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# PERCEIVED SOCIAL SUPPORT AND QUALITY OF LIFE AMONG MOTHERSOF CHILDREN WITH CONGENITAL HEART DISEASE IN A SELECTED HOSPITAL, KOCHI

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## ABSTRACT

**Introduction:** Congenital heart disease is one of the common congenital anomalies amongthe children, which affect the growth and development of the child and increasing susceptibility towards failure to thrive. The main objective of the study was to evaluate correlation between perceived social support and quality of life among mothers of children with congenital heart disease. **Methods:** The present study was a quantitative correlation descriptive design. The study was conducted at Amrita Hospital, Kochi. Total 80 samples were taken using convenience sampling technique. **Results:** In the present study, 92.5 %, 71.3% and 87.5% of mothers perceived severe support from the family, friends and others respectively to take care of the child with congenital heart disease. While considering the quality of life among mothers of children with CHD by using SF36 questionnaire there was significant differences in energy (p=0.000) and emotional well-being than other domains of quality of life (0.01) at 0.001 and 0.05 level of significance respectively. There is positive correlation between perceived social support and quality of lifewhich is significant at 0.01 level of significance. **Conclusion:** The present study showed that the mothers manage their problems with the support from family, friends and other significant others and thereby improving the quality oflife.

**KEYWORDS:** *perceived social support, quality of life, congenital heart disease.*

## INTRODUCTION

Congenital heart diseases are abnormalities of cardiac structure that are present from birth. The abnormalities in the development of heart typically arise in the third to eighth week of gestation.[1] Congenital heart disease (CHD) is now estimated to be the second mostprevalent chronic illness. Worldwide, the prevalence of CHD is estimated at about 8 per 1,000 live births.[2] Soon after birth, babies with a critical state of health due to CHD must undergo surgery or interventional treatment—in many cases as early as at the first year of life.[3] Today, however, 95% of these children reach adulthood as a result of the success of modern treatment options. With improvement in basic neonatal medical care in most parts of our country, the traditional contributors to neonatal mortality such as birth asphyxia and infections have reduced in numbers. This has hence thrust greater focus on CHD. Facilities with capability to diagnose and intervene on neonates with critical CHD are available in most states.[4] Although there has been remarkable progress in disease management, the performance and physical abilities vary enormously due to a variety of CHD types. Congenital heart defects (CHD) can be detected prenatally by ultrasound but are sometimes not diagnosed until birth, which can cause stress and heightened emotion within the family. Parents face challenges including dealing with surgical procedures for their child and integration. A child's chronic illness may have effects that have pervasive consequences for family life. Recently, attention has focused on resiliency variables, especially social support and coping strategy, regulating the impact of stress.[5]

As the disease course progresses, the impact on parents health tends to decrease, but the risk of developing long-term psychological issues among the parents remains high. As there are many variations of CHD which sometimes occur in combination and with differing severities, prognosis and treatment may vary between individuals. NICE guidance (National Institute for Health and Care Excellence 2016) advises that “children, young people may need support, and sometimes expert psychological intervention, to help with distress, coping, and building resilience” and emotional and psychological wellbeing should be discussed with families regularly, particularly at times of transition.6 Presence of CHD has been shown to increase the vulnerability of the whole family to psychological and social distress (Doherty and Utens 2016; Mussatto Soulvi,e et al.). However, using the perspective of coping, many studies also show that parents and families manage to adjust to the presence and demands of childhood conditions.7 Parental satisfaction with the paediatric care of CHD and well- being among the parents, with the specific aim of: (a) assessing the extent of psychosocial problems and grade of satisfaction with care and (b) modelling factors associated with satisfaction and well-being among the parents. A holistic care of CHD, need for psychosocial resources and social vulnerability in the adaptation process is recommended to improve parental satisfaction with the care of CHD.8 Parents of children born with CHD experiences profound stress, from the time of diagnosis, through the infant’s hospitalization for cardiac surgery, and in the months and years that follow. While survival for neonatal cardiac surgery has dramatically improved, children remain at risk for neuro developmental delay, including fine and gross motor, speech, cognitive, behavioural, and academic difficulties. Many children must return for additional surgeries or interventions throughout childhood. Quality of life of parents of chronically ill children has become increasingly important as the mortality rates associated with such illnesses have decreased and survival rates have increased.

### MethodologyStudy Design

The present study was a correlational descriptive design, which was done at Amrita Hospital, Kochi. The main objective of the study was to evaluate correlation between perceived social support and quality of life among mothers of children with congenital heart disease.

### Study setting and study period

The study was conducted among the mothers of children between the age groups of 1-10 years diagnosed as congenital heart disease, who is either admitted in paediatric ward or who attend paediatric and cardiology outpatient department during the time of data collection in Amrita Institute of Medical Sciences and ResearchCentre (AIMS), Kochi. The study includes 80 mothers of children with congenital heart disease and the samples were selected using convenience sampling method.

### Study tool and data collection instruments

The data was collected using a three part questionnaire. The tool I includes demographic and clinical variables.in demographic variables includes age, marital status, education, religion, type of family, occupation and annual income. In clinical variablesincludes duration of illness and type of disease of the child. Tool II was adopted to assess the social support perceived by the mother and was done by using multidimensional scale of perceived social support. It is a Likert scale which includes 12 statements that measure the support from the family, friends, and a special person. In tool III, the structured questionnaire is used to assess the quality of life. The data is collected by using SF36 questionnaire. This will measures the physical functioning, bodily pain, role limitation, due to personal or emotional problems, emotional well – being, social functioning, energy/ fatigue and general health perceptions among mothers of children with congenital heart disease.

**Software Used for Data Entry, Compilation and Statistical Analysis:** Microsoft Excel spread sheet was used for data entry and data analysis was done using the SPSS 20.0 version.

**Ethical consideration:** The project has been approved by the ethics committee of the institution. Informed consent was obtained from the participants before initiating the study.

## RESULTS

**Table 1: Distribution of sample based on demographic profile. n=80.**

| SI. NO. | Variables | Frequency (f) | Percentage (%) |
|---|---|---|---|
| 1. | **Marital Status** | | |
| | Married | 78 | 97.5 |
| | Widowed | 1 | 1.3 |
| | Divorced | 1 | 1.3 |
| 2. | **Education** | | |
| | Read and write | 3 | 3.8 |
| | Primary school | 11 | 13.8 |
| | Secondary school | 39 | 48.8 |
| | Graduate | 27 | 33.8 |
| 3. | **Religion** | | |
| | Hindu | 9 | 11.3 |
| | Christian | 38 | 47.5 |

| | | | |
|---|---|---|---|
| | Muslim | 33 | 41.3 |
| 4. | **Type of family** | | |
| | Nuclear | 44 | 55.0 |
| | Jointed | 31 | 38.8 |
| | Extended | 5 | 6.3 |
| 5. | **Occupation** | | |
| | House wife | 69 | 86.3 |
| | Working | 11 | 13.8 |
| | **Annual Income** | | |
| 6. | < 10,000 | 31 | 38.8 |
| | 20,000 to 30,000 | 35 | 43.8 |
| | 30,000 to 40,000 | 8 | 10.0 |
| | >40,000 | 6 | 7.5 |

Table 1 presented the selected demographic profile to the sample. Approximately 97.5% caregivers were married, 48.8% were secondary school education, ,47.5% were Christians, 86.3% of caregivers were housewife, 43.8% had monthly income between 30,000 to 30,000, and 68% of subjects are with <5 years of illness.

**Table 2: Perceived social support among mothers of children's with CHD.**

| SI NO. | | MILD | | MODERATE | | ADEQUATE | |
|---|---|---|---|---|---|---|---|
| | | (f) | (%) | (f) | (%) | (f) | (%) |
| 1. | Q Family Scale | 1 | 1.3 | 5 | 6.3 | 74 | 92.5 |
| 2. | Q Friends Scale | 5 | 6.3 | 18 | 22.5 | 57 | 71.3 |
| 3. | Q Others Scale | 3 | 3.8 | 7 | 8.8 | 70 | 87.5 |

**n=80**

The table 2 depicts that the 92.5 %, 71.3% and 87.5% of mothers perceived adequate support from the family, friends and others respectively to take care of the child with congenital heart disease.

**Table 3: The mean scores of physical health among mothers of pre-operative and post operative children with congenital heart disease.**

| Domains | Preoperative | | Post-operative | |
|---|---|---|---|---|
| | Mean | Standard deviation | Mean | Standard deviation |
| **Physical functioning** | 65.64 | 25.28 | 67.19 | 25.04 |
| **Role limitationdue to physicalhealth** | 52.19 | 37.75 | 57.50 | 37.63 |
| **Pain** | 60 | 26.47 | 64.94 | 21.14 |
| **General health** | 62.63 | 20.75 | 64.63 | 17.80 |

**(n=80)**

Table 3 depicts that the mean and standard deviation of physical functioning in the domain such as physical functioning (67.19±25.04), role limitation due to physical health (57.5±37.63), pain (64.94±24.14), general health (64.63±17.8) were comparatively increased amongmothers of children who had undergone surgery whereas the mean, SD of physical functioning among mothers of pre-operative children were less in aspects of physical functioning (65.64±25.28), role limitation due to physical health (52.19±37.75), pain (60±26.47), general health (62.63±20.75).

**Table: The mean scores of emotional health among mothers of pre-operative and post-operative children with congenital heart disease.**

| Domains | Preoperative | | Postoperative | |
|---|---|---|---|---|
| | Mean | Standard deviation | Mean | Standard deviation |
| **Role limitation due toemotional health** | 52.50 | 41.26 | 61.67 | 29.76 |
| **Energy/ Fatigue** | 56.47 | 13.43 | 70.63 | 10.93 |
| **Emotional well being** | 59.90 | 21.59 | 70.40 | 15.84 |
| **Social functioning** | 64.88 | 27.02 | 69.69 | 22.80 |

**(n=80)**

Table 4 depicts that the mean and standard deviation of in the domains such as role limitation due to emotional health (61.67±29.76), energy (70.63±10.93), emotional wellbeing (70.40±15.84), social function (69.69±22.80) were comparatively increased among mothers of children who had undergone surgery whereas the mean, SD as role limitation due to emotional health (52.50±41.26), energy (56.47±13.43), emotional wellbeing (59.90±21.59), social function (64.88±27.02).

**Table 5: Comparing the mean scores of quality of life among mothers of children with congenital heart disease**.

| Domains | Mean (Preoperative) | Mean (Postoperative) | P value |
|---|---|---|---|
| **Physical functioning** | 65.64 | 67.19 | 0.800 |
| **Role limitation due tophysical health** | 52.19 | 57.50 | 0.548 |
| **Role limitation due toemotional health** | 52.50 | 61.67 | 0.254 |
| **Energy/Fatigue** | 56.47 | 70.63 | 0.000 |
| **Emotional well-being** | 59.90 | 70.40 | 0.010 |
| **Social functioning** | 64.88 | 69.69 | 0.470 |
| **Pain** | 60.00 | 64.94 | 0.284 |
| **General health** | 62.63 | 64.63 | 0.664 |

**(n= 80)**

Table 5 depicts that there is no significant difference in all other aspects of quality of life among preoperative and postoperative children except energy (p=0.000) and emotional wellbeing (0.01) at 0.001 and 0.05 level of significance respectively.

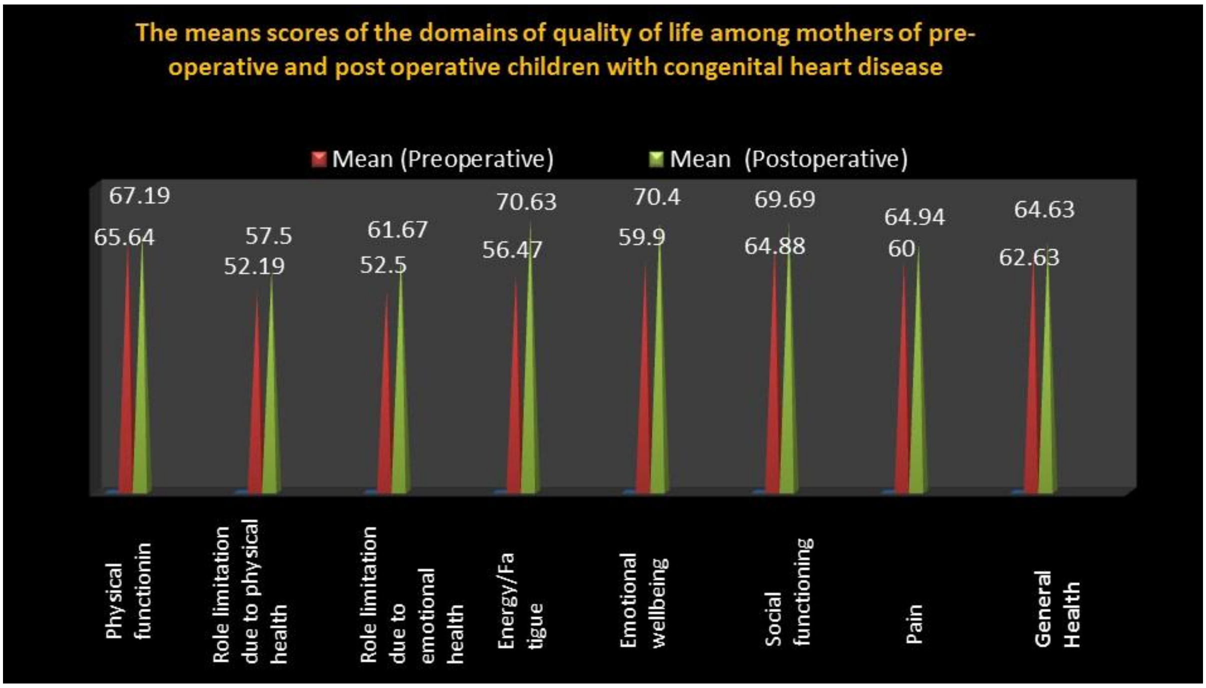

**Figure 1: The mean scores of emotional health among mothers of pre-operative andpost-operative children with congenital heart disease.**

**Table 6: Correlation between perceived social support and quality of life.**

| Variables | Pearson's correlation ( r ) | P value |
|---|---|---|
| Perceived social support and quality of life | 0.29 | 0.008 |

**n=80**

The table 6 shows that there is positive correlation between perceived social support and quality of life which is significant at 0.01 level of significance.

## DISCUSSION

Heart disease is the most severe chronic disabilities among children. Parents of children with heart diseases may experiences higher stress level and may feel great stress in relation to suchduring as dilemmas of normality and social integration. While considering the demographic variables in the present study, 97.5 %were married, 1.3% were divorced and widowed women, 48.8% were educated at secondary school,47.5% were Christian, 55% of women were living as a nuclear family, 86.3% were housewife,43.8% had monthly income between 30,000 to 40,000,68% is the duration of illness of children with <5 years. The high support for mothers from family is 92.5%, friends were 71.3% and other is 87.5%. The result of another study conducted by Zhi Hong Ni et.al on home care experience and nursing needs of caregivers of children undergoing congenital heart disease operations showed that 59.1% of caregivers were male, 63.6% were residing in county and 77.3% were with one child.[9] Regarding the extent of support received by the mothers, majority, 92.5 %, 71.3% and 87.5% of mothers perceived adequate support from the family, friends and others respectively to take care of the child with congenital heart disease. The findings is not in congruent with the study conducted by Nita Sharma where half (50.5%) of the mothers had high level of burden of care. Statistically significant association were found between age of the mother and level of burden of care (p value = 0.05). Similarly, the type of family (p value = 0.005), age of the children (p value = 0.000) and type of CHD (p value = 0.002) were significantly associated with the level of burden of care among the mothers.[10]

When considering the quality of life of mothers, the mean scores in physical and emotional domains were high among mothers of children after the surgery than the children in preoperative period. In a study conducted by Yamazaki S showed poor performance on the SF-36 with statistically significant differences on all sub-scales including general healthperception, physical functioning, role physical, role emotional etc.[11] In another study done among Children and adolescents with uncorrected CHD reported significant reductions in overall quality of life.[12] The finding of the present study also revealed that there is a positive correlation between perceived social support and quality of life. The result suggests that when there is a person to support the mother the quality of life is better. The study conducted by Lawako showed that parents with high availability of social integration reported higher quality of life than parents. Parents, especially mothers may need continuous psychosocial support before or after the child is treated as some studies indicate that the psychological stress and impaired quality oflife may continue long after the child has undergone corrective surgery or invasive treatment.

## CONCLUSION

According to the findings of this study, mothers of children with CHD tolerate many problems in the care of their child. Results of this study showed that the mothers managetheir problems with the support from the family, friends and significant others and thereby improving the quality of life. Planning and devising a strategy to support these mothers may need to be part of management and clinical care of children with congenital heart diseases.

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## REFERENCES

1. Bailey, Love, Short Practice of Surgery, 25th edition (2008), Hoddler Arnold publication, p258.
2. Vander Linde D, J Am Coll Cardiol et al. Birth prevalence of congenital heart disease worldwide: a systematic review and meta- analysis. The prevalence of congenitalanomalies, 2011; 2241-7.
3. Mason CA, Kirby RS, Sever LE, Langlois PH. Prevalence is the preferred measure of frequency of birth defects. Birth Defects Research Part A: Clinical and Molecular Teratology, 2005 Oct; 73(10): 690-2.
4. Krishna MR, Kumar RK. Diagnosis and management of critical congenital heart diseasesin the newborn. The Indian Journal of Pediatrics, 2020 Jan 28: 1-7.
5. Lindinger A, Schwedler G, Hense HW. Prevalence of congenital heart defects in newbornsin Germany: Results of the first registration year of the PAN Study (July 2006 to June 2007). Klinische Pediatric, 2010 Sep; 222(05): 321-6.
6. Bishop MN, Gise JE, Donati MR, Shneider CE, Aylward BS, Cohen LL. Parenting Stress, Sleep, and Psychological Adjustment in Parents of Infants and Toddlers with Congenital Heart Disease. Journal of Pediatric Psychology, 2019. Apr 26; 44(8): 980-87.
7. Lumsden MR, Smith DM, Wittkowski A. Coping in Parents of Children with Congenital Heart Disease a Systematic Review and Meta-synthesis. Journal of Child and Family Studies, 2019 Jul 1; 28(7): 1736-53.
8. Lawoko S .Factors Influecing Satisfaction and Well-being Among Parents of Congenital Heart Disease Children.Scandinavian Journal of Caring Sciences, April 5; 21(1):106-117.
9. Ni ZH, Lv HT, Ding S, Yao WY. Home care experience and nursing needs of caregivers of children undergoing congenital heart disease operations: A qualitative descriptive study. PloSone, 2019 Mar 14; 14(3): e0213154.
10. Sharma N, Sharma P, Mishra TA. Burden of Care Among Mothers Having Children with Congenital Heart Diseases. Journal of Nepal Paediatric Society, 2020 Sep 11; 40(2): 72-7.
11. Yamazaki S, Sokejima S, Mizoue T, Eboshida A, Fukuhara S. Health-related quality of life of mothers of children with leukemia in Japan. Quality of life research, 2005 May 1; 14(4): 1079-85.
12. Raj M, Abish Sudhakar RR, Champaneri B, Sudevan R, Kabali C, Kumar RK. Health- related quality of life (HRQOL) in children and adolescents with congenital heart disease: a cross-sectional survey from South India. BMJ paediatrics open, 2019; 3(1).