HEMAR-G

HEMŞİRELİKTE ARAŞTIRMA
GELİŞTİRME DERGİSİ

Effect of Planned Information Provision on Anxiety of Parents of Children Who Underwent Cardiac Surgery

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Abstract

Objective: *To determine anxiety causes of parents of children who underwent cardiac surgery in order to develop a planned information provision and to evaluate anxiety level of parents with two different information provision.*

Methods: *Parents of children administered to the pediatric cardiovascular clinic of a hospital in Turkey took part in two groups (group 1, 47; and group 2, 46) in the descriptive study. Parents were either provided with only routine information (group 1) or were provided with detailed information and given consultancy (group 2) regarding their child's home-care following discharge. Parents of children aged between 0 and 18 years who underwent cardiac surgery were included in the study (n=93). A descriptive form and State-Trait Anxiety Inventory were used to obtain data prior to discharge.*

Results: *Parents in group 1 reported greater anxiety about home-care of their children mostly concerning infections/fever (76.1%), diet and nutrition (41.3%), and care of the surgical incision (30.4%) compared to those in group 2. State and trait anxiety scores of the parents in group 2 were significantly lower than those in group 1 (state, 35.7±7.2 v 51.6±7.1; $p<0.05$ and trait, 38.5±8.0 v 52.5±6.4; $p<0.05$) regarding their children's home-care.*

Conclusion: *Parents of children undergoing cardiac surgery are at increased risk of anxiety. Post-operative therapeutic intervention is more effective in decreasing parental anxiety levels regarding their children's home-care after discharge than provision of only routine information. Nurses need to develop effective discharge planning strategies for informing and educating parents about their children's home-care following discharge.*

Keywords: *Surgery, heart, parents, anxiety, child, home-care.*

Planlı Bilgilendirme Sağlamanın Kalp Ameliyatı Olan Çocukların Ailelerinin Anksiyeteleri Üzerine Etkisi

Özet

Amaç: *Çocukları kalp ameliyatı olan ailelere planlı bilgilendirme oluşturulabilmesi için ailelerin anksiyete nedenlerinin belirlenmesi ve iki farklı bilgilendirmede ailelerin anksiyete düzeylerinin değerlendirilmesidir.*

Yöntem: *Türkiye'de bir hastanenin pediatrik kardiovasküler servisinde yatan çocukların aileleri iki grup (1. grup=47 ve 2. grup=46) olacak şekilde bu tanımlayıcı araştırmada yer aldı. Çocuklarının evde bakımı konusunda ailelerin bir kısmına sadece rutin bilgilendirme sağlandı (1. grup), bir kısmına ise detaylı bilgilendirme sağlandı ve danışmanlık verildi (2. grup). 0-18 yaş aralığında olan ve kalp ameliyatı yapılan çocukların aileleri araştırmaya alındı (n=93). Tanımlayıcı veri formu ve durumluluk-süreklilik anksiyete ölçeği verileri toplamak için taburculuk öncesi kullanıldı.*

Bulgular: *1. grupta yer alan aileler 2. gruptaki ailelere göre çocuklarının evde bakımı konusunda en fazla anksiyeteyi enfeksiyon/ateş (%76.1), diyet ve beslenme (%41.3) ve ameliyat bölgesinin bakımı (%30.4) konularında belirtti. 2. grupta yer alan ailelerin durumluluk ve süreklilik anksiyete puanları anlamlı düzeyde 1. gruptaki ailelere göre düşük bulundu (durumluluk; 35.7±7.2'ye karşın 51.6±7.1; p<0.05 ve süreklilik; 38.5±8.0'ye karşın 52.5±6.4; p<0.05).*

Sonuç: *Çocuğu kalp ameliyatı olan aileler anksiyete yönünden risk altındadırlar. Sadece rutin bilgilendirmeye karşın postoperatif terapötik girişim ailelerin çocuklarının taburculuk sonrası evde bakımı konusundaki anksiyete düzeylerini azaltmada daha etkilidir. Hemşirelerin, ailelerin taburculuk sonrası çocuklarının evde bakımı konusunda bilgilendirme ve eğitimleri için etkili taburculuk planlama stratejilerini oluşturmaya gereksinimleri vardır.*

Anahtar Sözcükler: *Cerrahi, kalp, ebeveynler, anksiyete, çocuk, evde bakım.*

Introduction

Congenital heart defect (CHD) is a chronic disease and the second most prevalent birth-related defect after developmental disorders.[1] The incidence of CHD ranges from 6 to 9 cases per 1,000 live-births.[2,3] Most infants born with a CHD now survive and their life span has markedly increased due to technological advances in treatment, resulting in an increasing number of families with a child with this chronic condition.[4,5]

Compared to parents with healthy children, parents of children with a CHD experience more anxiety, anger and despair.[6,7] Most cases of CHD are diagnosed at the prenatal or infant stage leading to parental anxiety over the prospect of caring for a young child with a chronic disease.[8] In addition, the unpredictability of the condition and the associated impairment of the child's development affect the quality of family relationships and create anxiety for the family most notably after surgical correction. [9,10]

Parental anxiety can greatly affect anxiety level in offspring. It has been reported that parents exert a great influence on their child's perception of surgery, and parental anxiety may indirectly affect the child's level of anxiety.[11,12] Additionally, high levels of stress can affect parental behavior and modulate the overall outcome for the child.[13,14] Interestingly, parental anxiety is more closely associated with coping skills and psychosocial adjustment than to the severity of their child's disease.[15,16] Education can strengthen coping skills and psychological adjustment and is therefore an important factor in the reduction of parental anxiety. The well-being and ability to cope of parents of children with CHD can also affect the child's coping skills and perception of their condition.[17,18] Therefore, research-based nursing interventions may contribute to the care of children and families by increasing education and facilitating parental participation in the care of the child. Formal and planned interventions for home care management of children post cardiac surgery have the potential for decreasing parental anxiety and increasing the child's comfort level.[19]

While anxiety has been well studied in parents of children with CHD, no studies to date have specifically addressed parental anxiety relating to postoperative home-care. Understanding the anticipated problems faced by parents can lead to development of appropriate support provided by the hospital to ensure a healthy family environment after discharge.

Aims

- To determine specific areas of anxiety of parents of children undergoing cardiac surgery prior to hospital discharge in order to develop planned information provision.
- To evaluate the parents' anxiety in 2 different methods:

  1) Routine information and

  2) Planned, formal information.

Methods

Subjects

Participants were parents of children undergoing open heart surgery at the inpatient cardiovascular surgical ward in an university hospital in Ankara, Turkey between January 1, 2007 and December 30, 2007. The ward cares for approximately 95% of all children treated for CHD reconstruction surgery in the hospital. During the study period approximately 10-15 children were discharged post-surgery per month. Children stayed in the inpatient cardiovascular surgical ward post surgery for 5-20 days. Parents were enrolled at the time of their child's post-surgical care. Inclusion criteria for the study were: 1) being parents of children aged 0-18 years; 2) having children in the pediatric inpatient cardiovascular surgery ward after heart surgery; 3) ability to speak and write in Turkish; 4) accept to participate in the study.

During the study period, 129 children entered the ward. Of these children's parents, nine parents returned incomplete questionnaires, 20 declined to participate, and seven were excluded due to language barriers. The total sample was therefore comprised of 93 participants. Forty-seven parents were assigned to a group receiving planned, formal information (2. group), while 46 were assigned to a group receiving routine information (1. group). Most of the interviews were conducted on mothers (n = 39, 1. group; n = 41, 2. group).

Ethical Side of The Study

Oral and written consent was taken from the parents to participate in the study after being provided with information about the voluntary nature of participation that emphasized confidentiality and that withdrawal would not affect a child's treatment. Approval for the study was received from the hospital committee.

Measurements

A questionnaire and the State-Trait Anxiety Inventory were used for data collection. The questionnaire consisted of 21 questions regarding the parent's education level, family income, mental and medical history of the parents, hospitalization and medical history of the child, family history of important life events and causes of anxiety about home care of their child. The questionnaire was also included a list of 8 causes of anxiety and "Other" choose. The questionnaire was completed by parents the day prior to their child's discharge from the hospital.

State-Trait Anxiety Inventory

The State-Trait Anxiety Inventory (STAI) was developed by Spielberger et al. (1970).[20] The state anxiety score is based on 20 items rated on a four-point Likert-type scale ranging from 1 (not at all) to 4 (very much so). The state anxiety inventory measures individual anxiety levels at a specific time and under specific conditions. The trait anxiety score is also composed of 20 items measuring general anxiety levels from 1 (almost never) to 4 (almost always). Total scores obtained from each scale, therefore, ranged from 20 to 80 points with higher scores indicating higher anxiety. The STAI is applicable to individuals older than 14 years.

A Turkish version of the STAI was used in the present study. The validity and reliability of the scale was established by Öner and Le Compte (1985) during adaptation of the STAI to Turkish.[21] Test-retest reliability coefficients ranged from 0.71 to 0.86 and 0.26 to 0.68 (trait anxiety and state anxiety, respectively). The Kuder Richardson (alpha) reliability of the Turkish version of the scale ranged from 0.83 to 0.87 (trait anxiety) and from 0.94 to 0.96 (state anxiety), showing a high degree of internal consistency.

Procedure

The study was a descriptive study with consecutive inclusion of participants. Participants were placed into either the 1. group (those enrolled into the study between January 1 and June 30, 2007) or 2. group (those enrolled between July 1, 2007 and December 30, 2007) depending on when they were enrolled into the study. First group parents were those prior to implementation of the standardized planned post-op education and second group parents were those post implementation of the standardized planned education.

Starting in May, and continuing for a month and a half, an information booklet was prepared by researchers based on participant responses about perceived causes of anxiety. Intervention was based on the information in the booklet. The booklet was given to the hospital's Department of Nursing Services and Department of Pediatric Cardiovascular Surgery to examine. In addition, employed nurses went through a two month training program given by researchers in the ward to continue this new program.

Parents in the first group were given routine information about their child's home care (postoperative care of the surgical incision, medication, and follow-up appointments). Routine information varied depending upon the nurse caring for the child and did not follow any specific guidelines. Routine information about home care of the child was generally given 1-2 days prior to discharge.

Parents in the second group were interviewed and provided with oral and written detailed (formal and prepared) information. Discharge education for the second group started 1 day after admission to the ward. Since most of the children were admitted to the ward the day prior to surgery, discharge education commenced post-surgery.

The information provided to parents in the second group concerned the details of their child's care after surgery, postoperative skin color, pain management, vaccination, dental care, diet and nutrition, medications, activities, psycho-social development, prevention of infection, follow-up appointments, and precautionary measures. Ward nurses provided information during the child's care in hospital and the researcher provided further information during an interview. A 35- to 45-min interview was conducted with each parent in the second group. During the interview, parents were given the home care booklet. In addition to information, parents were encouraged to share their concerns about home care for their child. Parents needing more information were given extra time with the researcher. Parents were positively encouraged to participate in their child's care during hospitalization in the ward after surgery.

Statistical Analysis

The Statistical Package for Social Sciences (SPSS) Version 12 was used for data analysis. Percent and frequency distribution of variables were determined, and relationships between variables were analyzed using dependence tests. STAI scores acted as dependent variables, while parental age, education level, age of the child, gender of the child, hospitalization history of child, the mother's working situation, and family history of important life events acted as independent variables. The Student's t-test was used for data normally distributed while the Mann-Whitney U-test was used for non normal distributions. Statistical significance was set at $p < 0.05$.

Results

Males made up 58.7% of the first group (n = 27) and 53% (n = 25) of the children in the second group (Table 1). The ages of the children ranged from 1 month to 16 years (mean ages were 21.3 and 22.0 months; 1. and 2. group, respectively). Time since diagnosis of CHD ranged from 1 hour to 11 years (mean time was 12.6 and 13.1 months; 1. and 2. group, respectively). Data were provided predominantly by mothers in both the first (84.8%) and second (87.2%) groups. Parental education in both groups was mostly at the high school level and most mothers were housewives. Most parents across groups reported no important life events (death of a family member, earthquake etc.) in the six months prior to interview. The previous cardiopulmonary bypass (CPB) surgery ratio of children was similar across groups. Most of the heart defects were atrial and ventricular septal defects in the first (32.6%) and second (38.3%) groups. The hospitalization period was between 8 and 25 days (mean days were 17.3 and 16.9 days, 1. and 2. group, respectively).

The above demographic characteristics of the first and second groups are shown in Table 1. There were no statistically significant differences in any demographic variable between the two groups, suggesting a high level of homogeneity of variance between the two groups.

Parental state and trait anxiety scores for the first and second groups are presented in Table 2. Parents in the second group scored significantly lower than parents in the first group on state anxiety (35.7 ± 7.2 vs. 51.6 ± 7.1; second group vs. first group, respectively: $p < 0.05$) and trait anxiety regarding home-care for their children (38.5 ± 8.0 vs. 52.5 ± 6.4; second group vs. first group, respectively: $p < 0.05$). Mean parental state and trait anxiety scores were considered low in the second group and moderate in the first group.

As shown in Table 3, there were significant differences between the groups regarding parental anxiety about their child's-home care ($X^2 = 39.8$, $p < 0.05$) according to the parents' answers from questionnaire form. Parents in the first group reported greater anxiety concerning infections/fever, diet and nutrition, care of the surgical incision, medication, psycho-social development, heart-related problems, vaccination, and accidents.

Discussion

The aim of the present study was to determine the anxiety causes of parents and to determine the anxiety levels of parents in two different information provision. The results indicate that parents who have an intervention experience less anxiety than parents who receive only routine information. These findings highlight the need to include

Table 1: Demographic Characteristics of the Subjects in First and Second Groups (N = 93)

	First Group (n = 46)	Second Group (n = 47)	p – value*
Children Age (month) M ± SD	21.3 ± 20.3	22.0 ± 19.8	.301†
Length of Diagnosis (month) M ± SD	12.6 ± 14.3	13.1 ± 15.2	.174†
Mother Age M ± SD	27.8 ± 6.1	29.6 ± 6.0	.125†
Father Age M ± SD	31.6 ± 5.7	33.6 ± 6.0	.105†
Child Gender n (%)			
Female n (%)	19 (41.3)	22 (46.8)	.592†
Male n (%)	27 (58.7)	25 (53.2)	
Mother Education n (%)			
Elementary and secondary school n (%)	16 (35.8)	11 (23.4)	.532†
High school n (%)	24 (52.2)	28 (59.6)	
University n (%)	6 (13.0)	8 (17.0)	
Father Education n (%)			
Elementary and secondary school n (%)	6 (13.0)	7 (14.9)	.709†
High school n (%)	32 (69.6)	29 (61.7)	
University n (%)	8 (17.4)	11 (23.4)	
Maternal Employment n (%)			
Housewife n (%)	35 (76.1)	39 (83)	.523†
Working n (%)	11 (39.9)	8 (17)	
Important Life Events n (%)			
Not Experienced n (%)	45 (67.8)	47 (100)	.309†
Prior Hospitalization n (%)			
Yes n (%)	31 (67.4)	28 (59.6)	.433†
Previous CPB Surgery n (%)			
Yes n (%)	7 (15.2)	8 (17)	.657†
Heart Defect with Indication for Surgery n (%)			
ASD/VSD/AVSD	15 (32.6)	18 (38.3)	.548†
Other Acyanotic Defects	14 (30.4)	12 (25.5)	
TGA	11 (23.9)	10 (21.3)	
Other Cyanotic Defects	6 (13.1)	7 (14.9)	
Days in Hospital M (SD)	17.3 (13.2)	16.9 (12.7)	.482†

CPB, cardiopulmonary bypass; ASD/VSD, atrial and ventricular septal defects; AVSD, atrioventricular septal defects; TGA, transposition of the great arteries

*Group comparisons Mann Whitney-U test for continuous and student t-test for nominal and categorical variables.

† Not significant at $p > 0.05$

Table 2: Comparison of State and Trait Anxiety Scores of Parents in the First and Second Groups (N = 93)

Score Types	First Group (n = 46)		Second Group (n = 47)		p	Student t test (95% CI)*
	Mean ± SD	Median (min-max)	Mean ± SD	Median (min-max)		
State Anxiety Score	51.6 ± 7.1	51.5 (40-68)	35.7 ± 7.2	35 (26-58)	.000†	10.76
Trait Anxiety Score	52.5 ± 6.4	52 (42-69)	38.5 ± 8.0	37 (26-56)	.000†	9.31

*CI: confidence interval

† Significant at $p < 0.05$

Table 3: Comparison of Causes of Anxiety about Child's Home Care of Parents in the First and Second Groups*

	First Group (n = 46)		Second Group (n = 47)		p – value†
	n	%	n	%	
Feeling Anxiety About Their Child's-Home Care					
Yes	45	97.8	17	36.2	.000‡
No	1	2.2	30	63.8	
Topics About Feeling Anxiety§					
Infections/fever	35	76.1	10	21.3	
Nutrition	19	41.3	6	12.8	
Incision care	14	30.4	2	4.3	
Medication	9	19.5	1	2.1	
Psychosocial problems	9	19.5	2	4.3	
Heart-related problems	7	15.2	2	4.3	
Vaccinations	5	10.9	0	0	
Accidents	4	8.7	0	0	

*Parents' answers from questionnaire form.

†Group comparisons independent t-test.

‡Significant at $p < 0.05$

§Participants were allowed more than one answer.

appropriate preparation for parents as a component of holistic care for children at discharge following heart surgery.

The period of diagnosis to hospitalization, and finally to care-giving at home following heart surgery is extremely stressful for parents.[4] It is therefore important to prepare parents fully to decrease anxiety levels. In the present study, the anxiety level experienced by parents given only routine information was assessed as moderate, while the anxiety level decreased significantly in a group of parents given more thorough intervention. The findings of the current study are similar to results reported by Bellew et al. (2002), showing that an information leaflet on pediatric anesthesia reduced preoperative anxiety, and that the provision of verbally delivered information and written material increased satisfaction and reduced anxiety levels.[22]

The present findings suggest that the families of children undergoing CHD surgery can benefit from substantially more information than is generally given. The higher anxiety levels in the first group may be the result of a lack of knowledge and experience regarding their child's care. A previous study (Stinson and McKeever 1995) investigated the informational needs of mothers of children undergoing cardiac surgery both at the time of surgery and 3-10 days post-discharge.[23] The need for maternal understanding of their child's condition and needs was found to be higher after discharge than during hospitalization. In addition, the mothers in this study stated they would have more been confident at discharge if given more opportunities to participate in their child's care during hospitalization.

Following CHD surgery there is much information for parents to consider for their child's care. Therapy, symptom management, community support, follow-up appointments, the nature of the heart defect, the surgical procedure, and medications are all important areas for parents to assimilate after their child's heart surgery.[4] Information that is typically excluded by health care professionals includes protection from infection, feeding, typical recovery, immunizations, pain, circumcision, and travel.[23] In the present study, the majority of parents given only routine information expressed anxiety over home-care following discharge, including infection, fever, nutrition, hygiene, psycho-social development, accidents, and vaccinations as well as heart-related problems, medications, and care of the surgical incision. In addition, parents in the present study did not receive community support. Therefore, receiving information and gaining confidence in the ability to provide care for their child at home following discharge was of significant importance in the reduction of anxiety. Parents that are less anxious can care for a child more effectively and are less likely to transfer their anxiety onto their child.

Behavioral difficulties have been reported in 17% of children after congenital heart surgery.[24] However, the social aspects of cardiac surgery are often ignored or neglected at discharge. The process of discharge is complex, and there is a need for clear guidelines to help parents understand how best to provide home-care for their children.

One limitation of the present study is the exclusive inclusion of parents of children undergoing heart surgery, followed in a hospital pediatric inpatient cardiovascular ward. Future studies should expand the population sample to include parents of children undergoing other types of surgery. In addition, the anxiety level of parents in the 1. and 2. group should be measured before the dispensing of information.

The inclusion of factors other than those relating to surgery that may affect parental anxiety and well-being should be considered in future studies. Further research is needed to understand the issues faced by and the needs of parents caring for children after heart surgery. Studies should focus on the context of the lives of parents, family support and satisfaction, marital relationships, and stressors related to jobs. Also, the first group received their information 1-2 days prior to discharge and the second group began receiving theirs 1 day after admission to the unit. The duration of the provision of the information could have affected the results of anxiety levels of parents. On the other hand, because the length of stay after surgery could be differentiating in the majority of cases and the intervention has not been previously offered provided an opportunity to test, the findings could not generalizable outside of the study sample.

Conclusions

Education and participation in care are key components in empowering parents in making decisions and in minimizing their anxiety regarding their child's healthcare.[25,26] Nurses can guide parents by helping them find appropriate information concerning the home-care of their child. Nurses can also help to prepare parents for this stressful period by encouraging them to participate in their child's care throughout hospitalization.

Contributions

Study design: E K-T, F K

Data collection and/or analysis: E K-T, F K, R K

Manuscript preparation: E K-T, F K, R K

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