

## **Emotional and Behavioural Problems in Children and Adolescents with Congenital Heart Disease**

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### **Introduction**

Major physical illnesses usually have an impact on the psychological well-being of any individual. An illness of early onset, with necessity of frequent diagnostic and therapeutic interventions can adversely affect the emotional balance and behavioural adaptation of children and adolescents. This is applicable for congenital heart disease, especially if it is severe and life-threatening. Psychological implications are a significant part of chronic illnesses and they can affect prognosis and outcome. Congenital heart diseases which are diagnosed early can influence mother infant interactions from the beginning, in a crucial period of the infant's psychological development and thus may adversely affect the mental health of children and adolescents. Children and adolescents with congenital heart diseases can have anxiety, depressive reactions, low self esteem or impulsiveness. The behavioural and emotional problems of children and adolescents, if not diagnosed and managed early, can lead on to significant psychological morbidity in later life.

The newer diagnostic modalities and the rapid development of cardiac surgical techniques, in conjunction with advances in medical technology have improved the longevity of children and adolescents with congenital heart diseases. With continuous improvement of surgical techniques and with the infant operative mortality having decreased from 50% to nearly 15%, a large number of children with surgically palliated forms of congenital heart diseases are likely to survive longer. These children are at higher risk to develop emotional and behavioural problems. Several medical factors may put congenital heart disease children at increased risk of developing later adjustment problems, such as age at surgical repair, medical complications during or after surgery, number of operations & concomitant extracardiac anomalies.

## **Review**

Children with congenital heart disease (CHD) have more medical fears, and more physiological anxiety than normal peers [Gupta et al 2001]. These children show an increased feeling of inferiority and of basic anxiety and a more impetuous behaviour (Kramer et al 1989). They have low self-esteem and depression and are at particular risk for poor school adjustment (Youssef NM, 1988). Withdrawn aggressive behavior, somatic complaints, depression and anxiety are seen in children with congenital heart diseases (Yildiz S, et al 2001).

Janus and Goldberg (1995) from the hospital for sick children Toronto, Canada, noted more behavioural problems in children with congenital heart disease.

Male adolescents with CHD presented with a reduced perceived capacity and self-esteem (Salzer-Muhar et al 2002). There is significant incidence of depression and anxiety disorders in adolescents with congenital heart disease (Green A 2004). Children and adolescents with congenital cardiac diseases have significantly more behavioural problems compared to reference population and boys have more behavioural problems compared to girls (Fredriksen et al 2004).

## **Type of Congenital Heart Diseases**

39 children patients with acyanotic ventricular septal defect or atrial septal defect who received cardiac operation, were compared with age and sex matched normal control group on a battery of neuro-psychological tests, intelligence tests and child behavioral checklist. Significantly more behavioral problems especially the so called externalizing and internalizing behavioral problems, were found in cardiac patients than the controls. (Liu M, Yang L, 1992)

Neuropsychological and behavioural states of thirty nine Chinese children with acyanotic congenital heart disease of the age group five to fourteen years were assessed by Yang et al (1994). They identified greater behavioural disturbance in acyanotic congenital heart disease compared to controls matched for age, educational level and social class. Acyanotic heart disease was thus found to impact negatively the behavioural functioning.

Children with cyanotic form of congenital heart disease are at higher risk for developing anxiety, depression and behavioural problems compared with children having acyanotic heart diseases [Gupta et al 1998]. Poorer overall psychological functioning has been documented in children with transposition of the great arteries and tetralogy of Fallot compared with children who spontaneously recovered from congenital heart disease without medical intervention (DeMaso DR et al,1990).

Alden B et al (1998), assessed the long term psychological outcome of children after surgery for transposition of the great arteries. 19% of children had clinically significant child psychological symptoms, mainly internalizing problems.

## ***Velocardiofacial Syndrome***

Velocardiofacial Syndrome is associated with higher incidence of behavioural problems as part of the syndrome. The name velocardiofacial syndrome comes from the Latin words "velum" meaning palate, "cardia" meaning heart and "facies" having to do with the face. The most common features are cleft palate, cardiac defects, characteristic facial appearance, minor learning problems and speech and feeding problems. Behaviour problems and personality aspects of forty children with velocardiofacial syndrome (VCFS) was assessed by Heineman de Boer et al (1999). They reported that children with velocardiofacial syndrome showed more behavioural problems than the matched control children. Attention deficit hyperactivity disorder (ADHD) is a common comorbid condition in children with velocardiofacial syndrome. (Antshel KM et al 2005). The VCFS children show more behavior problems and personality problems than the matched control children with a craniofacial anomaly (Heineman-de Boer JA, 1999).

### **Role of treatment characteristics**

The role of treatment characteristics in causing problems in patients with congenital heart disease was determined by Janus and Goldberg (1997). The behavioural problems in patients with congenital heart disease were 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.

Utens et al (1993) assessed the behavioural and emotional problems in children and adolescents; at least nine years after surgical correction for congenital heart disease in childhood. On the child behaviour checklist and youth self report, children and adolescents with congenital heart disease obtained significantly higher problem scores than same aged peers from normative reference groups. No significant differences were found between problem scores for different cardiac diagnostic groups.

In a study from the University of Sydney, Australia, behavioural profile of children following cardiac surgery was examined (Oates et al; 1994). It was found that the parents perceived a higher degree of behavioural problems in children who had undergone cardiac surgery.

In the study by Wray J & Sensky T (1998), children with CHD considered themselves as weaker, more frightened and more ill than the healthy children. But significant improvement in self-perception was demonstrated in children following surgery for CHD.

Utens et al (1998) conducted a study to determine the medical variables which were predictors of long term behavioural/emotional outcome after surgical correction for congenital heart disease in infancy and childhood. The Child Behavior Checklist (CBCL) was used to predict parent-reported behavioural/emotional problems in 125 10–15 year-old congenital heart disease children from: (1) biographical status (2) medical history (3) heart surgery (4) short-term post-operative course number of heart operations and (6) extra cardiac concomitant anomalies. Higher total behavioural

problem scores as per child behaviour checklist were associated with a greater number of heart operations and deep hypothermic circulatory arrest. 'Internalizing problems' were associated with greater number of heart operations, deep hypothermic circulatory arrest, short gestational age, low systemic oxygen saturation and older age at surgical repair. 'Externalizing problems' were associated with greater number of heart operations only. This study revealed several medical variables as significant predictors which could be used to identify those congenital heart disease children who are at risk of long term behavioural/emotional maladjustment.

## **Conclusion**

There is high prevalence of behavioural and emotional problems in children and adolescents with congenital heart disease. Early detection of distressed families will help in alleviating stress and reducing behavior problems in children with congenital heart disease. A comprehensive approach in this field is essential, so that effective psychological interventions and guidance can be planned.

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