

Original Research Article

Parental perception of quality of life in children following cardiac surgery

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ABSTRACT

Background: Congenital heart disease (CHD) is one of the major causes of mortality in the pediatric population of both the developing and developed countries. Along with medical and surgical treatment, access to quality care is equally essential in children operated with CHD. This study aims at assessing how the parents perceive quality of life in the child post-operatively and the impact on family.

Methods: About 185 parents of children operated for CHD were interviewed using Pediatric Quality of Life Inventory™ 3.0 Cardiac, Paediatric Quality of Life Inventory™ (PedsQL™) Family Impact Module scale and Participation Measure using International Classification of Functioning, Disability and Health-Child Youth by World Health Organization-2007 (ICF-CY) after three months of surgery.

Results: CHD was found to be more common among males (57.8%) with commonest surgery being ventricular septal defect (36.8%) followed by tetralogy of fallot and others. Overall 44.8% parents perceived their child had problem following surgery, cognition being the most affected domain. Problems in communication were perceived by 47.6% parents and were worried about the future. Using ICF-CY, 55.1% perceived complains of mild difficulty in mobility and moderate difficulty in self-care and schooling for the child.

Conclusions: The overall quality of life of children operated for congenital heart disease was perceived as not affected by parents except for cognitive problems. Parental worry and communication were the most affected domains. As far as schooling and self-care is concerned there was moderate difficulty. There is need for parental counselling and rehabilitation to function for children operated for cardiac surgery post operatively.

Keywords: Congenital heart disease, Children, International classification of functioning, Parents, Quality of life

INTRODUCTION

Congenital heart diseases are the second leading cause of death in infancy and childhood.¹ Recent advances in diagnosis and therapy of these diseases have increased the survival of infants and children. However, access to quality care of children with congenital heart disease (CHD) is largely restricted to developed parts of the world.^{2,3} The child postoperatively may face problems in

term of physical, emotional, and social wellbeing, leading to functional limitation. Where parental support and family functioning plays a vital role in improving child's quality of life, the associated stress in parents cannot be ignored. Physical therapist plays a vital role during the post-operative phase in preventing complications and facilitating overall functioning. However, it is generally restricted during the immediate postoperative phase to discharge. The overall quality of life and participation

back to society is generally lost to follow-up, especially for patients coming from remote places. This study aims at assessing the perception of parents regarding the quality of life in their child three months following surgery and its impact on family. It also evaluates participation restriction in the children post cardiac surgery, hence assisting in establishing the need of pediatric cardiac rehabilitation. In pediatric healthcare setting facilitating patient-therapist or doctor communication on long term follow up may improve parent satisfaction, identify hidden morbidities and assist in decision making.⁴

METHODS

An observational, cross sectional study was undertaken after obtaining ethical clearance from Institutional Ethics Committee of the tertiary care hospital. 185 Parents of children in the age group of 4 to 14 years of either sex who were operated for CHD were recruited during their third follow up i.e. three months postoperatively between September 2016 and May 2017. Parents of children having any other associated neurological or musculoskeletal disorder and who refused to consent were excluded. A detailed written information about the methods, aims, and the voluntary nature of participation in the study was explained. Parents were made comfortable and interviewed about the child's quality of life using Paediatric Quality of Life Inventory™ 3.0 Cardiac Module (PedsQL™-CM) and semi structured questionnaire based on Participation Measure using ICF (International Classification of Functioning, Disability and Health-Child Youth by World Health Organization-2007. The questionnaire was based on domains of mobility, role functioning, community, social, and civic life, self-care, interpersonal relationships, communication, and education. The common themes appearing out of the interview were noted and charted systematically. To assess the impact of the disease on parents and family, they were interviewed on Paediatric Quality of Life Inventory™-Family Impact Module (PedsQL™-FIM).

Cardiac module scale

The PedsQL™-CM presents a list of items to the child or parent to identify how problematic each item has been to the child in the past month. It consists of 27 items comprising 6 dimensions, heart problem and treatment (7 items), treatment II (5 items), perceived physical appearance (3 items), treatment anxiety (4 items), cognitive problems (5 items), communication (3 items).⁵

Family impact module scale

The PedsQL™-FIM is a parent report instrument designed to assess the impact of pediatric chronic health conditions on parents and the family. It includes measuring parent self-reported functioning: physical functioning (6 items), emotional functioning (5 items),

social functioning (4 items), cognitive functioning (5 items), communication (3 items), worry (5 items) as well as 2 subscales: daily activities (3 items) and family relationships (5 items).⁶

The items on cardiac module and family impact module scale are marked on five-point Likert response grading from 0=Never had problem to 4=Almost always had problem. The items were reversed scored and linearly transformed to a 0-100 scale with "Excellent" which means the child never had problem and "Very Poor" means the child always had problem. (i.e. Higher the score better the quality of life 0=100, 1=75, 2=50, 3=25, 4=0).

The data was analysed using Pearson Chi-Square test at 5% significance with confidence interval of 95%.

RESULTS

The Data was analysed using SPSS version 16. Frequency distribution PedsQL™-CM and PedsQL™-FIM components was calculated. CHD was found to be more common among males (57.8%) than females (42.2%) with mean age of 7.50 (± 3.22 years).

Table 1: Demographic characteristics of children with CHD following cardiac surgery, *N(%).

Demographic characteristics		Total
Gender	Male	107 (57.8)
	Female	78 (42.2)
Age mean (\pm SD)		7.50 \pm 3.22
Diagnosis	ASD	39 (21.1)
	VSD	68 (36.8)
	TOF	51 (27.6)
	Others	27 (14.59)

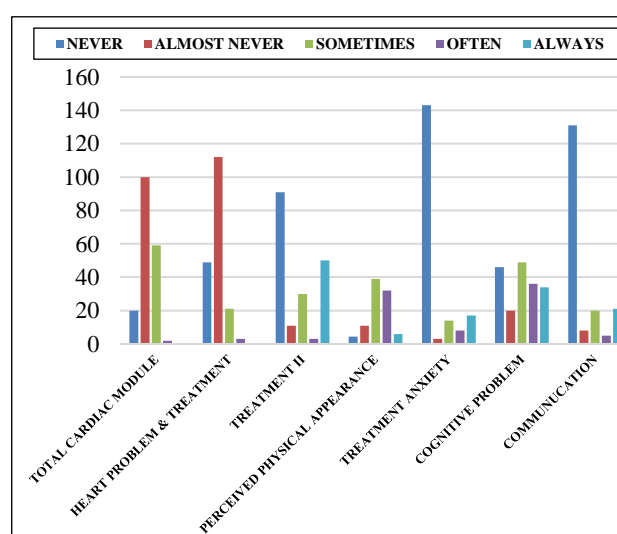


Figure 1: Frequency distribution of overall total score of pediatric quality of life inventory™ 3.0 cardiac module.

Ventricular septal defect was the commonest intra cardiac repair performed (36.8%) followed by TOF (27.6%), ASD (21.1%) and other (14.59%). Most of the parent enrolled were mothers (55.67%) who accompanied the child during follow-up (Table 1).

On PedsQL™-CM, 44.8% children following cardiac surgery had problem. Problem related to heart and treatment was 73.5% medical treatment was 27%, perceived physical appearance was 47.6%, treatment anxiety was 22.7% and communication was 29.2%. Children showed variable difference like 24.9% had no cognitive problem were as 26.5% sometimes had problem (Figure 1).

On evaluation of participation using ICF-CY, it was found that post cardiac surgery 55.1% children had mild difficulty. Mobility, selfcare and major area of life (schooling) were the most affected domain (Figure 2).

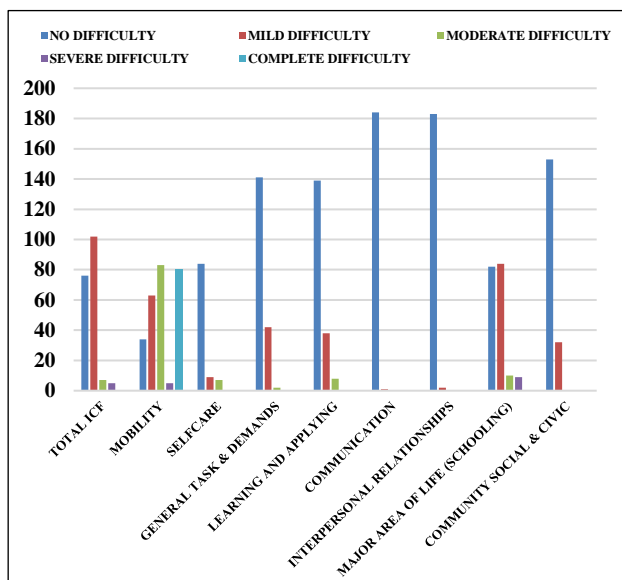


Figure 2: Frequency distribution of overall total score of participation measure using ICF.

On PedsQL™-FIM there appeared that 47.6% of parents had problem. 42.7% parents sometimes had problems with physical functioning, 50.3% emotional functioning, 42.7% cognitive functioning, 61.6% social functioning, 63.2% communication, 53.5% about child's health worry and 30.3% family relationships and 40% their daily activities (Figure 3).

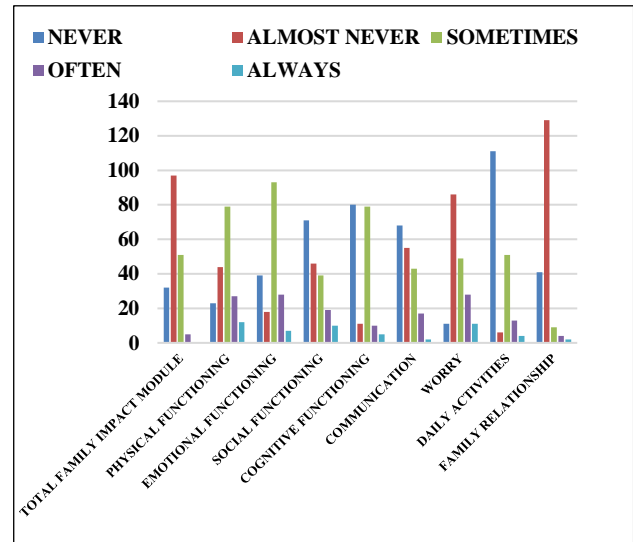


Figure 3: Frequency distribution of overall total score of pediatric quality of life inventory (PedsQL™) family impact module.

As the parents perceived varied response to the problems they were put into two groups i.e. group A: 3-6 months post-cardiac surgery (n=98) and group B: more than 1 year post-cardiac surgery (n=87) and the components were analysed using Pearson Chi-Square test at 5% significance with confidence interval of 95%. According to the cardiac module, problems with treatment II, perceived physical appearance, treatment anxiety, cognition and communication domain showed higher significant difference in Group A compared to Group B with $p < 0.05$ (Table 2).

Table 2: Frequency distribution for cardiac module: *N(%).

Cardiac module (problems with)	Group A		Group B		Chi-value	P-value
	Always	Never	Always	Never		
Total	28 (28.57)	70 (71.42)	34 (39.08)	53 (60.91)	2.284	0.0653
Heart problem and Treatment	11 (11.22)	87 (88.77)	13 (14.94)	74 (85.05)	0.564	0.226
Treatment II	28 (28.57)	70 (71.42)	55 (63.21)	32 (36.78)	2.237	0.000
Perceived physical appearance	51 (52.04)	47 (47.95)	26 (29.88)	61 (70.11)	9.311	0.001
Treatment anxiety	26 (26.53)	72 (73.46)	13 (14.94)	74 (85.05)	3.72	0.026
Cognitive problems	71 (72.44)	27 (27.55)	48 (55.17)	39 (44.82)	5.994	0.007
Communication	30 (30.61)	68 (61.22)	16 (18.39)	71 (81.60)	3.685	0.027

Table 3: Frequency distribution for family impact module: *N(%).

Family impact module (Problem with)	Group A		Group B		Chi-value	P-value
	Always	Never	Always	Never		
TOTAL	29 (29.59)	69 (70.41)	27 (31.03)	60 (68.96)	0.045	4.41
Physical functioning	57 (58.16)	41 (41.83)	61 (70.11)	26 (29.88)	2.85	0.04
Emotional functioning	61 (62.24)	37 (41.84)	67 (77.01)	20 (22.98)	4.71	0.01
Social functioning	38 (38.77)	60 (61.23)	30 (34.48)	57 (65.51)	0.36	0.27
Cognitive functioning	47 (47.95)	51 (52.05)	47 (54.02)	40 (45.97)	0.678	0.205
Communication	40 (40.81)	58 (59.19)	22 (25.28)	65 (74.71)	4.988	0.012
Worry	45 (45.91)	53 (54.09)	43 (49.42)	44 (50.57)	0.227	0.316
Daily activities	41 (41.83)	57 (58.17)	27 (31.03)	60 (68.96)	2.313	0.064
Family relationships	9 (9.18)	89 (90.82)	6 (6.89)	81 (93.10)	0.323	0.284

Table 4: Frequency distribution for participation measure using ICF: *N(%).

ICF	Complete difficulty	Severe difficulty	Moderate difficulty	Mild difficulty	No difficulty
Total	-	5 (2.7)	7 (3.8)	102 (55.1)	76 (41.1)
Mobility	80 (43.2)	5 (2.7)	83 (44.9)	63 (34.1)	34 (18.4)
Self-care	-	-	7 (3.8)	9 (4.9)	84 (45.4)
General task and demands	-	-	2 (1.1)	42 (22.7)	141 (76.2)
Learning and applying	-	-	8 (4.3)	38 (20.5)	139 (75.1)
Communication	-	-	-	1 (0.5)	184 (99.5)
Interpersonal relationships	-	-	-	2 (1.1)	183 (98.9)
Major area of life (schooling)	-	9 (4.9)	10 (5.4)	84 (45.4)	82 (44.3)
Community, social, civic	-	-	-	32 (17.3)	153 (82.70)

Similarly, according to family impact module, problems with physical functioning, emotional functioning and communication domain were significantly more between Group A and Group B with $p < 0.05$ (Table 3). However, the overall QOL scores of cardiac and family impact module were insignificant between both groups. Using ICF participation restriction measures, 44.9% children had moderate difficulty in mobility domain, and 45.4% children had mild difficulty in major area of life (schooling) were the most affected domain (Table 4).

DISCUSSION

Parental perception of child health

The overall total score in this study revealed that 44.8% parents perceived that children had problems. Parents complained of problems like breathlessness, tiredness on exertion, having frequent rest pause with peer group in sports and recurrent infections like catching cold easily. Immediately post cardiac surgery, the QOL was perceived to be better when the parents compared child's health condition which was prior to the surgery. But over a period of one year, less or no further improvement was seen by the parents.

There was a significant perception ($p=0.000$) of problem related to the treatment domain and was reported

significantly more in children after one year of surgery. This could be due to the child's prolonged duration of medication after surgery. In the domain of perceived physical appearance as all children had incisional scar on their chest following surgery, it was not significantly ($p=0.00$) viewed as a problem. However, parents reported that they avoided their child from wearing clothes that would reveal the incision to others. They felt that this would be a "stigma" and give rise to comments and questions in child's environment, especially at the school. Parents of older children reported of child being embarrassed or disliking others to see the scar especially girls. Treatment anxiety and communication problem was perceived during the initial follow-up of 3-6 months while waiting for the doctor or visiting hospitals, but it reduced after one year ($p=0.02$).

There was a significant problem ($p=0.00$) perceived in cognitive domain. School performance was impaired as reported by the parents due to difficulty in paying attention in class, solving mathematical problems, remembering what he read. The children usually lagged behind the progress of their healthy schoolmates due to long treatment process involving frequent hospital admissions, prolonged absence from school and limitation in learning abilities. Probably the nature of cardiac lesion may continue to affect cognitive and academic performance.⁷ The most common difficulty found to be is the target commitment, such as at the

perception and the accomplishment of a task that has been assigned to them, the organization of the time and the way to accomplish the task, as well as the ability to remember which steps are required for the acquisition of the task (Dionysia N et al).¹ It is also relevant that the cognitive impairment experienced by children with congenital heart diseases is associated with cyanosis or the severity of the disease. Landolt et al, further disclosed worse motor cognitive, social and emotional functioning than healthy children and the duration of cardiopulmonary bypass, time of hospitalization, need for medication and adverse family relationships had a negative impact on QOL of the children, only in accordance with the evaluation of their parents and caregivers.⁸⁻¹⁰ According to Uzark K et al, overall quality of life perceived by parents was not significantly different in young children with cardiovascular disease, but children with more severe cardiovascular disease have worse physical and psychosocial quality of life.¹¹

Participation measures

In a semi-structured interview of the parents using ICF-CY domains 55.1% of children with CHD overall had mild difficulty. The significantly affected domains found were mobility, self-care and major area of life (schooling).

Parents did not allow their children to carry or lift weights including school bags as it may increase workload on heart. They informed that the child had difficulty while walking long distance, stair climbing, running, or performing any sports/physical activities. Children were not permitted for riding bicycles due to fear of causing accidental harm at the incision site.

Self-care activities were done by parents themselves as they found their children were young to carry out these activities efficiently. As many parents belonged to low SES, with the toilet facilities outside the house, carrying bucket filled with water was difficult for the child and some from the rural areas had to draw or pump water from well so parents had to accompany them.

Schooling was the most affected domain. 65.2% children within 3-6-month follow-up did not resume school after surgery. Absenteeism was reported as the common problem by the parents. Children had cognitive difficulties like acquiring concepts, problem solving, focusing attention, hyperactivity, etc. parents also mentioned surgery coinciding with major academic assessment, missing school and having to catch up on missed work. Parent informed about the child's health issues, so some faculty overlooked the child's behavior and performance, and some were not even admitted in school before surgery due disease severity. In childhood, there is evidence that the presence of CHD can affect physical and overall development, motor, cognitive and neurological operation and there is even a higher incidence of academic difficulties, behavioral problems,

speech delay, lack of attention and hyperactivity in patients with complex congenital heart disease.¹²

Overprotective behavior of the parents who do not allow the child to take their own initiatives and at the same time reduces their ability to take care of themselves, significantly contributed the patient's low self-esteem. Steptoe A et al, showed that regular involvement in sports or vigorous recreational physical activity benefits children's well-being and reduces emotional and behavioral problems.¹³ Parents had lack of information related to activities and participation necessary for the child for healthy lifestyle following surgery. Moreover, it was fear and anxiety which stopped the child from doing particular activities which may overall affect the functioning capacity and performance level of the child thereby causing negative impact on their quality of life after surgery.

Impact on family

The overall total score in our study revealed that 47.6% parents had problems. Physical and emotional functioning domains were significantly affected ($p < 0.00$). Parents complained feeling of tiredness, physical weakness, anxiety and depression. In 3-6 months following surgery, social and cognitive functioning were affected due to reduced participation and socializing, decreased attention in work and forgetfulness. Communication domain was significantly affected in 3-6 months post-surgery ($p < 0.000$) as parents felt others may not understand their family situation and it was hard for them to talk about the child's health. Even the parents had problem in communicating with the doctors. According to worry domain parents were bothered about the surgical procedure, side-effects of medication and future of the child. They were also worried about impact of the disease on other family members. Parents never had problem in daily activities and family relationships but complained of stress in the family member. Markus et al. concluded parental HRQOL is low in the immediate period after their child's open-heart surgery but normalizes after six months. The impact of child's disease on the family's life may lead the parents to neglect their own health and their own needs during caretaking of their children.¹⁰ Fonseca et al, showed that parents of children with a congenital anomaly (40% of which were CHD) were more distressed compared to parents of healthy children, even if they had similar quality of life.¹⁴

It is well established that family is a dynamic team of inter-dependent members which are in constant interaction. Therefore, family environment, as it is developed through the relations of the family members and the parent's personality is crucial for the outcome of the disease. Accurate information to the parents reduces their anxiety, contributes to the treatment of the disease, and thereby to the improvement of the children's quality of life.

Educational level of the parents is significantly associated with their children's quality of life. Parents with low educational and income level tend to have difficulties in recognizing that their children need advisory support, or they ignore its importance and consequently, their children show symptoms of anxiety, depression or even aggressive behavior towards the environment.⁹ Also, poor financial status of the family is positively correlated to poor assessment of quality of life in both the children's and the family. Given the fact that the disease demands frequent visits to the hospital and hospitalization cost, it is understandable that family faces financial problems which may often destroy the relationship between the parents.

Nowadays, the result of surgery is not evaluated solely by increase in life expectancy, which was highest prior before 1980's, but we should also take into account the improvement in quality of life. The growth of the children with CHD is often characterized by relevant research as abnormal because of the demanding lifestyles changes imposed by the cardiac deficits, the frequent hospital admissions, abstention from physical and social activities, isolation from the environment, etc. All these factors exert a negative impact on their QOL. Hence assessment of QOL in children with CHD should be continuous. As it was previously mentioned that the surgery might ensure survival, but it does not allow normal life for the reason that post operatively are required frequently and planned reassessment of the disease as well as implementation and compliance with the treatment guidelines.¹

After cardiac surgery, quality of life of children with CHD was good but they had problems with physical and cognitive functioning. Therefore, effective pediatric cardiac rehabilitation needs to be implemented among these children to further improve the long-term outcome of the children with CHD in future. Parents reporting a high impact of child's disease on family life should be identified during OPD consultation after discharge and appropriate support should be provided. There is a need for early identification and screening of parents at risk of stress and mental health problems. Special efforts to improve communication with these parents must be made in hospital. Parental education regarding social participation aspect of the child needs to be emphasis upon as it was found that the parents did not allow the child to participate in any activity which hampered their physical performance.

CONCLUSION

Thus, author concluded that following cardiac surgery, the overall quality of life of children operated for congenital heart disease is perceived as not affected by parents. However, the most affected sub-domains were problems with medical treatment, perceived physical appearance, anxiety and cognitive problems. Similarly, the overall parental quality of life was not affected but

physical functioning, emotional functioning and communication were the most affected sub-domains.

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