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Effectiveness of Behavioral Intervention among Congenital Heart Defect Children

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ABSTRACT

Development in medical intervention has significantly decreased the mortality rates for children with complex congenital heart disease (CHD) but among these survivors with complex heart disease there occurs a unique pattern of neuro-developmental and neuropsychology impairment characterized social interaction impairment, impulsive Behavior, and impaired executive functions. Presence of behavioral problem is found significantly high in pediatric population with chronic illness than children with absence of chronic illness. The sample of 200 children with congenital heart defect was selected between age 4-8 years using multistage stratified sampling. The childhood psychopathology measurement schedule (CPMS) by Dr. Savitha Malhotra was used for assessing Behavioral problems present in children with CHD. "Pre- Post experimental design was used to investigate the study and the results were statistically analyzed using paired T test. The result revealed that the effectiveness of intervention program to retrain Behavior showed high significance. With increased survival rates, the aim of the intervention and research based on clinical practices gets a shift from short term medical assessment to long term assessment and intervention of morbidity.

1. Introduction

1.1 Congenital Heart Defect (CHD)

The Congenital Heart Disease is a birth defect which affects the heart structure and corresponding blood vessels. These are primarily seen in children. Congenital heart defects make up the largest portion of heart disease among children. It affects new-borns and account for a high proportion of infant mortality worldwide, witnessing an advanced progression of treatment and management.^[1] Improvement in technology has made diagnosis evident that the birth defect can be screened even before the birth

of the child. With available medical facilities over 75% of infants born with CHD can survive beyond the first year of life and many can lead nearly normal lives thereafter. However, this privilege of early identification and timely treatment is restricted only to children of developed countries. Recent development in Medico surgical progression had led to decrease in mortality rate but lack of identification. Early screening and intervention increase the risk of neurodevelopmental and neuropsychological problems in children affecting their wellbeing and quality of life^[2]. India has 440 million children. About twenty seven million children are born annually in India, however nearly two million of them don't live to the age of five. It is estimated

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that one lakh twenty five thousand children are born each year with congenital heart condition^[3].

1.2 Prevalence

The birth prevalence of congenital heart disease is estimated as 9/1000 more than 2,00,000 children are born with CHD in India. Currently advanced cardiac care is available to only a minority of such children. A number of cardiac centres have been developed over the last 10 years. However, most are in the private sector, and are not geographically well-distributed. Challenges to paediatric cardiac care include financial constraints, health-seeking behavior of community, and lack of awareness. Government of India is taking a number of steps for improving health of children through its various programs and schemes that are likely to benefit children with congenital heart disease, especially those who are vulnerable and marginalized^[3-4].

1.3 Causes

The causes of congenital heart defect are usually multifactorial which means that "many factors" (multifactorial) are involved in causing the birth defect. The factors are usually both genetic and environmental.

Conditions such as Down syndrome exhibit a higher incidence of infant heart malformations Chromosomal problems that result in genetic syndromes. 30% Of Children with abnormalities in chromosomes reported having cardiac defect^[4-6]. Congenital heart defect is frequently associated with non-cardiac defects in malformation syndromes and is classified according to the causes, such as chromosome abnormalities and single gene or gene pair abnormalities.

1.4 Neurological Deficit in CHD

Heart and brain develop simultaneously at same period. Hence defect in one organ may cause defect on another. It is perhaps not surprising that disruption of organogenesis in one organ will impact the development of the other. A defect in the heart indicates to insufficient blood supply to the brain. Newborns with congenital heart condition show a high frequency of non- inheritable focal brain injury.^[7] These brain damages often lead to problems in domains of neurodevelopmental and neuropsychological dysfunction affecting cognition, Behavior, thinking, and learning.

1.5 Epochs of Brain Development and Neuropathology in Congenital Heart Defect

The development of the brain is highly lively process. It involves timing and orchestration of higher cellular

events. Development of brain is a long process which begins at third week of gestation and development continues to life long. After birth, during the first five years there is 100% increase in brain volume. Individual with congenital heart defect are at risk of altered brain development and pathological insults which may result in poor neurological outcomes. It varies from motor delay and later on progression affects the language, social and finally the executive functioning^[8]. Some children have unaffected or undisturbed milestone till they reach the school age. As soon as they reach the school age, the child starts to exhibit deficits in neurodevelopment and neuropsychological domains. Many children also struggle with emotional and behavioral disturbances which vary from mild to severe. Most of the aspects of neurodevelopment and neuropsychology delays start to reveal its impact only during the school-age. The spectrum of neurodevelopmental and neuropsychological impairment is wide and leads to spectrum of multivariate developmental delay.

1.6 Behavioral Problems of Children with Congenital Heart Defect

Presence of behavioral problems among children with CHD is more when compared with children without chronic illness. Behavioral problems in children can be classified into externalizing behaviors and internalizing behaviors. Externalizing Behaviors are marked by defiance, impulsivity, hyperactivity, disruptiveness, aggression and antisocial features. Internalizing Behaviors are evidenced by withdrawal, dysphoria and anxiety.^[9]

CHD children show worsen behavioural and emotional problems irrespective of type, duration and severity of the condition. Irrespective of the severity of the heart disease, the congenital heart disease patients exhibited more Behavioral problems.^[10-14]

A large number of children with surgically operated congenital heart diseases are probably to survive longer. This population is at higher risk to develop emotional and Behavioral issues. Several medical factors could place congenital heart defect children at redoubled risk of developing later adjustment issues. These children show a raised feeling of inferiority and of basic anxiety and a lot of impetuous Behavior. They have low self-esteem and depression and are at specific risk for poor school adjustment. Withdrawn aggressive Behavior, physical complaints, depression and anxiety seen.

2. Methodology

2.1 Material and Methods

The study was conducted to assess the behavioral and

emotional problem among congenital heart defect children and determine the effectiveness behavior training among congenital heart disease affected children.

2.2 Objectives of the Study

For the current examination, the accompanying objectives were defined:

1. To assess the behavioral and emotional problem among children with congenital heart defect;
2. To determine the effectiveness of behavioral training among congenital heart defect children;

2.3 Hypothesis of the Study

Based on the previous studies, the following hypothesis was formulated and was tested:

H1. There will be an improvement in factors of Behavior and emotion after neuropsychological retraining process among congenital heart disease affected children.

2.4 Participants

The sample consists of a total of 200 children between the age group of 4-8 years selected using multistage stratified sampling technique.

2.5 Tools for Data Collection

a. Demographic form

The demographic form was put in place to elaborate on the information pertinent to the study. The demographic forms consist of general information and socio-demographic factors such as type of family, educational qualification of mother, occupation of the mother.

b. Childhood Psychopathology Measurement Schedule (CPMS)

It is an Indian adaptation of Child Behavior Checklist (CBCL; Achenbach & Rescorla 2001), for using it on Indian population. The only scale that has been systematically standardized studied in India.

2.6. Structure of the Research

The present investigation adopted an experimental design, described as “Pre- Post experimental design with control group”. In this design, the procedure assured that all subjects have the same chance of being in the experimental or control group. Because of strict random assignment of subjects, it is assumed that the two groups are equivalent on all important dimensions and that there are no systematic differences between the two groups. The pre-test is administered to all subjects in both groups- experimental and control and ensure that both groups

experience the same conditions except that in addition the experimental group experiences the intervention.

The experimental group undergoes the treatment program or designed intervention of interest. Researchers then find the variations between the two groups on a selected outcome. The post-test is administered to all subjects in both groups. Likewise this experimental study is carried out to assess the effectiveness of neuropsychological retraining of cognition and intelligence, emotion and Behavior and temperament among female children.

2.7 Procedure

200 samples consist of both who have undergone either surgical or conservative treatment. The sample of N=200 consisted of 4 years (N=52), 5 years (N=51), 6 years (N=44), 7 years (N=39), 8 years (N=14). The Parents were clearly explained about the complete procedure and a signed parent consent form was collected. 200 samples underwent basic line demographic assessment followed by inventory of standardized psychological scale named the childhood psychopathology measurement schedule (CPMS) was used to assess Behavior and emotion. The samples were divided randomly into experimental group- 100 samples, of age group 4 years (N=25), 5 years (N=27), 6 years (N=21), 7 years (N=20), 8 years (N=7). and control group of 100 samples. Assessment was conducted on all 200 samples. This assessment was considered as Pretest assessment. 100 samples of experimental group and were given neuropsychological Behavioral retraining for 30 days 2-3 hours/day. Parents along with the children have participated in the training. Post training, posttest assessment of three scales was conducted. The values were tabulated for analysis and interpretation.

2.8 Formulation of Cognition, Behavior and Emotion Training Program

Cognition, Behavior and emotion Training program employs approaches not only to deal with up with present illness but for a complete well-being. The skills are achieved by gaining a positive attitude towards one well-being, academic performance and whole life. All possible subdomains of cognition, emotion and behavior are trained during the interventional program under proper guidance and support. This proactive program utilizes activities and games which are Child – Friendly. The environment is designed and structured in the way it reinforces active participation of the child^[14]. This collaboration of activities along with tailored structured environment motivates the child to involve maximum and produce positive results. This program is designed based

on the principles drawn from field of Neuro-psychology and behavioral psychology employing framework such as cognitive rehabilitation methods namely – Cognitive stimulation therapy, Cognitive behavioral therapy, neuro-plasticity behavioral approaches, play therapy. Home follow up and practicum of skill training in between sessions are emphasized to children. This diverse methodology is exclusively tailored for children with CHD. The Program is designed based on age appropriateness and the level is increased from simple to complex activities based on previous task accomplishments. Home follow up assignments were given, doubts regarding the session were thoroughly cleared to the parents before and after daily schedule for maximum participation from each and every participant throughout the session.

3. Statistical Analysis

The data collected was analyzed and quantitative analysis was done through statistical techniques which included: (1) Mean and SD (2) t-test Here, we use the statistical package of social sciences (SPSS21stversion).

4. Results

Table 1. summarizes the demographic characteristics of the samples from information provided by the parents (N = 200)

S.No	Variables	Group	N	%
1.	Age(Years)	4Years	52	26.0%
		5Years	51	25.5%
		6Years	44	22.0%
		7Years	39	19.5%
		8Years	14	7.0%
2.	Type of family	Nuclear Family	171	85.5%
		Large Family	29	14.5%
3.	Qualification of Mother	Illiterate	8	4.0%
		Primary	17	8.5%
		Higher Secondary	76	38.0%
		Graduate and above	99	49.5%
4.	Occupation of Mother	Unemployed	37	18.5%
		Semi/Part time- employed	50	25.0%
		Full Time –employed	113	56.5%

The socio-demographic characteristics of the sample (Table 1) shows that, in a total sample of 200 female children with congenital heart defect 26.0% of the children were in the age group 4years, followed by 5 years (25.5%), 6 years (22.0%), 7 years (19.5%) and 8 years (7.0%). Majority (85.5%) of the children hailed from the nuclear families and the rest of them (14.5%) were large family background. On basis of educational qualification of the mother 4.0% were Illiterate, 8.5% were primary level in education, 38.0% belong to higher secondary level of education and 49.5% were graduate and above. Regarding to

the occupation of the mother 18.5% were unemployed or house wives 25.0% were part time employees and 56.5% were full time employed.

Table 2. The overall analysis of Behavior and emotion before and after retraining process

Childhood Psychopathology scale Pre –Test				Childhood Psychopathology scale Post – Test				‘t’ value	p-value
Mean	N	SD	SE	Mean	N	SD	SE		
23.15	200	5.54	0.39	35.73	200	13.57	0.95	±13.05	0.00*

*-Significant

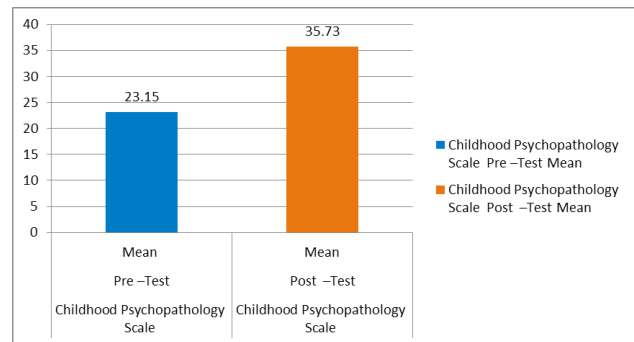


Figure 1. Overall analysis of Pre and Post mean scores of Childhood psychopathology scale

The childhood psychopathology scale score pre-test and post-test intervention for 200 samples was analyzed using paired t- test. The scores showed a significant difference between pre-test (M= 23.15 S.D=0.391) and post-test (M=35.73 S.D=13.57) . The post-test compared to the pre-test, with the t score= ±13.05, being significant at the 0.00 level. This result suggests that when an intervention program is introduced to train and modify behavior the group scores on Childhood Psychopathology Schedule increased revealing improvement in Behavior and emotion. Thus the hypothesis 1 stating that “There will be an improvement in Behavior and emotion after retraining process among congenital heart disease affected children” is accepted.

5. Discussion

The objective of the research study was to evaluate the effectiveness of Behavioral interventions among children with CHD. Hypothesis 1 states (H1) that there will be an improvement in factors of Behavior and emotion after neuropsychological retraining process among congenital heart disease affected children, According to Table 2, a significant difference was found in the improvement of Behavior and emotion after retraining process among congenital heart disease affected children. The neuropsychological retraining was effective when Behavior and emotional factors were trained. Early introduction of behavioral and emotional intervention show success rates

with positive correlation than late interventional programs i.e. 9-12 years. These findings are in accordance with the study of BenItzhak and Zachor, (2007) stating training behavior through Behavior programs have shown highly significant outcome in pediatric population with neuropsychological and developmental deficits. ^[15].

The neuropsychological retraining was effective when psychological domains were trained. The reason could be because of introduction of behavioral intervention at an early age may produce positive results compare to the introduction of intervention in late childhood i.e. 9-12 years. This needs to be examined through further research. These findings are in accordance with the study of BenItzhak and Zachor, (2007) reporting that rigorous behavior intervention has shaped positive outcome in young children with neurodevelopmental defects in their individual skills. The effectiveness of psychological interventions was examined in various aspects for in depth understanding. After pre assessment the children were exposed to package of intervention followed by post assessment. It showed remarked evidence that the package of psycho-educational interventions scheduled and implemented in the present study were found to be effective. Early the intervention, effectiveness is evident and plays a major role in determining the child quality of life and well-being. Developmental Evaluation is important which is followed by neuropsychological assessment. The need of these ages based evaluation is mandatory and selection of age specific assessment is recommended. These assessments provide clear information about psychological functioning which enables the documentation of deficits in the CHD population. Children who are at high risk for Developmental Disorder exclusively with defects in heart defects may be considered to optimize neurodevelopmental and neuropsychological outcome.

6. Conclusions

Nonexistence of standardized practical guidelines for assessment and treatment of these impairments in spite of well documented presence of developmental delay in CHD and lack of professional efforts on creating these guidelines leads to late identification and interventions. Structured protocols shall provide the clinicians about the existence of these disabilities in CHD population hence the treatment procedure will be multidisciplinary which appreciates early screening and interventional process in all dimensions decreasing risk of late screening and related quality of life and wellbeing. This paves a futuristic pathway in treatment of congenital heart disease where the Physician and Psychologist work together to deliver the treatment as a whole.

7. Limitation

- a) The study could not include the focus on large number of children with congenital heart defect due to limitation of time.
- b) The Study did not consider children who are psychologically handicapped.
- c) The study was based on the intervention program including the parent and child hence the sample was limited to a small number.

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