J Pediatr Res 2022;9(3):214-22
DOI: 10.4274/jpr.galenos.2022.48379

Original Article

Determination of the Relationship Between Disease Managements and the Perception of Nursing Support of Parents Whose Children are Monitored in an Intensive Care Unit

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ABSTRACT

Aim: This study was conducted descriptively to determine the relationship between disease managements and the perception of the support given by nurse of the parents whose children were monitored in a Pediatric Intensive Care Unit (PICU).

Materials and Methods: This study was carried out between August-December 2018 in a PICU. The sample of the study comprised 108 parents whose children were being monitored for a chronic disease diagnosis. The study data were collected via two data collection forms, "The Family Management of Childhood Chronic Conditions" (FaMM) and "Nurse Parent Support Tool" (NPST).

Results: The parents' gender, knowledge about the disease and the FaMM three sub-dimension score averages were not statistically significant ($p>0.05$). However, the difference between the parents' educational background, income status, the factors of support from the social environment and the sub-dimension score averages were significant ($p<0.05$). While the difference between the interviewed parents' gender and income status and NPST score averages were not significant ($p>0.05$); the difference between the interviewed parents' educational background, knowledge about the disease, the status of support from the social environment and NPST score averages were significant ($p<0.05$).

Conclusion: It was concluded that as the perceived support from nurses of the parents of the child with chronic disease increases, the disease management increases.

Keywords: Pediatric intensive care, parents, nurse support, disease management

Introduction

Chronic diseases keep increasing rapidly and are already the most important health problem in the world, especially in industrialized countries. The number of children with chronic illnesses has increased significantly over the last two decades. Incidents of death due to chronic illnesses now rank higher than hunger, mother and child mortality, and infections (1). Chronic diseases are also among the most important health problems in Turkey. According to estimates, the incidence of chronic illnesses in children is between 10-15% in the population of under 18 years of age and it reaches 30-40% with the inclusion of children with mental, sensory, learning, and behavioral problems (2-4).

Chronic diseases for children pose serious challenges from a health management perspective (5). Most of the children with chronic illness are cared for at home and their

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Received: 26.01.2022 **Accepted:** 21.04.2022

primary caregivers are their parents. Therefore, healthcare workers should remember that the experience of illness affects all family members, not only the patient. Parents often play an important role in the care of childhood chronic diseases (6). Nurses who are in close contact with children and their families are indispensable members of the healthcare team as primary caregivers. Therefore, they increasingly assume leadership roles especially in the management of chronic illnesses (7,8). Pediatric chronic diseases have three levels of consequences; 1) those experienced by the child or individual family members (school absence, activity limitation, psychosocial and behavioral problems) and 2) those experienced by the family system (disruption of usual routines, alteration of roles and relationships) and 3) other outcomes related to the family's interactions with the child's health care providers. When the literature is examined, it is seen that nurse given support plays an important role in the management of the disease for the child and family (9-11). In line with this, the ability to cope with stress, acceptance of the illness, and thus adaptation of the child to the illness are all significantly associated with nursing support.

Although chronic disease management and nurse support are an important issues for childhood diseases, no study has been carried out in this area in the pediatric intensive care unit (PICU) to the best of our knowledge. This study was carried out to determine the relationship between the perceived support given by nurses and disease management of the parents whose children were followed up in the PICU with a diagnosis of chronic illness.

Materials and Methods

Sample and Procedures

This study was conducted descriptively between August and December 2018 at the PICU of the University of Health Sciences Turkey, Şişli Hamidiye Etfal Training and Research Hospital, in İstanbul, Turkey.

The study universe consisted of the parents of 150 children who had been followed up in the unit within the previous year (2017) with a diagnosis of a chronic illness. The sample of the study was based on the formula with a known number of individuals in the universe. The sample consisted of 108 parents who did not have any health problems to prevent communication and who agreed to participate in this study. Data were collected 24 hours after the child was admitted to the PICU. The parents filled out the forms themselves in a quiet place where they were alone.

Instruments

Data were collected using The Data Collection Form, The Family Management of Childhood Chronic Conditions (FaMM) and the Nurse Parent Support Tool (NPST), all of which investigated the characteristics of children and their parents.

The data collection Form: This form consists of questions including socio-demographic characteristics regarding the parents and their children, information on the disease, and the effect of the disease on the parents. In order to test the comprehensibility of the data collection forms, a pilot study was conducted with 5 parents.

FaMM: It was developed by Knafl et al. (10). The original scale consists of 53 items and six sub-dimensions. The Turkish validity and reliability study was conducted by Ergun et al. (12). The Turkish version of the scale consists of 42 items and three sub-dimensions. The first dimension is "illness management and the daily life of the child" and higher scores indicate a rather normal life and families finding themselves more capable of illness management. The second dimension is the "difficulties of life and the impact of illness" and the higher the score, the more severe the condition is and the more the difficulties are experienced. The third dimension is "parental agreement" and high scores indicate that parents work together in the management of the child's illness. Each item in the scale is scored from 1 to 5 (10,12). The Cronbach's alpha coefficients of the 3 sub-dimensions of the FaMM in parents in the sample group were 0.93, 0.87, 0.84 respectively.

NPST: This was developed by Miles et al. (13) to measure the level of support provided to parents by the nurses. It was adapted to Turkish and validated by Yiğit et al. (8). The scale consists of four sub-dimensions: "information and communication support, emotional support, respect support, and quality healthcare". It has 21 items in a 5-point Likert type scoring system. The scale is scored by adding the scores of the items answered and dividing them by the total number of items and possible scores range from 1 to 5. High scores reflect increased support which parents receive from nurses (8). The Cronbach's alpha coefficients of the 4 sub-dimensions of the NPST for the parents in the sample group were 0.76, 0.68, 0.68, 0.67 respectively.

Statistical Analysis

The data obtained in this study were analyzed using the SPSS for Windows 22.0 program. In the data assessment, the number, percentage, mean, and standard deviation among descriptive statistical methods were used.

Independent t-test and ANOVA tests were used for data analysis. Regression analysis was performed to determine the relationship between continuous variables. The results were evaluated at a 95% confidence interval and p<0.05 was the significance level.

Ethical Approval

This study was approved by the Okan University Ethics Committee (approval number: 96, date: 04.07.2018). The parents were informed about the research and their written consent was obtained.

Results

More than half (61.1%) of the children participating in this study were girls. 27.8% of the children were in the 7-12 years age range. Of the parents who participated in this study and provided care for their children, 81.5% were mothers and 30.6% had a university degree. It was found that 51.8% of the parents' income equaled their expenses. Among the parents, 57.4% stated that they were adequately informed about the illness and 54.5% stated that they did not receive support from their social circle (Table I).

The difference between the gender and age of the children whose parents participated in this study and the mean sub-dimension FaMM scores was statistically insignificant (p>0.05). The mean score of mothers in the difficulties of life and the impact of illness sub-dimension was found to be higher than that of the fathers and this difference was significant (p<0.05). The mean scores in the illness management and daily life of the child and parental agreement sub-dimensions were found higher in those parents with a university degree (p<0.05). On the other hand, the mean score in the difficulties of life and the impact of illness sub-dimension was lower in those parents with a degree and this difference was significant (p<0.05). It was also found that those parents whose income was higher than their expenses had relatively higher mean scores in the sub-dimensions of illness management and the daily life of the child and parent agreement, whereas they scored lower in the difficulties of life and the impact of illness sub-dimension and that these differences were significant (p<0.05). The study found that those parents with adequate knowledge of the illness had a higher mean score in the sub-dimension illness management and the daily life of the child with a significant difference (p<0.05). Those parents who received support from their social circles had higher mean scores in the sub-dimensions of illness management and the daily life of the child and parental agreement than those who did not receive any support (p<0.05) (Table II).

The difference between the children's gender, age, and the mean scores of the contact parent in the NPST sub-dimension was statistically insignificant (p>0.05). It was determined that the mean scores of both parents for the NPST and its sub-dimensions were similar (p>0.05). It was found that illiterate parents scored higher in the sub-dimension of information and communication support and their mean score had a significant difference (p<0.05). Parents with a university degree had a higher mean score in the emotional support sub-dimension and the mean total score of NPST and this difference with the other parents was significant (p<0.05). Those parents whose income was higher than their expenses had a higher mean score in the sub-dimensions of emotional support and respect support and this difference was significant (p<0.05). Those who were adequately informed about the illness had higher

Table I. Characteristics of parents and children (n=108)

Characteristics	**n**	**%**
Child's gender		
Female	42	38.9
Male	66	61.1
Child's age		
0-12 months	12	11.1
1-3 years	19	17.6
4-6 years	25	23.1
7-12 years	30	27.8
13-18 years	22	20.4
Interviewed parents		
Mother	88	81.5
Father	20	18.5
Education		
Illiterate	7	6.4
Literate without diploma	10	9.3
Primary school graduate	26	24.1
High school graduate	32	29.6
University degree	33	30.6
Income Level		
Income lower than expenses	42	38.9
Income equals expenses	56	51.8
Income higher than expenses	10	9.3
Information level on the illness		
Adequate	62	57.4
Partial	38	35.2
Inadequate	8	7.4
Support from social circle		
Received	49	45.5
Not received	59	54.5
Total	108	100

mean scores in the sub-dimensions of emotional support and respect support, as well as in the NPST overall and this difference was found to be significant ($p<0.05$). Those parents who received support from their social circle scored higher in the sub-dimensions of emotional support, providing quality care, and the total mean score of NPST and these differences were found to be significant ($p<0.05$) (Table III).

The three sub-dimensions of FaMM, which were modeled as a predictor of the NPST score account for 55.5% of the NPST score. There is a strong positive correlation

Table II. Comparison of parents' FaMM sub-dimension mean values according to certain child and parent characteristics (n=108)

	Illness management and the daily life of the child		**Difficulties of life and the impact of illness**		**Parental agreement**	
Characteristics	$\bar{X}$	**Ss**	$\bar{X}$	**Ss**	$\bar{X}$	**Ss**
Child's gender						
Female Male	3.01 2.99	0.59 0.67	3.73 3.82	0.58 0.65	3.73 3.70	0.82 0.77
t/p	0.223/0.824		-0.725/0.470		0.236/0.814	
Child's age						
0-12 months 1-3 years 4-6 years 7-12 years 13-18 years	2.97 2.85 2.94 3.05 3.12	0.55 0.52 0.69 0.64 0.73	3.80 3.88 3.86 3.71 3.69	0.68 0.46 0.63 0.66 0.69	4.03 3.85 3.45 3.64 3.80	0.81 0.66 0.86 0.79 0.73
F/p	0.554/0.696		0.434/0.784		1,474/0.215	
Contact parent						
Mother Father	2.96 3.16	0.61 0.73	3.85 3.49	0.59 0.71	3.68 3.87	0.82 0.59
t/p	1,231/0.221		**2,373/0.019***		-0.980/0.329	
Education						
Illiterate^1 Literate without diploma^2 Primary school graduate^3 High school graduate^4 University degree^5	2.70 2.90 2.73 2.83 3.46	0.70 0.57 0.46 049 0.67	4.41 3.93 4.05 3.78 3.39	0.36 0.68 0.47 0.50 0.65	3.36 3.84 3.37 3.52 4.19	1.14 0.63 0.76 0.75 0.55
F/p	**8,119/0.001*** **5>1,3,4**		**7,989/0.001*** **3>5; 1>5**		**6,157/0.001*** **5>1,3,4**	
Income level						
Income lower than expenses^1 Income equals expenses^2 Income higher than expenses^3	2.71 3.10 3.62	0.52 0.61 0.67	4.01 3.71 3.24	0.54 0.62 0.62	3.44 3.83 4.17	0.85 0.67 0.73
F/p	**11,440/0.001*** **3>2>1**		**7,747/0.001*** **1>2>3**		**5,074/0.008*** **3>2>1**	
Information level of illness						
Adequate Partial Inadequate	3.13 2.85 2.66	0.69 0.52 0.48	3.71 3.85 4.03	0.66 0.55 0.62	3.77 3.60 3.75	0.86 0.68 0.62
F/p	**3,565/0.032***		1,281/0.282		0.536/0.587	
Support from social circle						
Received Not received	3.17 2.85	0.67 0.57	3.68 3.86	0.68 0.56	3.92 3.54	0.77 0.76
t/p	**2,649**	**0.009***	-1,527	0.130	**2,535**	**0.013***

t= Independent t-test; F= One-way ANOVA
$p<0.01$*
FaMM: The Family Management of Childhood Chronic Conditions

Table III. Comparison of parents' NPST and sub-dimension mean values according to parents' identifying and illness-related characteristics (n=108)

	Information and communication support		**Emotional support**		**Respect support**		**Providing quality care**		**NPST- Total**	
Characteristics	$\bar{X}$	**Ss**	$\bar{X}$	**Ss**	$\bar{X}$	**Ss**	$\bar{X}$	**Ss**	$\bar{X}$	**Ss**
Child's gender										
Female	3.30	0.25	3.03	0.80	3.07	0.44	3.47	0.39	3.82	0.74
Male	3.36	0.31	2.90	0.82	3.08	0.56	3.46	0.38	3.67	0.86
t/p	-1.019/0.311		0.761/0.449		-0.122/ 0.903		0.164/0.870		0.925/0.357	
Child's age										
0-12 months	3.35	0.27	3.02	0.57	3.10	0.55	3.55	0.41	3.83	0.79
1-3 years	3.29	0.31	2.68	0.73	2.92	0.46	3.47	0.35	3.74	0.77
4-6 years	3.25	0.35	2.96	0.76	3.06	0.46	3.49	0.42	3.66	0.87
7-12 years	3.34	0.21	3.05	0.77	3.15	0.56	3.40	0.39	3.80	0.80
13-18 years	3.34	0.26	3.13	0.97	3.12	0.54	3.48	0.36	3.60	0.88
F/p	1,658/0.165		0.684/0.605		0.639/0.638		0.398/0.810		0.184/0.946	
Interviewed parents										
Mother	3.38	0.29	2.89	0.77	3.07	0.51	3.50	0.37	3.73	0.81
Father	3.30	0.29	3.25	0.94	3.10	0.52	3.33	0.42	3.75	0.86
t/p	0.630/0.530		-1,800/0.075		-0.203/0.839		1,792/0.076		-0.105/0.916	
Education										
Illiterate[1]	3.58	0.21	2.52	0.97	3.03	0.63	3.60	0.51	4.17	1.02
Without diploma[2]	3.33	0.25	2.9	0.58	3.17	0.54	3.54	0.34	3.46	0.64
Primary school[3]	3.40	0.30	2.64	0.67	3.02	0.51	3.43	0.38	3.43	0.77
High school[4]	3.25	0.28	2.78	0.65	2.92	0.42	3.43	0.40	3.44	0.77
University degree[5]	3.33	0.28	3.48	0.85	3.25	0.54	3.47	0.37	4.25	0.61
F/p	**2,506/0.047* 1>2,3,4,5**		**6,380/0.001* 5>1,3,4**		1,860/0.123		0.397/0.810		**7,337/0.001* 5>2,3,4**	
Income level										
Income lower than expenses[1]	3.38	0.28	2.72	0.67	2.91	0.45	3.41	0.35	3.52	0.78
Income equals expenses[2]	3.32	0.29	2.98	0.83	3.14	0.52	3.48	0.40	3.83	0.82
Income higher than expenses[3]	3.25	0.30	3.80	0.70	3.40	0.54	3.58	0.38	4.08	0.82
F/p	0.942/0.393		**8,050/0.001* 3>2>1**		**4,737/0.011* 3>1**		0.907/0.407		2,764/0.068	
Information level of illness										
Adequate	3.36	0.27	3.11	0.87	3.22	0.55	3.48	0.42	3.98	0.79
Partial	3.29	0.29	2.85	0.62	2.90	0.33	3.43	0.31	3.48	0.70
Inadequate	3.41	0.36	2.20	0.75	2.75	0.61	3.52	0.42	3.06	0.89
t/p	0.813/0.446		**5,147/0.007* 1>3**		**6,887/0.002* 1>2,3**		0.303/0.739		**8,197/0.001* 1>2>3**	
Support from social circle										
Received	3.30	0.31	3.09	0.88	3.17	0.56	3.55	0.39	4.11	0.70
Not received	3.37	0.27	2.84	0.74	2.90	0.46	3.39	0.37	3.42	0.78
t/p	-1,191/0.236		**1,620/0.108**		1,851/0.067		**2,156/0.033***		**4,795/0.001***	

t= Independent t-test, F= One-way ANOVA
$p<0.01$
NPST: Nurse Parent Support Tool

between the NPST scores and the illness management and the daily life of the child (AB1) and parental agreement (AB3) subdimensions and a strong negative correlation with the difficulties of life and the impact of illness (AB2) sub-dimension (p<0.001) (Table IV).

Discussion

Of the parents who participated in this study and provided care for their children, 81.5% were mothers (Table I). Similar studies with the parents of children with chronic illness show that the caregivers are mostly mothers (14,15). This may be due to the assumption that the role of caregiving in Turkish society is the responsibility of the mother rather than the father. It was found that 51.8% of the parents' income equaled their expenses. Among the parents, 57.4% stated that they were adequately informed about the illness and 54.5% that they did not receive support from their social circle (Table I). Similar studies show that more than half of the parents were well informed about the illness, received support from their social circles in caregiving but they were economically affected by their child's illness (8,14).

The difference between the gender and age of the children whose parents participated in this study and the mean sub-dimension FaMM scores was statistically insignificant (Table II). This shows that the parents' management of the existing condition is not affected by the age or gender of their child. In a similar study, the difference between the perceived stress and coping status of the parents and the child's gender and age variables were found to be statistically insignificant. Güneş Çalıcıoğlu and Uysal (16) and Kızıler et al. (17) reported that the age of the child does not affect the parent's coping level as a result of their study with the parents of children who had been diagnosed with cancer.

Table IV. Linear regression analysis predicting parents' scores in the FaMM sub-dimension of the NPST

Constant: NPST score	B(b)	Standard Error for B	Beta (β)	T	p
FaMM-AB1	12,665	2,999	0.472	5,309	0.001*
FaMM-AB2	-5,725	2,599	-0.290	-2,203	0.003*
FaMM-AB3	9,859	1,897	0.451	5,197	0.001*
		R	**R2**	**F**	**p**
		0.555	0.308	47,192	0.001*

FaMM-AB1: Illness management and the daily life of the child, FaMM-AB2: Difficulties of life and the impact of illness, FaMM-AB3: Parental agreement
*p<0.001
FaMM: The Family Management of Childhood Chronic Conditions, NPST: Nurse Parent Support Tool

The mean score of the mothers in the difficulties of life and the impact of illness sub-dimension was found to be higher than the fathers and this difference was significant (Table II). This result may be due to the fact that the care and treatment burden of the child in the hospital and at home are mostly undertaken by the mothers, as in the findings of this study. Similarly, the literature suggests that mothers display more submissive and helpless behavior in dealing with the problems associated with chronic illness in comparison to the fathers (17).

The mean scores in the illness management and daily life of the child and parental agreement sub-dimensions were found to be higher in those parents with a university degree (Table II). In one study, it was stated that the disease management scores of those mothers who had high school or higher education qualifications were higher (3). A similar study reported high mean care burden scores for those mothers with lower levels of education (15). This may be explained by the fact that those parents with higher levels of education have a better understanding of the information provided by the healthcare workers regarding the child's condition. Moreover, a higher level of education also means easier access to information from other sources.

It was also found that those parents whose income was higher than their expenses had relatively higher mean scores in the sub-dimensions of illness management and the daily life of the child and parent agreement; whereas they scored lower in the difficulties of life and the impact of illness sub-dimension (Table II). This may indicate that parents who have to struggle with their child's chronic illness have difficulty in meeting the needs of their child due to economic limitations, which in turn leads to increased stress. In another study on mothers caring for children with chronic illness, Özsoy (3) found that the child's chronic illness and daily life were more difficult to manage for those mothers with poor income as compared to those with moderate to high income levels. In another study conducted with the mothers of children receiving chemotherapy, it was found that as the level of income increased, the degree of anxiety in the mothers somewhat decreased (18). In a study conducted by Zhang et al. (11) in China to determine the factors affecting illness management in families with chronically ill children, it was found that those parents with lower income needed more family support.

This study found that those parents with an adequate knowledge of the illness had a higher mean score in the sub-dimension illness management and the daily life of the child with a significant difference (Table II). This finding suggests that as a result of the information exchange with the parents about the child's illness, care, and the daily life impact, parents could continue their normal lives and see themselves as being more competent in illness management. Similarly, Taanila (19) found that those parents who received little information and practical advice about how to adapt to their child's chronic illness experienced five times more insecurity and helplessness than those who said they were adequately informed on these issues. Adaptation to the illness is a complex process for parents and being well-informed helped their well-being, adaptation, and coping. In another study conducted by Alahan et al. (14), the mean care burden score of those who were not well-informed about caregiving was found to be high.

Those parents who received support from their social circle had higher mean scores in the sub-dimensions of illness management and the daily life of the child and parental agreement than those who did not receive any support (Table II). It can be concluded that the more support received from the social circle, the more confident the parents felt in the daily life impact of the illness and the more they cooperated with each other. Similarly, the studies conducted by Tak and Mccubbin (20) showed that the more support the parents received from their social circle, the more capable they were in coping with the associated stress.

In the absence of support from nurses, parents can find themselves in crisis and they may try inappropriate methods of coping which can be detrimental to the short-term or long-term adaptation to the child's illness (21). In this study, it was determined that there was no difference between the gender, age, interviewed parents and nurse-given support score averages of the children (Table III). In a similar study, it was reported that child's gender did not make any difference in the mean scores in NPST (22). However, another study returned higher mean scores in the sub-dimensions of information and communication support and respect support for the parents of male children (23). This may be interpreted as a cultural difference whereby the gender of the child still bears some weight in some countries or population segments. In this study, it was determined that the mean scores of both parents for NPST and its sub-dimensions were similar (Table III). Contrary to the findings of this study, Sanjari et al. (9) found that fathers had a higher mean score in the sub-dimension of providing quality care in comparison to mothers.

It was found that illiterate parents scored higher in the sub-dimension of information and communication support and their mean score had a significant difference. Parents with a university degree had a higher mean score in the emotional support sub-dimension and the mean total score of their NPST and the difference with other parents was significant (Table III). In line with these finding, it can be suggested that each group had a stronger perception of the kind of support needed by them, as seen by the fact that illiterate parents needed information more than anything else since they had difficulty in accessing information regarding the illness, but those parents with a university degree needed more social circle support with regard to the illness and its daily life impact. Contrary to this result, Sanjari et al.'s (9) study shows that as the level of education increases, the mean score for the emotional support sub-dimension of the NPST decreases and there is no significant difference in the mean scores of the other sub-dimensions. In the study conducted by Yılmaz (24), it was determined that those parents who had just graduated from primary school had higher NPST scores. Another study found no difference between the parents' level of education and their mean total scores in NPST and its mean sub-dimension scores (25).

In this study, it was determined that the difference between the income levels of the parents and the total mean scores of the support given by the nurse was insignificant (Table III). These findings suggest that the average support provided by nurses in terms of information, emotion, respect, and care is perceived similarly by parents regardless of their economic and employment status. In their study, Akkoyun and Tas Arslan (25) reported that mothers with high income levels had lower total mean scores for NPST. However, some other studies showed no correlation between the parents' levels of income and their mean total scores for NPST and its sub-dimensions (9,25,26).

In the results of this study, it can be seen that the emotional support and respect support sub-dimension mean scores were also higher in addition to the NPST mean score of those parents who stated that they had knowledge about the disease (Table III). This result suggests that those parents who were adequately informed on the illness perceived better nurse-given support in terms of coping with the daily life impact of the illness and care of their children.

Those parents who received support from their social circle scored higher in the sub-dimensions of emotional support, and providing quality care, and also their total mean scores of NPST (Table III). This suggests that nurse support is one of the most important factors in the concept of social support for parents.

In this study, it can be seen that there is a strong positive correlation between nursing support and the scores of illness management and the daily life of the child and parental agreement and a strong negative correlation with the difficulties of life and the impact of illness sub-dimensions (Table IV). Although there are no studies comparing nurse given support and disease management, similar studies have shown that support given by nurses plays an important role in the management of the disease for the child and the family (9-11). This result shows the positive effect of the nurses' support given to the parents on the daily life of the child's illness and on the relationship between the parents.

Study Limitations

This study was only conducted with the parents of child patients hospitalized in the PICU of a hospital and cannot be generalized to the universe.

Conclusion

In conclusion, the management of childhood chronic conditions improves in parallel with the parents' perception of nurse support. Therefore, it is of utmost importance for nurses to encourage parents to participate in the care of their child and help them understand the healthcare and treatment processes given to their child. It is also crucial to provide information in a straightforward manner and with clear language.

Acknowledgments

The authors are grateful to the parents of the child patients hospitalized for their participation in this study. They also wish to thank Mr. David F. Chapman for editing this manuscript.

Ethics

Ethics Committee Approval: This study was approved by the Okan University Ethics Committee (approval number: 96, date: 04.07.2018).

Informed Consent: The parents were informed about the research and their written consent was obtained.

Peer-review: Externally peer-reviewed.

Authorship Contributions

Concept: G.U., H.A., Data Collection and/or Processing: H.A., G.U., Statistical Analysis: H.A., G.U., Literature Review: G.U., H.A., Writing: G.U., H.A.

Conflict of Interest: The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Financial Disclosure: The author(s) received no financial support for the research, authorship and/or publication of this article.

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