INTERNATIONAL JOURNAL OF ADVANCE RESEARCH, IDEAS AND INNOVATIONS IN TECHNOLOGY

ISSN: 2454-132X
Impact factor: 4.295
(Volume 4, Issue 4)
Available online at: www.ijariit.com

Disease impact of congenital heart disease- parents vs. children perspective

Pratibha Verma Bagga
bagga.pratibha@gmail.com
Manav Rachna International Institute of Research and Studies, Faridabad, Haryana

Dr. Priyanka Srivastava
srivastavapriyanka9357@gmail.com
Manav Rachna International Institute of Research and Studies, Faridabad, Haryana

ABSTRACT

The paper analyses the Disease impact on patients as well as their parents, with congenital heart diseases. The aim of the study is to analyse the perspective of adolescents and their parents on perception about the disease. The study was initiated to compare the attitude of parents and children (age 13-18 years), who can lead a normal life after corrective surgery/treatment. Methods: The data was collected from two reputed hospitals of Delhi, having paediatric cardiology department running for almost more than 10 years. A Questionnaire from PCQLI was used to collect data, with their permission. The questionnaire is already valid and reliable. A study was conducted, with permission from hospital authorities. A sample of around 30 patients (Parents /Children) were collected to study the quality of life aspect using various Disease impact parameters. An independent sample t-test was applied to compare the perspective of two groups. Findings: The result was analysed between the perspective difference between parents and children population on the Disease impact aspect. The data showed some variables reflect a significant difference between parents and children but some variables do not reflect any difference. Recommendation: The findings from the study indicate a need to peep into Disease impact aspect and would help the treatment provider to better treatment methods of patients with congenital heart disease so that they can be helped to better manage their health perspective in future.

Keywords: *Congenital heart disease, Psychology, Gender aspects, PCQLI, Parents vs. children*

1. INTRODUCTION

The burden of a disease can be studied under various impacts i.e. economically, psychologically, and socially. The person having the disease is not the only stakeholder but family members also bear the impact along with the individual. Congenital Heart Disease (CHD) is among a birth defect whose burden has to be born lifelong. Disease impact also helps to find out the morbidity and mortality among the population and how it is taken in that population. CHD is among one such disease whose burden fell on the individual itself but also affects the family members of the individual.

No doubt corrective surgeries and medical help an individual to live a better and improved life, but it also helps them to change their perspective towards life, if understood deeply. CHD significant impacts the lives of children as well as parents, some parents face difficulties in upbringing, such children, some have to give up their jobs for caretaking etc., as such many more problems are being faced by parents as well as children. But somehow their perspective and attitude are different in some sense or other. The way parents deal with the situation is quite different from the way children deal.

With the improvement in medical technology, the life perspective of such patients has been changing, but awareness among parent helps to improve this perspective. The main objective of the paper is to study the following perspective:

1. To compare the perspective of parents and children
2. Analyse the attitude of parents and children on disease impact

2. METHODS

The present study was conducted on the patients with congenital heart disease between the age group of 13-18 years along with their parents. The total sample consists of 30 patients of congenital heart disease (parents =30 and Children (13-18 years) =30) in the preferred age group was collected to study the psychological impact of the disease.

For the purpose of the study, a questionnaire of PCQLI has been used with due permission from the author. The objective of the study was well explained to the subject before administration. A questionnaire from PCQLI was obtained to be used, by taking permission from concerned authorities. The patients visiting the pediatric department of two hospitals in Delhi, having a pediatric department for more than 10 years and the patients admitted for corrective surgery were taken into consideration. Selection of subjects was done with the help of medical professional and with ethical permission of the hospital authorities.

3. DESCRIPTION OF TOOL

PCQLI– A disease-specific measure of health-related quality of life for children and adolescents with congenital or acquired heart disease

AUTHOR– Bradley S. Marino, MD, MPP, MSCE, Department of Pediatrics, Division of Cardiology and Critical Care Medicines at Ann and Robert H. Lurie Children's Hospital of Chicago, Chicago II
Amy Cassedy, Ph.D., Department of Pediatrics, Division of Biostatistics and Epidemiology, at Cincinnati Children's Hospital Medical Centre, Cincinnati, OH
Dennis D. Drotar, Ph.D., Department of Pediatrics, Division of Behavioral and Clinical Psychology, at Cincinnati Children's Hospital Medical Centre, Cincinnati, OH

Age Range– 13-18 years (adolescents) and parents
Duration– 20 minutes
Hindi Translation– Pratibha Verma Bagga
Structure– Total 29 items, 16 items were taken for studying disease impact.
Description– The questionnaire consists of 29 items, but only 16 items were taken to consider the attitude of parents and children on disease impact.
Data Analysis– Data was analyzed using SPSS (version 20.0) statistical program. Scores of various parameters were calculated on Likert 5 point scale based on the p-value obtained by independent sample t-test for parent and children P<0.05 was considered to indicate statistical significance.

Table 1: Comparison between the perception of parents and children on Disease impact

Variable	Male/Female	N	Mean	S.D.	P-Value
He/She cannot do the physical activities he/she want to do	Parent Children	30 30	3.5 3.5	.93 .97	.796
He/She misses too much school	Parent Children	30 30	3.6 3.6	.71 .88	.289
He/She feels guilty about the stress his/her heart disease causes her family.	Parent Children	30 30	2.33 3.66	.80 1.10	.031
School work is difficult for him/her	Parent Children	30 30	3.43 4.03	.85 .66	.007
He/she gets unwanted attention	Parent Children	30 30	2.33 3.36	.81 1.21	.000
He/She tires easily	Parent Children	30 30	3.46 3.30	.97 .95	.972
He/she takes too much medicines	Parent Children	30 30	3.53 3.63	.98 .76	.327
Grown-ups around him/her are overprotective	Parent Children	30 30	2.33 2.96	.92 1.09	.027
He/She feels sluggish	Parent Children	30 30	3.53 3.63	.81 .85	.796
He/She hold back when he/she is doing physical activities	Parent Children	30 30	3.46 3.63	.81 .85	.753
He/She is in pain	Parent Children	30 30	3.80 3.76	.66 .67	.510
He/she is likely to have other health problems	Parent Children	30 30	3.66 3.83	.80 .83	.931
He/She takes medicines that cause bad side effects	Parent Children	30 30	3.80 4.00	.71 .74	.255
His/her condition is likely to get worse	Parent Children	30 30	3.80 4.00	.66 .74	.503
He/She gets special treatment	Parent Children	30 30	2.46 3.66	1.00 1.02	.800
He/She misses social activities	Parent Children	30 30	3.93 4.03	.52 .66	.546

*Significance at .05 level of confidence

4. RESULTS

The analysis of data and the results are tabulated in the following table below:

1. The sample consisted of 30 parents and 30 children. There was a limitation to the sample collected because of inclusion criteria. The patients admitted for corrective surgery and can lead a normal life after correction were considered for inclusion. Patients with age between 13 to 18 years along with their parents were selected to fill up the questionnaire.
2. The study found that
3. Results show a significant difference between the perception of parents and children on some variables while some showing no significant difference. Parents mean value lies between 4.03 and 2.33 for various variables with S.D. value lying between 1.21 and 0.66. Whereas children mean value with S.D.value, indicating children reporting almost the same influence of disease impact along with parents with approximately same mean value.

5. DISCUSSION

The data collected shows almost same disease impact on parents as well as children, but parents are more concerned about the future perspective of their child, who has sometimes to go for corrective surgeries many times in lifespan.

1. The study shows a need for creating awareness and educating the parents so that they can better deal with their children and motivate their child with a positive attitude.
2. Supportive family members and parents would help a child to develop mentally as well as emotionally well, along with better medical perspective. With advancement in medical technology, new hopes are emerging to cope with CHD in a better way.
3. It was felt that there is a need to better educate parents so that they prove helpful for their growing children in a better way. As advancement in medical technologies is leading many children with CHD entering into adulthood, it is felt to need to create a better understanding between parents and children, only then their psychological, emotional and social needs can be fulfilled in a better way.
4. During the sample collection, it was also observed that now with the spread of education and awareness parents have become more conscious about their children and hence better line of treatment can be provided.
5. As the social impact of the disease lay a significant impact on the families, the awareness among parents as well as children would help to better deal with the problem.

6. REFERENCES

[1] Assocham, I. (Sept. 2011). Cardiovascular diseases in India: Changes and way ahead. *International Heart Protection Summit.*

[2] Blackwell, G. E. (Dec 2006). Turning up the Heat: Inflammation as a Mechanism Linking Chronic Stress, Depression, and Heart Disease. *Current Direction in Psychology Science, Vol.15, No.6*.

[3] Cohen, D. L. (2007, May). Quality of Life, depressed mood, and self0esteem in adolescents with heart disease. *Psychosomatic Medicine, 69*(4), pp. 313-318. doi:10.1097/PSY.0b013e318051542c.

[4] D A Lane, G. Y. (2002, April). Health-Related Quality of life and Health status in adult survivors with previously operated complex congenital heart disease. *Heart*. doi:10.1136/hear87.4.356.

[5] Dionysia Nousi, A. C. (2010). Factors Affecting the Quality of Life in Children with Congenital Heart Disease. *Health Science Journal, 4*(2), pp. 94-100.

[6] Elena Germani, R. P. (2011). Clinical Psychology and Cardio Vascular Disease: An Up-to-Date Clinical Practice Review for Assessment and Treatment of Anxiety and Depression Clinical Practice & Epidemiology in Mental Health. *Bentham Open Access, 7, 148-156 1745-0179.*

[7] Saxena Anita et.al (2016). Birth prevalence of Congenital Heart Disease: A Cross-Sectional observation study from North India. *Annals of Pediatric Cardiology*, 205-209.

[8] Jonson, B. a. (2005). Emotional and Behavioural Problems in Children and Adolescents with Congenital Heart Disease. *JIACM, Vol. , No. 4*.

[9] Karen Uzark, K. J. (2008, May). Quality of Life in Children with Heart Disease as perceived by children and parents. *Pediatrics, 121*(5).

[10] Kim, G. B. (2014). Psychosocial adjustment and quality of life of adolescents and adults with congenital heart disease. *Korean Pediatr*, pp. 257-263.

[11] Lidia Bons, M. P. (2012, January). Do Adults with Congenital Heart Disease have good Quality of Life? A Systematic Review. *Erasmus Journal of Medicine, 2*(2).

[12] Linda C. Gallo, S. G. (2004, October). Emotions and Cognitions in Coronary Heart disease: Risk, Resilience, and Social Context. *Cognitive Therapy and Research, Vol.28, No.5*, pp.669-694.

[13] M Kamphuis, J. O. (2002, January 31). Health-related quality of life and health status in adult survivors with previously operated complex congenital heart disease. *Heart*, pp. 356-362.

[14] Marino BS, T. R. (2009). Heart Disease and Quality of Life: What do Patients, Parents and Health Care provider really think? *Pediatrics*.

[15] Minne Fekkes, R. P.-v. (2001). Health-related quality of life in a young adult with minor congenital heart disease. *Psychology & Health, 16*(2). doi:10,1080/08870440108405502.

[16] Moons, P. (n.d.). ACHA Q and A: Quality of Life in Congenital Heart Disease. *The Adult Congenital Heart Association*.

[17] P., M. (2005). Individual Quality of life in Adults with Congenital Heart Disease: a paradigm shift. *European Heart Journal*, 298-307.

[18] Silva, A. M. (2011). Quality of life of patients with congenital heart disease. *Cardiology in young*, 670-676.