

**Original article:**

## Physical and psychological changes in children with congenital heart defects

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### ABSTRACT

**Background:** Children with congenital heart defects tend to live with many restrictions in their life. For a physiotherapist it is an important aspect to know the hurdles like easy fatigability, dyspnoea, decreased exercise tolerance between the development of these children. Thus, the study aims to find physical and psychosocial challenges in children with congenital heart defects.

**Objective:** Our objectives were psychosocial challenges in children with Congenital Heart Defects by using Paediatric Symptom Checklist (PSC-17) and physical challenges in children with Congenital Heart Defects by using Paediatric Evaluation of Disability Inventory (PEDI).

**Material and Method:** 18 participants were taken from Department of Paediatrics, Pravara Rural Hospital, Loni were selected conveniently. 18 participants with congenital heart defects, children between 4 to 17 years of age were involved in the study. The inclusion criteria for the study were: 1) Participants in the age group of 4-17 years 2) Both Boys and Girls 3) Children with Congenital Heart Defects. The exclusion criteria for the study were: 1) Auditory and Visual Problem 2) Mentally Challenged 3) Children with congenital heart disease associated with other problems. Filled consent was taken from the parents of the children. Parents were explained about the questionnaire and method of filling. The parents were asked to fill the questionnaire properly and correctly after reading all the questions. Paediatric Symptom Checklist – 17 (PSC-17) and Paediatric Evaluation of Disability Inventory (PEDI) were taken as the outcome measure.

**Result:** The result shows that behavioural difficulties were common (50%) in children with congenital heart defects. According to PSC-17 internalizing problems were more frequent. According to PEDI Scale functional limitations in socialization ( $47.44 \pm 7.197$ ), daily living skills or self-care ( $55.16 \pm 4.148$ ), mobility ( $37.05 \pm 5.023$ ), care-giver assistance in self-care ( $22.88 \pm 3.496$ ), mobility ( $20.5 \pm 3.601$ ), socialization ( $14.055 \pm 2.071$ ) were noted in 20% to 25% of children. With Paediatric Evaluation of Disability Inventory 20% to 22% of subjects were more dependent than their peers in self-care and social cognition although few (37%) had mobility restrictions.

**Conclusion:** CHD have impact on various aspects of physical activity, physical and psychological health in children. According to this study there is more impact seen on physical activity than physical health because the children's with CHD have a tendency to get easily fatigue, decreased exercise tolerance thus leading to rapid breathing (tachypnoea).

**Keywords:** Congenital Heart Defects, Physical and Psychosocial changes, children

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### INTRODUCTION

At birth when there is defect in the structure of the heart it is referred to as congenital heart disease. A congenital heart defect is often detected during ultrasound done during pregnancy<sup>1</sup>. These are one of the most common type of birth defect. In this congenital defect the walls of the heart, the valves, the arteries and veins near the heart are involved. Thus, the normal blood flow through the heart is disrupted<sup>2</sup>.

When the level of oxygen saturation in the blood is reduced, it is considered as cyanotic type of congenital heart defect and when the level of oxygen saturation in the blood is unaltered or normal it is acyanotic. Cyanotic defects include Tetralogy of Fallot(TOF), Transposition of great arteries, Tricuspid atresia and Hypoplastic left-sided heart syndrome(HLHS) whereas acyanotic heart defects include atrial septal defects, ventricular septal defects(VSD), patent ductus arteriosus(PDA) and Co-arcuation of aorta. Due to structural defect in the interventricular septum, blood flows (shunted) from left side of the heart to the right side in acyanotic type<sup>3</sup>, whereas in cyanotic type blood flows from right side of the heart to left side<sup>4</sup>. Signs and symptoms of severe defects are rapid breathing, cyanosis - a bluish tint to the skin, lips, and fingernails, fatigue, poor blood circulation<sup>2</sup>

The causes of congenital heart diseases are infection(rubella) to the mother, smoking or consumption of alcohol by mother during pregnancy. Risk of congenital heart disease is increased in consanguineous unions, especially at first cousin level<sup>5</sup>. Some genetic conditions are associated with a higher incidence of congenital heart disease, including Down's syndrome, Turner's syndrome, William syndrome<sup>6</sup>. Maternal diabetes mellitus is associated with an increased incidence (8.5 per hundred live births) of congenital heart disease<sup>7</sup>. Various risk factors affect neuromotor development in these children which includes hemodynamic instability, hypoxia, brain embolism and hemorrhages. Children with congenital heart defects are often born with immature brain, brain injury, or structural brain lesions affecting motor performance<sup>8</sup>.

A thorough investigation is mandatory including developmental history of the child as well as history of any infection to mother or use of any drug during pregnancy and family history of cardiac conditions. The initial investigation of choice is echocardiography because it is a non-invasive procedure. It tells about the normal anatomy and flow and also gives a final diagnosis in most of the cases<sup>9</sup>.

There are various complications of congenital heart defects which include heart failure, atrial fibrillation, tachycardia, endocarditis, polycythemia, developmental delay<sup>10</sup>, malnutrition and growth failure<sup>11</sup>. Children also face behavioural complications like anxiety, depression, ADHD. Children who underwent open heart surgery at very young age are prone to develop attention-deficit, hyperactivity disorder on reaching school age<sup>12</sup>. Congenital heart disease children who have been operated upon showed, on average, significantly more behavioural /emotional problems than same-aged peers from normative reference groups<sup>13</sup>.

The PSC-17 is used to screen for childhood emotional and behavioural problems including those of attention, externalizing, and internalizing. The scale is used for the recognition of emotional and behavioural problems so that appropriate treatment protocol is initiated as soon as possible. It is administered in children with age group of 4-17 years<sup>14</sup>. The PEDI Scale is used to assess functional development.

With this background, children with congenital heart defects tend to live with many restrictions in their life. For a physiotherapist, it is an important aspect to know the hurdles (dyspnoea, decreased exercise tolerance) between the development of these children. Thus, the study aims to find physical and psychosocial challenges in children with congenital heart defects.

#### **AIMS & OBJECTIVE**

**AIM:** The study aims to find the physical and psychosocial challenges in children with heart defects.

**OBJECTIVE:** To find out

- 1) Psychosocial challenges in children with Congenital Heart Defects by using Paediatric Symptom Checklist (PSC-17) and

- 2) Physical challenges in children with Congenital Heart Defects by using Paediatric Evaluation of Disability Inventory (PEDI).

#### **HYPOTHESES**

**Null Hypothesis (H<sub>0</sub>):** There will be no significant physical and psychosocial changes observed in children with congenital heart defects.

**Alternative Hypothesis (H<sub>1</sub>):** There will be significant physical and psychosocial changes observed in children with congenital heart defects.

#### **METHODOLOGY**

18 participants were taken from Department of Paediatrics, Pravara Rural Hospital, Loni were selected conveniently. 18 participants with congenital heart defects, children between 4 to 17 years of age were involved in the study. The inclusion criteria for the study were: 1) Participants in the age group of 4-17 years 2) Both Boys and Girls 3) Children with Congenital Heart Defects. The exclusion criteria for the study were: 1) Auditory and Visual Problem 2) Mentally Challenged 3) Children with congenital heart disease associated with other problems. Filled consent was taken from the parents of the children. Parents were explained about the questionnaire and method of filling. The parents were asked to fill the questionnaire properly and correctly after reading all the questions. Paediatric Symptom Checklist – 17 (PSC-17) and Paediatric Evaluation of Disability Inventory (PEDI) were taken as the outcome measure.

#### **PROCEDURE**

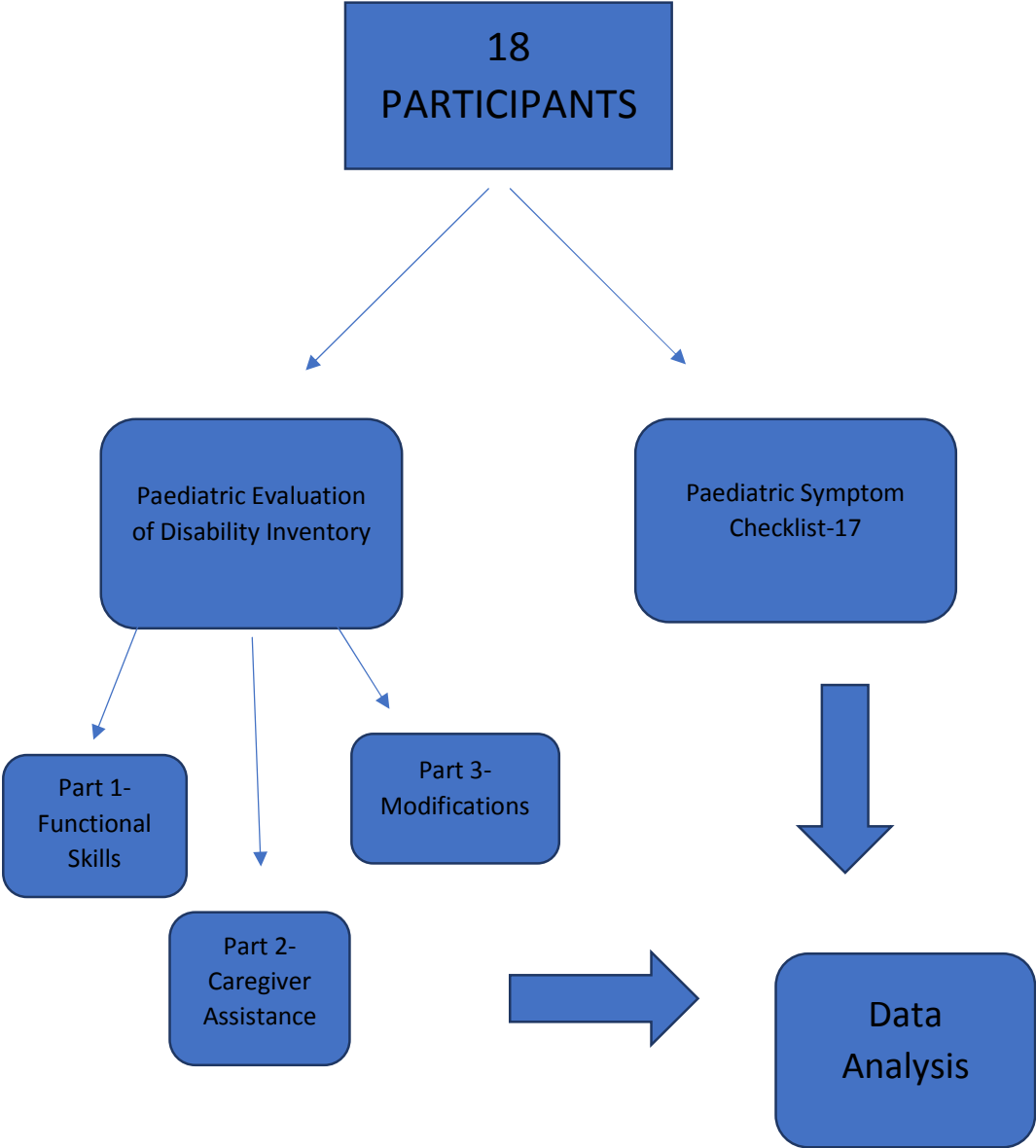
The participants were taken from department of paediatrics, pravara rural hospital, loni. All the participants who were formerly clinically diagnosed with Congenital Heart Defects were screened as per the inclusion and exclusion criteria and they were requested to participate in the study. Parents were briefed about the study, an informed written consent was obtained from the parents and a questionnaire of 17 questions, Paediatric Symptom Checklist-17 (PSC-17) and Paediatric Evaluation of Disability Inventory (PEDI) which was filled by the primary investigator.

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**DATA ANALYSIS AND RESULT**

**Table no.1.Total no. of males and females according to age group**

AGE	MALE	FEMALE	TOTAL
4-10 Years	04	07	11
11-16 Years	04	03	07

**Table no.2.Mean Value of Functional Skills**

SELF CARE MEAN +- SD	MOBILITY DOMAIN MEAN +- SD	SOCIAL FUNCTION DOMAIN MEAN +- SD
55.166 +- 4.148	37.055 +- 5.023	47.444 +- 7.197

**Table no.3.Mean Value of Care-giver Assistance**

SELF CARE MEAN +- SD	MOBILITY DOMAIN MEAN +- SD	SOCIAL FUNCTION DOMAIN MEAN +- SD
22.888 +- 3.496	20.5 +- 3.601	14.055 +- 2.071

**Table no.4: MODIFICATIONS REQUIRED**

Modifications	Total no.
N- No modifications	5
C- Child oriented Modifications	6
R- Rehabilitation Equipment	5
E-Extensive Modifications	2

**RESULTS**

The result shows that behavioural difficulties were common (50%) in children with congenital heart defects. According to PSC-17, internalizing problems were more frequent. According to PEDI Scale, functional limitations in socialization (47.44 ± 7.197), daily living skills or self-care (55.16+-4.148), mobility (37.05+-5.023), and care-giver assistance in self-care (22.88 ± 3.496), mobility (20.5+-3.601) socialization (14.055+-2.071) were noted in 20% to 25% of children. With Paediatric Evaluation of Disability Inventory, 20% to 22% of subjects were more dependent than their peers in self-care and social cognition, although few (37%) had mobility restrictions.

**DISCUSSION**

The present study “Physical and Psychological Challenges In Children with Congenital Heart Defects” was conducted in Dr. A.P.J. Abdul Kalam College Of Physiotherapy, Loni. Children with age group 4-17 years old were included and Paediatric Evaluation of Disability Inventory Scale (PEDI Scale) and Paediatric Symptom Checklist – 17 (PSC-17) were used in the study.

Unlike other studies that classify the groups of children with heart disease by its severity or hemodynamic compromise, this study helps to assess the physical limitations faced by the child in daily activities, dependency of the child in carrying out a certain activity and modifications required by the child to carry the whole activity.

This helps the paediatrician or the therapist to know the specific limitations or difficulties faced by the child and accordingly the treatment protocol is planned. This study also aims to assess any associated psychological disorder based on the child's behaviour and history given by the mother. This helps the therapist or paediatrician to deal with child according to his behavioural disorder.

The family member when become the caretaker of a child with chronic illness has their life affected in many ways, as interference in work and personal life. In most cases, the family member who takes care is the mother. Information from health professionals are usually restricted to the physical aspects of treatment such as food, observation of signs related to pathology and notions of hygiene to prevent infection. These guidelines leave mothers/caregivers restricted to physical symptoms increasing attention and care, imposing a number of limitations, overprotecting the child. Lack of adequate or appropriate information can be related to the large number of mothers that limit the child's activities, and in this study most mothers does not let the child play with the normal individuals, walk or run, or activities that require more energy like jumping or running<sup>15</sup>. Child's emotional adjustment is majorly influenced by Congenital heart disease. An overprotective and overpampering parenting style in CHD may be a risk factor for many behavioural problems like hyperactivity, social withdrawal, aggression<sup>1</sup>.

Children with CHDs show developmental difficulties at school entry that increases the risk for learning challenges and decreased social participation, poor attention span. Most children with CHDs experience difficulties with visual-spatial relationship skills, motor skills and have impaired functions like memory, problem solving and thus shows learning disabilities<sup>16</sup>.

The child with congenital heart defect goes through depression and anxiety due to recurrent hospitalizations, severity of the disease and ignorance by the normal individuals in school environment.

Inadequate nutrition doesn't meet the body's energy requirements. This causes children to tire quickly or not be able to keep up physically with others their same age.

## CONCLUSION

CHD have impact on various aspects of physical activity, physical and psychological health in children. According to this study there is more impact seen on physical activity than physical health because the children's with CHD have a tendency to get easily fatigue, decreased exercise tolerance thus leading to rapid breathing (tachypnoea).

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