

Original Article

Home Care Needs and Symptoms of Children Undergoing Heart Surgery and Quality of Life of Parents

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Abstract

Background: This study is a descriptive study aimed at determining the symptoms and home care needs seen during the home care process in children undergoing surgery due to congenital heart disease and the quality of life of parents in hospital and at home after discharge.

Methods: Parents of 60 children who were planned to undergo surgical procedure due to congenital heart disease were included in the study between 10.03.2018 and 30.06.2018. Research data were obtained using the socio-demographic data form, WHOQOL-Bref quality of life scale, and home care needs and symptoms determination list.

Results: It was determined that all of the parents who participated in the study provided the care of their children themselves. It was found that 60% of them needed health personnel during the post-discharge home care process. A team was observed in the home care process in children who underwent surgery.

Conclusions: It is observed that parents take an active role as a caregiver in the home care process after heart surgery in children. In this process, some complications are seen in children. It was determined that parents feel inadequate during this period and need health personnel in different areas. It is thought that children undergoing heart surgery should be monitored by health professionals for symptoms that may occur at home and complication management should be performed.

Key Words: Congenital heart disease, home care, surgical, symptom

Introduction

It is stated that 1.35 million children are born with congenital heart disease every year worldwide. Congenital heart disease, (CHD) is known to be the most common (9/1000) heart defect (Van Der Linde, et al., 2011). It is reported that one-third of the children born are lost due to CHD, which is the most important cause of deaths in the first years of birth (Conk, et al., 2013). It is known that the main treatment for CHD is surgical intervention. On the other hand, it is stated that surgical interventions carry a high risk and the importance of post-operative care for survival/recovery is emphasized (Huang, 2017). Post-operative care consists of three phases: intensive care process, clinical and home care. It is known that patients are usually discharged early after surgery. It is therefore stated that a number of responsibilities are imposed on parents during the

home care process (Chen, Wang, & Yang, 2015; Menahem, Poulakis & Prior, 2008). Caregiver family members undertake many complex tasks related to care, such as symptom management and drug therapy. These intense responsibilities lead to difficulties and the caregivers are described as hidden patients (Kristjanson & Aoun, 2004). When the literature is examined, it is seen that studies analysing the home care needs of children undergoing surgery due to CHD and the quality of life of parents as caregivers are limited. In the study conducted by Spijkerboer et al., 2008, it is stated that the parents of children undergoing surgery due to CHD often experienced negative emotional responses and needed support from healthcare personnel during the home care process. In a similar study conducted by Ni et al., 2009 it is established that the parents of children who underwent surgery due to CHD, experience

psychological pressure and extreme stress during the hospital and home care process. There were no studies on the symptoms seen at home in children with CHD right after the surgery and the discharge. In this study, it was aimed to determine the post-discharge symptoms seen during the home care process in children undergoing surgery due to CHD and the quality of life of parents and home care needs, and to contribute to the literature.

Materials and Methods

Method: The population of the study consisted of parents of children of 0-12 years of age who were planned to undergo surgery due to CHD between 10.03.2018 and 30.06.2018, who agreed to participate in the study. Within the specified date range, 80 children underwent surgery and 60 people who agreed to participate in the study made up the sample group. Ethical approval of the study was obtained from the ethics committee numbered 2018/88 and institutional permission numbered 53838792-929 was obtained to obtain the data. The parents included in the study were given the necessary explanations about the research, their questions were answered and informed consent forms were signed. Permission was obtained from the author for the use of WHOQOL-BREF Quality of Life Scale Form used in the study. In the collection of research data, socio-demographic data form prepared by the researcher in accordance with the literature, home care needs assessment and the WHO Quality of Life Scale WHOQOL-BREF were used. Questionnaires and the scale were applied to parents through face-to-face interviews in hospital and by voice calls a week after discharge. Each interview was approximately 15-20 minutes.

Socio-Demographic Data Form: Questionnaire developed by the researcher in line with the literature was composed of a total of 24 questions covering the items related to the age, gender, education status, family structure, number of children, income level, drug use, presence of social support, etc. of the parent who has a child with congenital heart anomalies.

Home Care Needs and Symptoms Determination List: In the literature, the symptoms that paediatric patients undergoing heart surgery experience at home after discharge are frequently; pain, shortness of breath, loss of appetite, weakness, exhaustion, sleep problems, wound related problems, palpitations and constipation. Since there are no measurement tools to determine their symptoms and home care

needs, symptom determination list and home care needs list, which consisted of 22 questions, were created by the researcher in accordance with the literature to evaluate the patients (Tregay, et al., 2015; Brown, et al., 2016).

WHOQOL-BREF Quality of Life Scale: As a health-related quality of life scale, WHOQOL-BREF-TR, the Turkish Version of World Health Organization Quality of Life Scale Short Form was developed by WHO, and the validity and reliability of it was conducted by Eser et al.¹² The scale evaluates physical, mental, social and environmental well-being and consists of 26 questions. Since each dimension refers to the quality of life in itself independently, the dimension scores are calculated between 4 and 20 points. The quality of life improves as the score increases.

Data Analysis: Number, average and percentage distributions were used to evaluate the socio-demographic characteristics of the parents, the effects of the disease and the effect of the disease on the parent. Frequency and percentage were used in the assessment of the data related to the symptoms seen during home care of children, the home care needs and the need of healthcare personnel in home care. Two separate data of the quality of life scale filled both in the hospital and at home were presented with mean and standard deviation. The differences between hospital and home data were analysed via dependent sample t-test. In addition, Bonferroni post-hoc test was used to determine which groups had significant differences. Furthermore, the relationships between them were examined with dependent sample t test. Overall quality of life and general health perception questions were used as dependent variables.

Results

The diagnostic distribution of 60 children included in our study was: 28 cyanotic CHD; pulmonary atresia n:12; tetralogy of fallot n:16 and 32 acyanotic CHD; ventricular septal defect n:17; atrial septal defect n:9; and atrioventricular septal defect n:6. The mean age of children was 2.7 and the average age of parents was 32.3. When the demographic findings were examined, 96.7% of the caregivers were determined to be the mother of the child and the rest to be the father of the child. While only 8.3% of the parents worked in a job, 56.7% of them were found to have an income less than expenses. It was established that parents with less income had lower quality of life in the hospital environment compared to the

parents with an income equal to the expenses ($t = 4,709, p <,05$) (Table 1).

When the findings of the child's disease were analysed, it was found that 45% of the children who underwent surgery learned the disease immediately after birth. It was determined that 41.7% of the children went for a check-up once a month before surgery. In 68.3% of parents, it was found that coming to the hospital affected their daily lives. It was established that 68.3% of the caregiver parents were concerned about the future of their child. It was found that 60% of their concern was about the health of their children. 58.3% of the caregiver parents received emotional support from their families and relatives. In addition, 48.3% of the parents stated that they needed psychological help. However, it was identified that only 10% of parents received professional psychological support. It was determined that 61.7% of children who underwent surgery had medications to use at home. When the information obtained about the need of health personnel in home care was examined, it was found that 60% of caregiver parents needed health personnel while providing home care for the child. The areas and care that parents needed most during home care were; drug use (21.7%), wound care (13.3%), surgical site complication (11.7%) (Table 2).

When the symptoms observed in children during the home care process after hospital discharge were examined, it was determined that 73.3% of children had eating difficulties/loss of appetite and 65% did not have a regular and balanced diet. It was also found that 50% of the children experienced shortness of breath while 51.7% had palpitations (Table 3).

It was established that 41.7% of the parents did not control their children's weight after discharge and 48.3% did not pay attention to the crowd in the home environment. It was determined that 56.7% of children did not receive a regular oral care (Table 4).

A significant difference was found between the quality of life stated by parents in the quality of life scales they responded to in hospital and in-home environment ($t = -2,791, p <,05$). Accordingly, parents' quality of life at home was determined to be higher than the quality of life in the hospital (Table 5). 16.7% of parents were determined to have a chronic disease. It was determined that the quality of life of parents with chronic disease assessed in the home environment differed significantly ($t = 4,529, p <,05$). As a result, it was found that parents with chronic diseases had lower quality of life in the home environment.

Table 1. Comparison of income level and quality of life

Income level	– How do you find your quality of life?					
	Hospital			Home		
	\bar{x} SD	t	p	\bar{x} SD	t	p
Income less than expenses (n=34)	2.88 ±.84	4.709	0.013	3.38 ±.89	1.503	0.231
Income equal to expenses (n=20)	3.65 ±.99			3.60 ±.82		
Income more than expenses (n=6)	3.17 ±.75			4.00 ±.63		

Table 2. Distributions of health care needs in home care

The need of health personnel in home care	N		%	
	Number	Percent	Number	Percent
Yes	36	60.0		
No	24	40.0		
The areas and care needed most	Number	Percent		
Drug use (dose adjustment)	13	21.7		
Wound care	8	13.3		
Surgical site complications	7	11.7		
Psychological incapacity	4	6.7		
Pulse calculation, drug use, wound care	3	5.0		
Nutrition, drug use	1	1.6		

Table 3. The distribution of the symptoms in children during home care

Evaluation of post-discharge symptoms of children seen during the home care				
	Yes		No	
	Number	Percent	Number	Percent
Urinating daily	56	93.3	4	6.7
Meeting the need for daily defecation	55	91.7	5	8.3
Regular breathing	52	86.7	8	13.3
Eating difficulties / loss of appetite	44	73.3	16	26.7
Adequate daily fluid intake according to age and weight	33	55.0	27	45.0
Experience heart palpitations	31	51.7	29	48.3
Experience shortness of breath	30	50.0	30	50.0
Adequate and healthy sleep	22	36.7	38	63.3
Regular and balanced diet	21	35.0	39	65.0
Increase in body temperature	6	10.0	54	90.0

Table 4. Distribution of children's home care needs

Evaluation of parents' requirements towards the home care needs of children after discharge				
Yes			No	
	Number	Percent	Number	Percent
Paying attention to hand hygiene	56	93.3	4	6.7
Observing the wound area for discharge / colour change	53	88.3	7	11.7
Paying attention to ventilation of the home environment	53	88.3	7	11.7
Avoiding scrubbing and rubbing while performing wound care	51	85.0	9	15.0
Performing regular wound care	48	80.0	12	20.0
Paying attention to home hygiene	47	78.3	13	21.7
Giving importance to the regular use of medicines	43	71.7	17	28.3
Going to check-ups regularly	43	71.7	17	28.3
Doing weight control	35	58.3	25	41.7
Paying attention to the sleeping position and not turning right to left while resting	31	51.7	29	48.3
Paying attention to the crowd in the home environment	31	51.7	29	48.3
Performing regular oral care	26	43.3	34	56.7

Table 5. Comparison of sub-dimensions of quality of life scales of the participants evaluated in hospital and at home

Quality of life scale (n=60)	Hospital \bar{x} SD	Home \bar{x} SD	t	p
How do you find your quality of life?	3.17 ±0.94	3.52 ±0.85	-2.791	0.007
How satisfied are you with your health?	3.50 ±1.16	3.72 ±1.06	-1.561	0.124
Physical Well-being	13.30 ±2.60	14.24 ±2.37	-2.467	0.017
Mental Well-being	14.23 ±2.98	15.84 ±2.37	-4.634	0.001
Social Well-being	14.22 ±3.70	14.69 ±3.45	-1.191	0.238
Environmental Well-being	13.59±2.53	13.92 ±2.88	-1.367	0.177

Discussion

In this study, the quality of life of parents in the hospital before the surgery and at home after the operation were evaluated along with the post-discharge symptoms and home care needs seen during the home care process in children undergoing heart surgery. Today, it is known that the health facilities available today are closely related to the economic situation. Hospital treatment is a costly process and it is thought that individuals' financial inadequacy may have an impact on their quality of life. Brown et al., 2016; reported that the socioeconomic status of the family directly affects the care of the child undergoing cardiac surgery. It is thought that a better health care for children may be related to the income level of the parents. In the study of Colakoglu, 2016; it was established that more than half of the parents did not work, the income level was moderate, and the parents with high income level obtained higher mean scores from the quality of life sub-dimensions. In this study, it was determined that almost none of the parents worked in a job and more than half had an income less than expenses. It was seen that the parents with an income less than expenses had a lower quality of life in the hospital environment than those whose income was equal to the expenses.

In a study examining the quality of life of the parents with children undergoing surgery due to CHD, it was found that 22.3% of the parents had a chronic disease and that there was a significant relationship between all sub-dimension mean scores except for the 'emotional regulation difficulty' and 'mental health' sub-dimensions included in the quality of life scale (Colakoglu, 2016). In our study, 16.7% of parents had a chronic disease. It was found that the parents with chronic disease had a lower quality of life in the home environment ($t = 4,529$, $p < .05$). Chronic diseases are thought to affect all family members. It is known that individuals with chronic diseases need psychological support as well as medical treatment.

Parents of children with CHD need to be evaluated in multiple ways. The difficulties faced by parents must be identified and planning for the cause must be made. Otherwise, it is thought that conditions such as depressive symptoms, increased levels of stress and anxiety will adversely affect the quality of life of individuals. In the study of Pye & Green, 2003; it is stated that when parents learn about the presence of CHD in

their children, they experience anxiety and sadness regardless of whether the disease is serious or not. Ni et al., 2019; claimed that parents who have CHD in their children blame themselves for this situation and are concerned about the future. Mahle, 2001; on the other hand, stated that parents of children with CHD experience a lot of psychological pressure. In a study examining the parents who have CHD in their children, it was found that 28.2% of the parents received psychological help-support (Colakoglu, 2016). In our study, it was determined that approximately half of the caregiver parents needed psychological support, but only 10% received psychological support. It is seen that parents are concerned about the future because of their children's health problems. CHD surgeries are usually performed at an early age and the children's post-operative care is provided by the parents. Therefore, parents' burden of care increases and they may encounter mental problems.

It is known that there are problems in nutrition and weight gain in patients with CHD and heart failure. CHD is an important factor affecting mortality and morbidity. The importance of nutrition is emphasized before and after the surgery (Koksall, 2003; Quinn, 2005). Tregay et al., 2016; stated that malnutrition is seen in children discharged after heart surgery. When the regular and balanced nutritional status of children during the home care process was examined, it was determined that more than half of them had a change in their eating habits, were unable to eat a regular-balanced diet and had eating difficulty/loss of appetite. It is known that the nutrition of children should be evaluated individually in CHD. It is thought that the nutrition of children with CHD can be improved by determining their energy requirements individually and by including micro and macro nutrients.

In the study of Hartman & Medoff-Cooper 2012; the parents of children who had surgery due to CHD were called regularly by nurses during the home care process, thereby the weight control of the children were done regularly. In our study, it was found that approximately half of the children did not have regular weight control during home care. Daily weight measurement is required to prevent nutritional deficiencies in children in post-operative period and to detect malnutrition in an early stage. Patients in the home care process need to be monitored by medical staff.

It was determined that the children who had surgery did not receive enough fluid daily according to their age and weight. Especially in new-borns, fluid intake is very difficult and low. Exhaustion and solid foods during breastfeeding cause abdominal distension in the child. For this reason, the fluid requirement should be obtained from foods that the child can consume easily and that possess a rich nutritional content (Koksal, 2003). CHD treatment is known to be vital in new-borns and children. It is stated that early diagnosis of these patients increases survival. Especially the post-operative care of CHD, in which surgical treatment is necessary, requires more attention than other surgical areas. Post-operative care is known to be extremely important in preventing possible complications. It is believed that the evaluation of the patients in terms of complications that may occur in the early and late postoperative periods will decrease mortality and morbidity. When the literature was examined it was found that the common complications seen after CHD surgery are bleeding or infection in the wound area, high fever, dyspnea, hypoventilation, hyperventilation, tachycardia, bradycardia, hypoxemia, hypertension, hypotension, diarrhea and vomiting (Tregay, et al., 2015; Brown, et al., 2016; Tregay, et al., 2016). Complications seen after CHD surgeries are critical compared to other surgical procedures. Postoperative monitoring for complications and early detection are life-saving measures. In this regard, considering the lack of knowledge of the caregiver parents in these issues, it is extremely important for the healthcare professionals to manage this process.

During the home care process, only 10% of children were found to have high fever. In the study of Ayar et al., 2015; in which home care service was evaluated in paediatric patients, fever, with a rate of 29.2%, was established as the most common symptom causing a doctor visit. The reason of this difference is thought to be the different sample groups covered in the studies. In our study, when the other symptoms during the home care process were examined, it was seen that children had palpitations and experienced shortness of breath-difficulty in breathing.

The oral care of more than half of the children undergoing surgery were neglected and they were not provided regular oral care. Oral and dental hygiene should be given sufficient importance in these children. It was identified that nearly half of the parents did not pay attention to the crowd in the home environment. New-borns and infants

with heart disease are very susceptible to respiratory infections, so contact of the child with people with active infections must be prevented. Necessary precautions should also be taken during patient visits. Nosocomial infections should be prevented with protective practices (Koksal, 2003; Saha, 2010; TUIK 2010-2018).

In the home care process, it has been determined that more than half of the parents need health personnel in different areas. If we list the areas where the health personnel are needed during the home care process provided by the parents; it is stated that parents have difficulty meeting the care needs due to drug use-dose adjustment, wound care, surgical site complication, and psychological incapacity and need health personnel during the home care process. Post-operative home care in children is a difficult process to manage. It is seen that the parents experience difficulties in the management of the complications and in the care of the child after the operation. As from the hospitalization, nurses should be aware of the needs of the child and the family. Discharge training should be started as early as possible. It is thought that following the hospital discharge, parents should be contacted and checked for the needs and symptoms seen in the home care process. It is observed that Sekar, & Vilvanathan, 2007; recommended the telecardiology method to control post-operative risks during children's cardiac care. It is thought that it would be beneficial to include the complications and the needs of children in the post-operative home care process in the project.

It is known that hospitalization adversely affects the sleep cycle. After hospital discharge, children try to adapt to the home environment, at the same time, surgical operation and ongoing medical treatment are thought to affect children negatively. In our study, it was found that more than half of the children did not get adequate and healthy sleep during the home care process. Sabzevari & Nematollahi, 2016; reported that, because of CHD, children experience difficulty in sleeping, and parents are negatively affected by this process during home care. In the study conducted by Ni et al., 2019; it is stated that the burden of care increases as parents try to ensure that children sleep during the home care process. Children's inability to take part in their own care due to their functional disabilities, affect parents negatively. As they take the responsibility of the care of the sick individual, parents' burden of care increases. Parents of children undergoing CHD

surgery experience difficulties in many areas due to the need for a long-term home care.

Starting from the patient's hospitalization, it is clear that the discharge and home care trainings are very important for reducing the burden of care. Meanwhile, caregiver parents' need for healthcare personnel during the home care process should be taken into consideration. In this regard, it is important to determine the requirements. Healthcare professionals' being in touch with the parents during the home care period and following the process closely, will help the process to proceed and to be managed in a positive way.

A significant difference was found in mental well-being sub-dimension of the quality of life scale that the parents filled in the hospital and home environment. Although parents felt inadequate in many areas during the home care process and needed health professionals, their quality of life at home was to be significantly higher compared to the hospital. The home environment is thought to have a positive effect on parents' mental well-being. It is believed that making parents feel safe by providing support with health professionals in the home care process, will help them reach the maximum level of quality of life.

The results of this study emphasize the importance of nurses to support children who underwent cardiac surgery and their parents during the post-operative home care process. The need for home care services in children is increasing rapidly. Strategies and studies should be conducted to increase and expand home care service programs especially for children who have undergone CHD surgery. Post-operative home care is known to be a challenging and risky process. In order to ensure recovery and prevent possible complications in children undergoing surgery due to congenital heart disease, the home care process should be followed up by health professionals, especially nurses. Appropriate nursing approach for possible complications in children undergoing surgery due to CHD should be provided. In the nursing approach of children undergoing CHD surgery, it is believed that factors such as;

- Monitoring the surgical site in terms of bleeding and signs of infection,
- Evaluating complications of dyspnea, hypoventilation, hyperventilation, tachycardia, bradycardia, hypoxemia, hypertension and hypotension,
- Monitoring pulse rate, respiratory rate, saturation, blood pressure and body temperature,

- Maintaining adequate-balanced diet, adequate fluid intake according to age and weight,
- Providing regular weight control, regular drug use and check-ups are thought to be essential for the prevention of possible complications or for the early detection of the problem, and for minimizing mortality and morbidity.

It should not be forgotten that the care burden of the parents is heavy and social, financial and psychological support should be provided if necessary in order to increase their quality of life. Training on the problems and needs that parents will frequently encounter during the home care process should be given during their hospital stay. Post-discharge requirements should be supported by home visits and managed with solutions such as telephone and digital consulting. In this process, nurses should take protective and preventive measures to improve the quality of life of the parents who are the caregivers of children undergoing heart surgery. Further studies on the symptoms seen in the home care after heart surgery in children and on the home care needs of the parents will be a guiding light in the management of the process.

Limitations: The limitation of this study is that its sample is small.

Conclusions: The results of this study highlight the importance of nursing care in children undergoing heart surgery. Comprehensive training on the home care process should be given to parents who care for children. It is especially important to provide home care services effectively by following the symptoms and needs seen in children during the home care process. In addition, social, financial and psychological support should be provided, if necessary, in order to increase the quality of life of parents whose care burden increases during this period.

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