



IGNITED MINDS
Journals

*Journal of Advances in
Science and Technology*

*Vol. 11, Issue No. 22,
May-2016, ISSN 2230-9659*

REVIEW ARTICLE

**REVIEW: CONGENITAL HEART DISEASE AND
QUALITY OF LIFE**

AN
INTERNATIONALLY
INDEXED PEER
REVIEWED &
REFEREED JOURNAL

Review: Congenital Heart Disease and Quality of Life

Pratibha Verma Bagga^{1*} Dr. Priyanka Srivastava²

¹ Scholar, Manav Rachna International Institute of Research and Studies, Faridabad, Haryana

² Professor, Manav Rachna International Institute of Research and Studies, Faridabad, Haryana

INTRODUCTION

With advancement in medical technologies and health facilities the patients with Congenital Heart Disease (CHD) have shown increased morbidity. But it was presumed earlier that they have diminished Quality of Life (QOL). Many studies were conducted to assess the QOL of patients with CHD.

Congenital Heart disease (CHD) is the structural/functional defect of the heart in neonatal by birth. The problem though prevalent by birth but sometimes detected in the later years of life. In India about 8-10 children per 1000 live births are detected with CHD. It is one of the major reasons in India where birth rate is very high. Approximately 10% of present infant mortality in India may be accounted for the CHD alone (Saxena, 2005). These statistics are based on the reported cases which came into light. Numerous others are not even detected or reported due to lack of awareness, deliveries at homes and lack of knowledge of the health practitioner.

Although there is not universally adopted definition of Quality of life (QOL) but many dimensions like physical health, psychological health and social health can be studied under the aspect. As such QOL is a complex concept to understand. Everyone has his/her own perception about QOL, as the life we live and lead depends upon the perceptions we perceive from our environment. There are many contributing factors which influence QOL of individual like our genes, our family, social interaction and many more. QOL is a subjective concept which is different for different individuals. It also depends on the difference in places and the experiences we acquire during our life.

Quality of life is a subjective matter and has different perceptions for different individuals. Many studies have been done by the researchers on quality of life deals with the individual perception towards his/her quality of life. As it affects the treatment of the patients it has become a matter of concern for the chronically ill patients. Earlier this aspect of life was not given much

consideration, it was seldom taken into account that, what factors should be considered to improve the quality of life of such patients.

Health also plays an important role in determining QOL. There are related to each other, as our health plays an important role in determining our QOL. Health affects the various aspects of QOL like physical, functional, social and emotional well-being. The main aim of the health care providers is to improve the QOL in patients and help them to lead a good QOL in relation to their healthy counterparts. As CHD patients have increase life expectancy, sometimes it is presumed that they have diminished QOL, but studied done so far do not predict such presumption to be true. Most of the studied done in the foreign countries assessed that these patients have good QOL perceptions in every aspect of life.

OBJECTIVES:

The study is done to review the present literature in the field and to relate the literature with Indian scenario. Attention to this aspect of the disease has not been paid for long and only the treatment aspect along with prevalence and incidence were taken into consideration. With increasing population of CHD patients and specially the population going to adulthood, need this aspect to be studied. Increasing morbidity, is leading to increase in the number of children going to adulthood with CHD.

METHODOLOGY

The study is based on the secondary data, and all the literature related to Quality of life of CHD patients is searched on web, pubmed, Heart, European Heart Journal, American Heart Association and other medical journals

LITERATURE REVIEW:

From the various sources and available literature in the field the following literature related to CHD and quality of life was studied and analysed:

It was found by Rijen (2002) that the patients with CHD face lot of problems in psychological aspect also. This was done to analyse the psychosocial behaviour of the patients with CHD. With the progress of surgical procedures and techniques the survival rate of these patients has increased upto a large extent. Since it was a longitudinal study covering a period of around 20-33 years. The first phase of the study was conducted in 1989 and 1991 on the patients who underwent for corrective surgery for CHD. Patients who were younger than 15 years at the time of surgery were eligible to be sample. The population under study was followed up in 2000-2001 consisted of a sample of 498 patients. Patients for various types of CHD like tetralogy of fallot, ventricular septal defect, articular septal defect were considered. It was found that most of the patients suffering from CHD are living on their own in comparison to reference population but 18% of them are found to be living with their parents or the caretakers. Their marital status showed that 72% among them are married or in a relationship with 34% of them had one or more offspring. 27% of them followed some sort of education and around 85% among them had paid jobs. Overall it was found that their living conditions, marital status and social status showed similarity to almost normal. But as concerned to their emotional pattern it was found that adult patients with CHD suffer from more psychological stress. It was found that more favourable emotional outcomes were found in patients with tetra logy of fallot as compared to patients with arterial septal defects. Social functioning of these patients were quiet favourable and was found to be positive. It was found that they were able to participate socially, in education, occupation and intensive sports thus able to live normal lives. The study showed some limitations.

A study conducted by Lane et.al (2002) examined the Quality of Life in adults with CHD. The study showed that medical and surgical advancements have resulted the decreased mortality rate among the children with CHD, hence reaching to adulthood. These types of studies are being done for the last 15 years but till now little is known about the impact of the disease on the QOL of patients and also about their day to day functioning and well-being. The earlier studies done have mostly focussed on psychological adjustment and development aspect of the problem. Patients above the age of 16 years were registered and are taken into consideration. It was concluded that surgical advances have increased the mortality rate. Now there is need to pay attention on the other outcomes than death. Successful treatment also focus on improved QOL.

A study conducted by Kamphuis et.all (2002) examined the impact of previously operated complex

congenital heart disease patients on their health related quality of life and their subjective health status and the relationship between these parameters and physical status was studied. It was concluded after the analysis that the adult survivors with previously operated complex CHD experienced limitation in the physical dimension of health related quality of life and subjective health status. On the other hand the medical variables or parameters were weakly related to health related quality of life parameters. The results were based on the TAAQOL questionnaires.

The study done by Moons et al (2004) analyses the aspects of the quality of life of adults suffering from congenital heart disease. The main concern of the study was to study the various aspects related to psychosocial, educational and behavioural changes which affect the quality of life. This study used standardised and pre-defined questionnaires to determine the various components related to quality of life. It was found that the degree of the overall life satisfaction is influenced by the individual perception towards certain aspects important to him. The study inferred that the quality of life of congenital heart disease patients depends on their perception towards the important aspects of their life.

A study done by Kim (2004) assessed the effect of CHD on psychosocial functioning of QOL on adult patients. The study assessed that QOL of patients with CHD is affected in various aspects of life, as adults and adolescents with CHD are increasing day by day due to improvement in medical and surgical procedure. They continue to face physical, psychosocial and environmental challenges. Although exact effect of CHD cannot be analysed and suggestions were also provided to deal with the problem.

A study conducted by Johnson (2005) analysed the emotional and behavioural problems faced by the children and adolescents suffering from CHD. The child has to suffer because of repeated examinations like ECG echocardiography and other surgical procedures which lead to physiological anxiety to him than his normal peers. Recent experiences concerning the scar, physical condition and imposed restrictions are the strongest predictors for behavioural and emotional problems as reported by patients themselves. The study states that "Psychological implications are a significant part of chronic illness and they affect prognosis and outcome. CHD which are diagnosed early can influence mother infant interaction 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." The study also describes various types of CHD and their treatment effect on the children analysed. The fear of being operated created a long lasting effect on the children as well as the family. In some studies it was found that the children face behavioural problems after cardiac surgery, it was also noticed that they

have changed personality aspects. It was concluded that they need a planned intervention and effective psychological guidance to deal with the problem.

A study done by Cohen (2007) assessed the health related quality of life along with depressed mood and self-esteem of adolescents with CHD and it was found that the patients with severe heart disease reported higher level of depressed mood and lower self-esteem than the patients with moderate and mild heart disease. The study showed that the patients with severe heart disease reported depressed mood and low self-esteem, whereas patients with moderate and mild disease did not show such values. So study concluded that lower HRQOL was found in adolescents with severe heart disease. Psychosocial factors play significant effect on the psychological state of adolescents.

A study conducted by Karen et.al (2008) were to evaluate and compare the parent reported and self-reported quality of life of children who have cardiovascular disease. It was found that the scores for the children with cardiovascular disease were significantly lower than compared with their healthy counter parts. It was concluded in the study that overall, children with the disease perceive lower quality of life than healthy children across all age groups. Children with severe cardiovascular disease have more worse physical and psychosocial quality of life.

The study by Silva et al (2011) tried to assess the quality of life of adolescents and young adults suffering from congenital heart disease and tried to examine the variables that have negative impact on the quality of life of these patients. It was found by them that quality of life domains are very much influences by the social support which is an important variable in determining the quality of life. The patients which receive better social support showed better quality of life. So it is a determinant which is positively related to the quality of life. It also showed that a positive family environment with good expressiveness and less conflict also influence the quality of the life of the patients with congenital heart disease. The study concluded that the patients under study showed better perception towards the quality of life.

A study conducted by Lane et. al (2016) examined the QOL in adults with congenital heart disease. The study showed that medical and surgical advancement has resulted in decreased mortality rate among the children with CHD, hence reaching to adulthood. These types of studies are being done for the last 15 years but till now little is known about the impact of the disease on the QOL of patients and also about their day to day functioning and well-being. The earlier studies done have mostly focussed on psychological adjustment and development aspect of the problem.

Patients above the age of 16 years were registered and are taken into consideration. It was concluded that due to surgical advances the morbidity has increased and now there is a need to pay attention on the outcomes other than death. Successful treatments also focus on improved QOL.

CONCLUSION:

From the available literature on QOL, it can be seen that no such study till now has been done in the Indian scenario, due to lack of proper data and also the social taboos prevalent in Indian society. People are still not aware and also do not want to talk about the disease.

REFERENCES:

- Cohen, D. L. (2007, May). Quality of Life, depressed mood, and self-esteem in adolescents with heart disease. *Psychomatic Medicine*, 69(4), pp. 313-318. doi:10.1097/PSY.0b013e318051542c
- 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/heart87.4.356
- 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.
- Jonson, B. a. (2005). Emotional and Behavioural Problems in Children and Adolescents with Congenital Heart Disease . *JACM*, Vol. , No. 4.
- Karen Uzark, K. J. (2008, May). Quality of Life in Children with Heart Diseas as perceived by chidren and parents. *Pediatrics*, 121(5).
- Kim, G. B. (2014). Psychosocial adjustment and quality of life of adolescents and adults with congenital heart disease. *Korean Pediatr*, pp. 257-263.
- 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).
- M Kamphuis, J. O. (2002, January 31). Health realted quality of life and health status in adult survivors with previously operated complex congenital heart disease. *Heart*, pp. 356-362.

- Marino BS, T. R. (2009). Heart Disease and Quality of Life: What do Patients, Parents and Health Care provider really think? *Pediatrics*.
- Minne Fekkes, R. P.-v. (2001). Health-related quality of life in young adult with minor congenital heart disease. *Psychology & Health*, 16(2). doi:10.1080/08870440108405502
- Moons, P. (n.d.). ACHA Q and A: Quality of Life in Congenital Heart Disease. *The Adult Congenital Heart Association*.
- P., M. (2005). Individual Quality of life in Adults with Congenital Heart Disease: a paradigm shift. *European Heart Journal* , 298-307.
- Silva, A. M. (2011). Quality of life of patients with congenital heart disease. *Cardiology in young*, 670-676.
-

Corresponding Author

Pratibha Verma Bagga*

Scholar, Manav Rachna International Institute of Research and Studies, Faridabad, Haryana