ORIGINAL INVESTIGATION ● Koşuyolu Heart J 2021;24(Suppl 1):S40-S46 • DOI: 10.51645/khj.2021.m95

Investigation of Anxiety, Depression and Perceived Caregiving Burden in Parents of Pediatric Patients Undergoing Open Heart Surgery and Being Followed Up in Intensive Care

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ABSTRACT

Introduction: This study aims to investigate the relationship between anxiety levels and perceived caregiver burden in mothers of children who had undergone congenital heart disease surgery and who were followed up in the intensive care unit with the surgical type and clinical variables applied.

Patients and Methods: The study was conducted with the mothers of both patient groups who underwent palliative surgery (n= 32) or corrective (biventricular) repair (n= 35) in the pediatric cardiovascular surgery clinic of Kartal Koşuyolu High Specialization Training and Research Hospital. Sociodemographic-clinical data form, Beck depression inventory, standardized mini-mental test, State-Trait Anxiety Inventory (STAI TX I-II), and Zarit Burden Interview (ZBI) were applied to the parents.

Results: The rate of interventional birth was higher in the palliative surgery group whereas there was no difference between the palliative surgery and corrective repair groups in terms of age, gender, birth weights, and presence of additional diseases (p= 0.001). There was no difference between maternal education levels and pregnancy duration. This difference was not significant even though the mean age of the mothers in the corrective repair group was higher compared to the palliative surgery group. The mean STAI-S scores of the palliative surgery group (state anxiety) were lower than the corrective repair group, and the STAI-T scores of the palliative surgery group (trait anxiety) were higher. The ZBI scores were significantly higher in the palliative surgery group (p= 0.03).

Conclusion: Congenital heart diseases and surgical interventions, as a result, are a major source of distress for affected families. Mothers are mainly affected by this situation. Changes in the mental status of the caregiver may have serious adverse effects on the operated child at every stage of the disease. Caregiving in parents is perceived as a burden and increased anxiety leads to different psychiatric clinical manifestations. Therefore, it is recommended that parents of children who have undergone congenital cardiac surgery receive routine psychiatric support from the early stages of the disease.

Key Words: Anxiety; caregiver burden; congenital cardiac surgery.

Açık Kalp Cerrahisi Uygulanan ve Yoğun Bakımda Takip Edilen Pediatrik Hastaların Ebeveynlerinde Anksiyete, Depresyon ve Algılanan Bakım Verme Yükünün İncelenmesi

ÖZ

Giriş: Bu çalışmada, doğumsal kalp hastalıkları cerrahisi (DKHC) geçirmiş ve yoğun bakım ünitesinde takip edilen çocukların annelerinde kaygı düzeyleri ve algılanan bakıcı yükünün uygulanan cerrahi tipi ve klinik değişkenlerle ilişkisini araştırmak amaçlanmıştır.

Hastalar ve Yöntem: Çalışma, İstanbul Kartal Koşuyolu Yüksek İhtisas Eğitim ve Araştırma Hastanesi Çocuk Kalp ve Damar Cerrahisi kliniğinde palyatif cerrahi (n= 32) veya düzeltici (biventriküler) tamir (n= 35) uygulanan her iki hasta grubunun anneleriyle yapılmıştır. Ebeveynlere sosyodemografik-klinik veri formu, Beck depresyon derecelendirme ölçekleri, standardize mini mental test, durumluk-sürekli kaygı ölçeği (STAI TX I-II) ve Zarit bakıcı yük ölçeği (ZBI) uygulanılmıştır.

Bulgular: Palyatif cerrahi ve düzeltici tamir uygulanan gruplar arasında çocuklarda yaş, cinsiyet, doğum ağırlıkları ve ek hastalık varlığı konusunda farklılık saptanmazken, palyatif cerrahi uygulanan grupta müdahaleli doğum oranı fazladır (p= 0.001). Anne eğitim durumları ve gebelik süreleri arasında farklılık saptanmamıştır. Düzeltici tamir grubu annelerin yaş ortalamaları palyatif cerrahi grubuna göre yüksek olmakla birlikte bu fark anlamlı bulunmamıştır. Palyatif cerrahi grubunda (durumsal anksiyete) STAI-S puan

Cite this article as: Yılmaz AA, Üstündağ MF, Yavuz Y, Ukil Işıldak F, Şavluk ÖF, Ceyran H. Investigation of anxiety, depression and perceived caregiving burden in parents of pediatric patients undergoing open heart surgery and being followed up in intensive care. Koşuyolu Heart J 2021;24(Suppl 1):S40-S46.

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Submitted: 09.05.2021
Accepted: 06.07.2021
Available Online Date: 11.07.2021

ortalamaları düzeltici tamir grubuna göre düşük, (sürekli anksiyete) STAI-T puanları yüksektir. Palyatif cerrahi uygulanan grupta ZBI puanları belirgin olarak yüksek (p= 0.03) olarak bulunmuştur.

Sonuç: Doğumsal kalp hastalıkları ve sonucunda uygulanan cerrahi girişimler etkilenen aileler için büyük bir sıkıntı kaynağıdır. Bu durumdan ağırlıklı olarak anneler etkilenmektedir. Bakım verenin ruhsal durumundaki değişiklikler opere olan çocuk üzerinde hastalığın her aşamasında ciddi olumsuz etkiler yapabilmektedir. Ebeveynlerde bakım verme yük olarak algılanmakta ve artan kaygı farklı psikiyatrik klinik tablolara zemin hazırlamaktadır. Bu nedenle doğumsal kalp cerrahisi geçiren çocukların ebeveynlerine psikiyatrik desteğin hastalığın erken dönemlerinden itibaren rutin verilmesi önerilir.

Anahtar Kelimeler: Bakıcı yükü; doğumsal kalp cerrahisi; kaygı.

INTRODUCTION

The survival rates of children with congenital heart diseases (CHD) have improved dramatically over the last decade. This allowed them to get rid of complex surgeries and have a life expectancy close to normal(1).

Research shows that parents of children with CHD have a higher level of distress compared to parents with healthy children or children with other chronic diseases(2). Parents of children with CHD experience a high proportion of anxiety, depression, and traumatic stress(3,4). Caregiver mothers are known to be at greater risk of mental health compared to fathers(3).

Care burden (CB) is defined as the difficulty of the caregiver, feeling under pressure, or being under pressure during the period of care of the individual with chronic illness or disability(5). A permanent health problem that may occur in the child creates changes in the roles of parents. The child receiving care may start to be perceived as a burden during the course of chronic illness. Risks increase when children with CHD need intensive care. It has been observed that the mothers of children hospitalized in the pediatric intensive care unit experience a higher level of anxiety, depression, confusion, anger, and stress compared to the mothers of children hospitalized in general pediatric service(6).

Resolving parents' mental problems may contribute to alleviating the treatment burden of children with CHD(7). In addition, parental anxiety causes the child's anxiety to increase(8). It is important to identify modifiable factors to optimize neurodevelopmental and behavioral outcomes for this growing population with improved survival for children with CHD(9). Parental mental health is one of such possible modifiable factors(10). It is well known that parents' ability to care for their children is adversely affected and this may lead to long-term cognitive and behavioral problems in children if the parents' mental problems are not treated(11,12).

This study evaluates the state-trait anxiety levels and care burden in mothers of children operated due to CHD and followed up in the intensive care unit. The relationship between these variables and the type of surgery applied are investigated. It is ensured that mothers are informed about the illness and can be helped to receive support when necessary, given the impact of the mother's mental state on the child's life during and after the illness. In addition, a different perspective is presented to healthcare professionals in this regard.

PATIENTS and METHODS

Design

Approval was obtained from Kartal Koşuyolu High Specialization Training and Research Hospital Non-Interventional Clinical Research Ethics Committee. This study aims to investigate the state-trait anxiety levels and caregiving burden of mothers of children who have undergone open-heart surgery due to CHD in the Pediatric Cardiovascular Surgery clinic.

Participants

Mothers who gave consent to participate in the study and who cared for children who would receive CHDS between March 2020 and August 2020 were included in the study. Mothers with severe mental disability and/or any diagnosed neuropsychiatric diagnosis (schizophrenia, bipolar disorder, Alzheimer's, etc.) and those currently diagnosed or treated for depression or anxiety disorder were excluded from the study. A mini-mental test was applied to all mothers to exclude mental disability. Those who scored twenty-five and above were included in the study. Sociodemographic data form, STAI-S, STAI-T, BDI, ZBI, and mini-mental tests were applied in a different order to all caregivers who gave consent to participate in our study and who did not have an obstacle to participate after the standard information about the surgery was provided before the surgical intervention.

The mothers participating in the study were divided into two groups according to the operations to be performed on the children and children they are obliged to provide care to. The mothers of the patients who underwent palliative surgery in the first group of patients and corrective (biventricular) surgery in the second group of patients were included (Table 1).

The surgical method and possible effects and complications to be applied to the mothers in both groups were shared by the same physician and the relevant forms and inventories were applied in a different order by giving sufficient time before the operation.

Table 1. Distribution of operations by groups

Palliative surgery (n= 32)	Corrective repair (n= 35)
Pulmonary artery banding (n= 5)	Atrioventricular septal defect repair (n= 3)
Bidirectional cavopulmonary anastomosis + shunt closure (n= 3)	Isolated ventricular septal defect closure (n= 9)
Norwood op. stage 1 (n= 3)	Atrial septal defect closure (n= 5)
Fontan procedure (n= 7)	Tetralogy of fallot, total correction with conduit (n= 2)
Establishment of aortopulmonary shunt (n= 8)	Tetralogy of fallot, total correction with transannular patch (n= 3)
Atrial septectomy + pulmonary artery banding (n= 2)	Rastelli operation (persistent truncus arteriosus) (n= 3)
Bidirectional cavopulmonary anastomosis (n= 4)	Rastelli operation (double outlet right ventricle- ventricular septal defect-pulmonary stenosis) (n= 1)
	Repair of aortic stenosis + ventricular septal defect closure (n= 1)
	Discrete subaortic membrane resection (n= 3)
	Tetralogy of fallot, total correction with annulus preservation (n= 2)
	Left atrioventricular valve repair (n= 1)
	Left ventricular outflow tract septal resection (n= 2)

Data Collection Tools

1. Beck depression inventory (BDI): BDI was used in the study to evaluate the presence and severity of depressive symptoms. BDI is a self-report scale that enables the evaluation of depression symptoms in 3 areas as physical, emotional, and cognitive with a total of 21 questions. The highest score to be obtained is 63. It was developed by Beck et al. and the validity and reliability study in Turkey was conducted by Hisli et al.(13,14). Participants who scored 9 or less were included in our study. The cut-off score of the scale is 17 and above indicates the presence of clinically significant depressive symptoms.

2. State and trait anxiety inventory (STAI TX I-II): The State-Trait Anxiety Scale was developed by Spielberger et al. in 1970, adapted to Turkish society by Öner and Le Compte in 1985, and it is a Likert-type scale that measures state and trait anxiety levels separately with 20 questions. High scores indicate high anxiety levels and low scores indicate low anxiety levels. The scale, which was translated into Turkish in 1975 and validity and reliability studies were conducted, consists of twenty-item state anxiety and trait anxiety scales(15). It is a four-degree scale ranging from "never" to "completely". The validity and reliability of the inventory in Turkey were made by Öner in 1977(16). The State Anxiety Inventory (STAI-S) is a highly sensitive tool in evaluating sudden changes in exciting reactions. The Trait Anxiety Inventory (STAI-T), which consists of 20 items in the second part of the inventory, aims to measure the continuity of the anxiety that the person tends to experience in general.

3. Zarit burden interview (ZBI): ZBI was used to evaluate the burden of caring for caregivers in the study. This scale was developed by Zarit et al. in 1985 and a Turkish validity and reliability study was conducted(17,18). The scale, which can be filled in by the caregiver himself or the researcher, consists of 22 items that determine the effect of caregiving on the life of the individual. Caregiver/patient relationship, caregiver's health status, psychological comfort, social life, and economic burden can be evaluated with this. Each question is evaluated with a 5-point Likert scale(19).

4. Standardized mini-mental testing (SMMT): It was used to measure mental state(20). SMMT consists of five sections: orientation, recording memory, attention, calculating, remembering, and language. Those who scored 25 or less were not included in the study.

5. Data collection form: It is a semi-structured form created by the researchers, including the characteristics of the participants such as age, gender, marital status, working status, etc.

Statistics Analysis

SPSS 17.0 package software was used for statistical analysis of the data. Categorical measurements were summarized as number and percentage whereas continuous measurements were summarized as mean and standard deviation (median and minimum-maximum where necessary). Chi-square test statistics were used to compare categorical measurements between groups. The t-test (Student t-Test) was used in independent groups if assumptions were met to compare continuous measurements between groups, and the Mann-Whitney U test was used if assumptions were not met. Pearson's Correlation analysis was used to compare continuous variables between groups. Statistical significance level was accepted as 0.05 in all tests.

RESULTS

Sixty-seven mothers whose children underwent congenital heart disease surgery were included in the study. Sociodemographic data of mothers and children are shown in Table 2. There were no statistically significant differences between PS and CR group mothers in terms of mean age,

Table 2. Descriptive statistics of demographic data (n= 67)

	Palliative Surgery (n= 32)	Corrective Surgery (n= 35)	t/x²	p
Child gender, (%)				
Male	50	40	0.29	0.48
Female	50	60		
Child age (months) (mean ± SD)	9.43 ± 6.02	12.80 ± 11.07	-1.736	0.47
Mother age (years) (mean ± SD)	26.03 ± 4.10	31.21 ± 6.07	-4.280	0.54
Mothers' education level (years) (%)				
0-8	59.4	51.4	0.76	0.94
8 >	40.6	48.6		
Income level, (%)				
Low	3	5	0.76	0.94
Middle	26	27		1/6
High	3	3		1/6
Pregnancy duration (weeks) (%)				
< 34	18.8	-	0.58	0.52
35-37	12.5	40		1/21
38-42	68.8	60		5/12
> 42	-	-		2/7
Birth method (%)				
NSVD	34.3	25.7	0.29	0.001*
IB	65.7	74.3		
Birth weight (Gr.) (%)				
< 2500	6.5	20	1.717	0.079
2501-400	90.3	80		2/2
> 4001	3.2	-		16/18
Additional disease (%)	28.1	57.1	0.027	0.962
CPB time (min) (mean ± SD)	167.34 ± 40.15	106.57 ± 46.66	4.422	0.085
X Clamp time (min) (mean ± SD)	130.46 ± 32.99	82.94 ± 35.93	4.436	0.092

SD: Standard deviation, NSVD: Normal spontaneous vaginal delivery, IB: Interventional birth.
t/x²: The Student's t-test/Descriptive St.-Frequency Test, CPB duration: Cardiopulmonary bypass time.
* Statistical significance.

educational status, and pregnancy duration. There were no statistically significant differences between PS and CR group children in terms of mean age, gender, and presence of additional diseases. The mean birth weight was statistically significantly higher in the PS group (p= 0.079). There was a statistically significant difference between the birth method of the children in the CR group and the rates of interventional birth were higher in the CR group (p< 0.01).

The STAI-S, STAI-T, and ZBI scores of the groups are shown in Table 3. The mean STAI-S score of the mothers of the PS group (44.66 ± 5.74) was lower compared to the mean score

Table 3. Comparison of STAI-T, STAI-S, and ZBI mean scores of mothers in study groups (n= 67)

	Palliative Surgery (n= 32)	Corrective Surgery (n= 35)	t/x²	p
STAI-S (mean ± SD)	44.66 ± 5.74	48.14 ± 9.86	-1.351	0.47
STAI-T (mean ± SD)	48.21 ± 9.27	41.05 ± 8.53	1.122	0.07
ZBI (mean ± SD)	40.24 ± 4.73	35.23 ± 7.43	1.966	0.03*

SD: Standard deviation, STAI-S: State anxiety scale, STAI-T: Trait anxiety scale, ZBI: Zarit Burden Interview, t/x2: The Student's t-test/Descriptive St.-Frequency Test.
* Statistical significance.

of the mothers of the CR group (48.14 ± 9.86) but this difference was not statistically significant. The mean STAI-T score of the mothers of the PS group (48.21 ± 9.27) was higher compared to the mothers of the CR group (41.05 ± 8.53) and this difference was statistically significant (p= 0.07). The mean ZBI score of the mothers of the PS group (40.24 ± 4.73) was higher compared to the mothers of the CR group (35.23 ± 7.43) (p= 0.03). A significant positive correlation was found between STAI-T and ZBI in the PS group as a result of Pearson's Correlation Analysis between ZBI, STAI-S, and STAI-T (p= 0.03).

DISCUSSION

We found that the mean STAI-S score of the PS group was lower compared to the CR group whereas the STAI-T values of the PS group were higher compared to the CR group. Children diagnosed with CHD and their parents have to face many problems starting from the first days of the disease. Management of CHD includes repeated invasive procedures, hospitalization, and often prognostic uncertainty(21). This process may require long and multiple hospitalizations, intensive care processes, one or more surgical interventions. It is known that especially if the child is hospitalized for heart surgery and needs intensive care, this is an important source of stress for parents(22). Mothers are more negatively affected in terms of mental health compared to fathers in CHD management. However, the cause of this result is not yet sufficiently known(2-4). Therefore, mothers who provide care for children with CHD were included in this study.

The patients included in this study were divided into two groups as PS and CR groups.

There are studies indicating that the severity of the heart lesion encountered during the diagnosis and treatment processes is related to the level of parental distress experienced(23). Palliative congenital heart surgery is predominantly performed in single ventricular physiology or in groups of patients who cannot handle corrective surgery because their general condition is poor. These operations are not aimed at providing cures in general and may require multiple different operations(24). For example, children with hypoplastic left heart syndrome are considered to be under high pressure and stress due to the uncertainty and difficulties in the diagnosis and treatment processes of the individuals who are the parents of these children, even though they carry a high risk of mortality and morbidity(25). CR surgery is applied to patients with better cardiovascular development compared to PS, and it is relatively less likely in long-term mortality and morbidity even though curing is more likely to be achieved after these operations(26). The continuation of the disease in the cardiovascular system in palliated children and consequently the fact that it may not provide the same organ (especially the nervous system) maturation with healthy peers is a separate trauma for families. The need for more than one operation may be seen as a social and economic burden(27,28).

Age, education, duration of pregnancy, and income levels of the mothers included in the study were similar in both groups. The fact that the rate of interventional birth was significantly higher in the CR group ($p< 0.001$) may be related to the fact that the mean age of the mothers in this group was higher compared to the PS group, as well as the limitation of our sample size. No research text could be found in the literature examined on this subject. The sociodemographic and clinical characteristics of the children included in the study were similar.

Numerous studies have been conducted on increasing anxiety levels in the surgical intervention and intensive care follow-up process in the parents of children with CHD(2,3,18). Factors affecting the increase in anxiety level include anesthesia, hospital environment, invasive procedures, results of the operation, future concerns, and insufficient/prejudices about the operation, etc.(29,30). Families, who define the surgical operation to be performed as a turning point for themselves, may remain in a dilemma about the operation and its results and may experience guilt when making decisions for corrective or palliative interventions, etc.(31,32).

Taşdemir et al. reported the mean anxiety score of 107 patients measured before different operations to be performed on them as (40.6 ± 11.23)(33). The average anxiety levels of mothers whose children have been operated on are in parallel with these results according to the results of our study. The high level of anxiety experienced by mothers is remarkable. It is known that emotional problems in families increase especially when the number of hospitalizations increases and impairment in functionality in children(34). Patients undergoing PS are undergoing repeated operations throughout their lives and the surgical intervention aims to improve the quality of life rather than providing cures. It is significant that the anxiety levels of these families towards acute changes and surgical interventions were found to be lower compared to the relatives of the patients in the CR group. The handicaps of mothers in the PS group are the frequency and severity of experiencing trait anxiety. Continuous anxiety in the CR group seems to be perpetual, unlike the meaning attributed to the current operation. The STAI-S level of the individual increases when the stress is severe and it decreases when the stress disappears(16). It can be thought in this respect that the high level of anxiety experienced in the CR group before the operation is related to the positive/negative results of the operation.

It has been reported that the care burden caused by the presence of chronic illness in children increases vulnerability to mental illnesses and puts the well-being of the family at risk(35). Dealing with children's medical procedures, long and multiple hospitalizations, intensive care follow-ups, digestive and/or nutritional problems have economic, emotional, and sociological costs for the family(3). The perceived care burden was significantly higher in the PS group compared to the CR group in our study (p= 0.03). The level of care burden felt in the PS group is similar to the care burden values felt by the mothers of children with physical disabilities(36). Many studies have shown that the quality of life of families of children with CHD decreases. It seems that the severity of children's disease affects the decreasing quality of life(32,37). Objective and subjective care burden values may be high due to the prolonged problems experienced by the families of the patient group in need of multiple hospitals and intensive care and the effects of decreased quality of life. A positive correlation was found between ZBI values and STAI-T values in the PS group as a result of Pearson's correlation analysis (p= 0.03). It is a remarkable result that caring for their children is perceived as a burden in this group with high STAI-T values and constant anxiety.

It is necessary to pay attention to the needs of children and their families since children undergoing CHD surgery and followed up in the intensive care unit and their parents are a special population(38). It is important to recognize the variables that affect the treatment and survival of these children(9). Parents' mental health is one of the factors that can be changed and affect the treatment burden(7,10). Parental anxiety causes the child's anxiety to increase(8). Providing counseling to parents before surgery may affect the treatment process of the child positively by reducing the mental symptoms of the parents(39). Increasing the family functionality affected by the care burden may increase the treatment compliance of the child(40).

LIMITATIONS

Our study has some limitations. The study cannot represent the entire population due to the limited number of participants. Since the research design of our study was organized to be cross-sectional, causality cannot be determined among the variables. The size of the samples limits the power and generalizability of the study. Another limitation is that all the scales used were based on self-report. Another limitation is that the effects on preoperative and postoperative anxiety levels/care burden are not examined. Long-term prospective studies with larger sample sizes are needed to analyze the correlation between Anxiety and burden care in congenital heart disease.

CONCLUSION

It should be kept in mind that the treatment and care processes of CHDs are most successful when given by multidisciplinary teams. One of the important elements of this team should be psychiatric support and the necessary sensitivity should be shown in solving the mental problems of families.

Ethics Committee Approval: Approval was obtained from Kartal Koşuyolu High Specialization Training and Research Hospital Non-Interventional Clinical Research Ethics Committee (Number: 2020.2/06-292, Date: 20.02.2021).

Informed Consent: Informed consent was obtained.

Peer-review: Externally peer-reviewed.

Author Contributions: Concept/Design - AY, MÜ; Analysis/Interpretation - MÜ, ÖŞ; Data Collection - YY, FI; Writing - MÜ, AY; Critical Revision - ÖŞ, FI; Final Approval - AY, HC; Statistical Analysis - YY, FI; Overall Responsibility - AY, MÜ.

Conflict of Interest: The authors have no conflicts of interest to declare

Financial Disclosure: The authors declared that this study has received no financial support.

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