Hospital, University of Calgary, Canada, conducted a study on 39 children with congenital heart disease and compared them with samples of normal children regarding the anxiety, fears, depression and behavioural problems. There were 24 children with cyanotic congenital heart disease and 15 with acyanotic congenital heart disease. The subgroup analysis was also done between children with cyanotic congenital heart disease and acyanotic congenital heart disease. The Child Behaviour Check-List - parent version was completed by mothers. Children with CHD had increased fear and anxiety compared to normal children. Children with cyanotic congenital heart disease had increased fear, anxiety, depression and delinquent behaviours compared to acyanotic congenital heart disease. The authors concluded that even children with CHD not showing psychological adjustment problems are still at risk for behavioural problems.

Preoperative patients with Congenital Heart Disease

Preoperative patients with congenital heart diseases have a generalized impairment in neuropsychological functioning and these children can have anxiety, or impulsiveness [16] Utens EM et al [17], found that the children scheduled for cardiac surgery aged 2 to 3 years had significantly higher scores on the Child Behaviour Checklist than did peers from normative groups.

Congenital Heart Disease - Post-cardiopulmonary bypass

Patients with operated tetralogy of Fallot and transposition of great arteries have special

psychosocial problems and hence they need multi-disciplinary care [18] O'Dougherty M et al [19] conducted a study on 31 children with transposition of great arteries who had undergone open heart surgery during infancy. In this study, it was found that adverse developmental outcome including behavioural problems was significantly associated with medical risk variables such as prolonged hypoxia, growth failure, congestive heart failure, stroke and central nervous system infections.

In a systematic review on the psychological adjustment in children and adolescents following open heart surgery for CHD, Latal B et al [20], concluded that a significant number of children who survived, have risk for psychological problems and impairment in the quality of life. Non specific effects of cardiac surgery with extracorporeal circulation can lead to cognitive impairment, especially, problems with attention [21].

In a randomized clinical trial, Bellinger et al [22] evaluated 155 children with surgically corrected TGA at ages between 4 and 8 years using the Child Behaviour Check-List - parent version, Conner's parent rating scale and Conner's teacher rating scale. The total behaviour problem scores were high as per the Child Behaviour Check-List and the Teacher's report form. This study gives evidence that children with congenitally malformed hearts are at risk of developing behaviour disorders.

Parents perceived a higher degree of behavioural problems in children who had undergone cardiac surgery [23]. On assessing the occurrence of behavioural problems of 125 congenital heart disease children after invasive treatment, parents of congenital heart disease children reported high levels of behavioural problems compared to reference group. The proportion of boys with congenital heart disease scoring in the deviant range (21.4%) was significantly greater than that of the reference sample (10%). According to parent report of child behaviour checklist, higher scores were found for the scales - somatic complaints, social problems, attention problems, internalising and total problems compared to the reference group [24].

Higher behavioral problems were also found in postoperative school-age children with acynaotic congenital heart defects [25] In this cross-sectional study using Child Behaviour Checklist, 15 school age children who underwent surgical correction of septal heart defect showed more withdrawn behaviour, social difficulties, thought problems and attentional problems compared to healthy controls.

Treatment Intensity and behavior problems

Janus and Goldberg [26] examined the behavioural problems in patients with congenital heart disease; which were then compared with that of healthy siblings. It was reported that high treatment intensity was associated with elevated behaviour problems in patients with congenital heart disease.

The neonatal arterial switch operation for transposition of great arteries is associated with long term behavioural impairment. In this study, Hovels-Gurich et al [9] analyzed 60 children with transposition of great arteries operated at neonatal period with deep hypothermic circulatory arrest and low flow cardiopulmonary bypass. These children were evaluated at ages between 7.9 and 14.3 years. The parent reported Child Behaviour Check-List total problem score was higher in these children compared to the normal population. Preoperative hypoxia and parent reported social problem were found to be inter related. Children with peri and post operative cardiocirculatory insufficiency had greater score on internalizing, externalizing, attention and total behaviour problems on Child Behaviour Check-List.

In the study conducted at Royal Belfast Hospital for Sick Children in United Kingdom McCusker et al [27], evaluated the relative effects of cyanosis and surgical interventions in the behavioural outcomes of 90 children with cyanotic and acyanotic heart diseases who underwent corrective or

palliative surgery. Children with complex congenital heart diseases and who required palliative interventions had poor behavioural outcomes. The authors suggested that secondary prevention programs should be implemented at the earliest for the at risk population.

Attention-deficit/hyperactivity disorder and congenital heart disease

Attention-deficit/hyperactivity disorder is a common behavioral disorder of childhood. Children with CHD are at increased risk for attention-deficit/hyperactivity disorder. Greater prevalence of inattention symptoms are seen in children with cyanosis or single ventricle physiology. Children with preoperative hypoxemia in infancy due to cyanotic cardiac defects are at increased risk for attentional dysfunction [28]. In a study conducted at Children's Hospital of Philadelphia, Shillingford AJ [29], examined a population of 5 to 10 year-old children who underwent newborn cardiac surgery for complex congenital heart disease and assessed the severity of hyperactivity and inattention. The number of children receiving clinically significant scores for inattention and hyperactivity on the Behaviour Assessment System for Children was 3 to 4 times higher than observed in the general population. Children who underwent open-heart surgery at younger than 1 year of age are more likely compared to healthy controls to have ADHD when they reach school age [30].

Parent ratings of inattention are significantly higher and ADHD symptoms are more prevalent in children with congenital heart diseases. There is increased prevalence of inattention symptoms in children with cyanotic heart diseases [31]. Parenting styles affect the behavioural outcome of congenital heart disease patients.

Conclusion

With the advances in the field of surgical management for congenital heart diseases, there is increased survival of infants born with complex congenital cardiovascular disorders. Scientific evidence shows that children with CHD have more behavioural problems than their healthy peers. These children are at risk of long-term motor and behavioural problems. Preoperative, operative and postoperative factors contribute to the behavioural outcome. Assessment and management of behavioural problems should be an integral component of the comprehensive treatment of children with CHD. Therapies to ameliorate the long term consequences must be implemented at the earliest in children with congenital heart disease.

References

1. Merikangas KR, Nakamura EF, Kessler RC. Epidemiology of mental disorders in children and adolescents. Dialogues Clin Neurosci. 2009;11:7-20.

2. Lavigne JV, Faier-Routman J. Psychological adjustment to pediatric physical disorders: a meta-analytic review. J Pediatr Psychol 1992;17:133–57.

3. Knapp PK, Harris ES. Consultation-liaison in child psychiatry: a review of the past 10 years. Part I: Clinical findings. J Am Acad Child Adolesc Psychiatry. 1998;37:17-25.

4. Wallander JL, Varni JW. Effects of pediatric chronic physical disorders on child and family adjustment. J Child Psychol Psychiatr 1998;39:29-46.

5. Cadman D, Boyle M, Szatmari P, Offord DR. Chronic illness, disability, and mental and social well-being: findings of the Ontario Child Health Study. Pediatrics. 1987;79:805-13.

6. Janus M., Goldberg S. Sibling empathy and behavioural adjustment of children with chronic illness. Child Care Health Dev. 1995; 21, 321 -31.

7. Achenbach TM, Edelbrock CS. The classification of child psychopathology: a review and analysis of empirical efforts. Psychol Bull. 1978;85:1275-1301.

8. Fredriksen PM, Mengshoel AM, Frydenlund A, Sorbye O, Thaulow E. Follow-up in patients with congenital cardiac disease more complex than haemodynamic assessment. Cardiol Young. 2004;14:373-9.

9. Hovels-Gurich HH, Konrad K, Wiesner M, Minkenberg R, Herpertz-Dahlmann B, Messmer BJ, Von Bernuth G. Long term behavioural outcome after neonatal arterial switch operation for transposition of the great arteries. Arch Dis Child. 2002;87:506-10.

10. Janus M., Goldberg S. Sibling empathy and behavioural adjustment of children with chronic illness. Child Care Health Dev. 1995; 21, 321 -31.

11. Utens EM, Verhulst FC, Meijboom FJ, Duivenvoorden HJ, Erdman RA, Bos E, Roelandt JT, Hess J. Behavioural and emotional problems in children and adolescents with congenital heart disease. Psychol Med. 1993;23:415-24.

12. Kramer HH, Awiszus D, Sterzel U, van Halteren A, Classen R. Development of personality and intelligence in children with congenital heart disease. J Child Psychol Psychiatry. 1989;30:299-308.

13. Fredriksen PM, Diseth TH, Thaulow E. Children and adolescents with congenital heart disease: Assessment of behavioural and emotional problems. Eur Child Adolesc Psychiatry. 2009;18:292-300.

14. Yang LL, Liu ML, Townes BD. Neuropsychological and behavioural status of Chinese children with acyanotic congenital heart disease. Int J Neurosci. 1994; 74, 1 – 4.

15. Gupta S, Giuffre RM, Crawford S, Waters J. Covert fears, anxiety and depression in congenital heart disease. Cardiol Young. 1998;8:491-9.

16. Zuo CY, Yang LL, Townes BD. Neuropsychological status of patients with congenital and rheumatic heart diseases: preoperative and postoperative comparison. Int J Neurosci. 1985;26:59-65.

17. Utens EM, Versluis-Den Bieman HJ, Witsenburg M, Bogers AJJC, Verhulst FC, Hess J. Cognitive, and behavioural and emotional functioning of young children awaiting elective cardiac surgery or catheter intervention. Cardiol Young. 2001;11:153-60.

18. Loup O, von Weissenfluh C, Gahl B, Schwerzmann M, Carrel T, Kadner A. Quality of life of grown-up congenital heart disease patients after congenital cardiac surgery. Eur J Cardiothorac Surg. 2009;36:105-11.

19. O'Dougherty M, Wright FS, Garmezy N, Loewenson RB, Torres F. Later competence and adaptation in infants who survive severe heart defects. 1: Child Dev. 1983;54:1129-42.

20. Latal B, Helfricht S, Fischer JE, Bauersfeld U, Landolt MA. Psychological adjustment and quality of life in children and adolescents following open-heart surgery for congenital heart disease: a systematic review. BMC Pediatr. 2009;9:6.

21. Vingerhoets G, Van Nooten G, Vermassen F, De Soete G, Jannes C. Short-term and long-termneuropsychological consequences of cardiac surgery with extracorporeal circulation. Eur J

Cardiothorac Surg. 1997;11:424-31.

22. Bellinger DC, Newburger JW, Wypij D, Kuban KC, duPlesssis AJ, Rappaport LA. Behaviour at eight years in children with surgically corrected transposition: The Boston Circulatory Arrest Trial. Cardiol Young. 2009;19:86-97.

23. Oates R.K., Turnbull J.A., Simpson J.M., Cartmill T.B. Parent and teacher perceptions of child behaviour following cardiac surgery. Acta Paediatrica. 1994; 83, 1303 -07.

24. Spijkerboer AW1, Utens EM, Bogers AJ, Verhulst FC, Helbing WA. Long-term behavioural and emotional problems in four cardiac diagnostic groups of children and adolescents after invasive treatment for congenital heart disease. Int J Cardiol. 2008;125:66-73.

25. Sarrechia I1, Miatton M, De Wolf D, François K, Vingerhoets G. Neurobehavioural functioning in school-aged children with a corrected septal heart defect. Acta Cardiol. 2013 Feb;68(1):23-30.
26. Janus M., Goldberg S. Treatment characteristics of congenital heart disease and behaviour problems of patients and healthy siblings. J Paediatr Child Health. 1997; 33, 219 -25.

27. McCusker CG, Doherty NN, Molloy B, Casey F, Rooney N, Mulholland C, Sands A, Craig B, Stewart M. Determinants of neuropsychological and behavioural outcomes in early childhood survivors of congenital heart disease. Arch Dis Child. 2007;92:137-41.

28. Hovels-Gurich HH, Konrad K, Skorzenski D, Herpertz-Dahlmann B, Messmer BJ, Seghaye MC. Attentional dysfunction in children after corrective cardiac surgery in infancy. Ann Thorac Surg. 2007;83:1425-30.

29. Shillingford AJ, Glanzman MM, Ittenbach RF, Clancy RR, Gaynor JW, Wernovsky G. Inattention, hyperactivity, and school perormance in a population of school-age children with complex congenital heart disease. Pediatrics. 2008;121:759-67.

30. Yamada DC1, Porter AA, Conway JL, LeBlanc JC, Shea SE, Hancock-Friesen CL, Warren AE. Early repair of congenital heart disease associated with increased rate of attention deficit hyperactivity disorder symptoms. Can J Cardiol. 2013 ;29:1623-8.

31. Hansen E1, Poole TA, Nguyen V, Lerner M, Wigal T, Shannon K, Wigal SB, Batra AS. Prevalence of ADHD symptoms in patients with congenital heart disease. Pediatr Int. 2012;54:838-43.