

RESEARCH ARTICLE

Psychosocial Problems and Unfulfilled Care Needs of Hospitalized Children as Perceived by Their Parents

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Abstract

Objective: The objective of this study was to determine psychosocial problems and care needs of hospitalized children as perceived by their parents.

Methods: This descriptive study was performed with parents of 124 children receiving treatment in pediatric clinics of a university hospital. Data were gathered with Descriptive Characteristics Form for Parents and Children and Research Information Form.

Results: Of all the parents included in the study, 65,3% reported being anxious, 62,1% reported being unhappy, 46% reported their children were anxious, 42,7% reported their children experienced problems with their eating habits and 41,9% reported their children continuously cried. 56,5% of the parents revealed the nurses were not available, 58,9% revealed their informed consent was not obtained before the procedures, 66,9% revealed they were not listened effectively, 72,6% revealed their children's consent was not obtained before the procedures, 77,4% revealed their children were not allowed to express their opinions and 82,3% revealed their children were not listened effectively.

Conclusion: The parents were found to have such psychosocial problems as anxiety, unhappiness, continuously wanting to cry, fear and despair and their children were found to have such psychosocial problems as anxiety, problems with eating habits, continuously crying and fear. In addition, both parents and children had insufficiently fulfilled psychosocial needs concerning informed consent, effective listening and expressing their opinions.

Key words: Child, Parents, Nursing, Psychosocial problems, Care needs.

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Introduction

Staying in hospital is perceived as a negative experience and can cause various emotional reactions (Ofiaz and Vural, 2010). Along with the health problem experienced, it affects emotional processes and predisposes psychosocial problems especially in children (Atay et al., 2011; Ustun et al., 2014; Longhi et al., 2015). They face strangers, are exposed to painful interventions and experience various psychosocial problems, which affects their behavior. It may lead them to have fears and anxiety and worsen their pain and discomfort (Ustun et al., 2014; Longhi

et al., 2015). To what extent children are affected by hospitalization is closely related to many factors such as their age, cognitive development, prior experiences and attitudes of their family (Gunduz et al., 2016). It has been revealed in several studies that children can have several hospitalization-related problems and perceive medical interventions as a reaction to their misbehavior (Gonener and Gorak, 2009; Gunduz et al., 2016). It has also been suggested that they may not completely satisfy their sleeping needs in hospital (Kostak et al., 2016). In a study by Sen-Beytut et al., children were found to picture hospital as something negative and have a higher rate of depression and low self-esteem (Sen-Beytut et al., 2009).

Although psychosocial functions of parents are important for physical and mental health outcomes of children (Commodari, 2010), hospitalization of children affects parents as much as children (Aykanat and Gozen, 2014; Celebi et al., 2015; Gunay et al., 2017). Treatment of children in hospital causes parents to think their children have a severe health problem. Also, increasing care needs of children, restricted daily life and lack of clarity about disease prognosis can lead to fear and anxiety in parents (Cakan and Sezer, 2010). Frequent and long hospital stays increase support needs of families (Arikan et al., 2014). A considerable change in daily life along with restlessness appearing during the disease process creates the risk of affecting caregiving parents. It is a fact that most of the mothers whose children stay in hospital need psychological support (Cakan and Sezer, 2010). It has been shown in the literature that parents whose needs are unmet and who have other children along with an unhealthy child, have low incomes, have children with chronic diseases, do not have an occupation and stay in hospital for a long time require psychosocial support (Tehrani et al., 2012; Arikan et al., 2014; Beyazit, 2017). It has been reported in some researches in Turkey that mothers' perceived inability for they have not been informed about the care of children by nobody, they can not ask questions related to maintenance and treatment, can not reach a nurse (Okyay, 2009; Turan et al., 2006). This highlights the importance of a family-centered care approach that aims to meet the needs of parents and children in nursing services offered in a hospital environment (Cooper et al., 2007). However, there have been few studies to deal with how care needs should be fulfilled (Lye, 2010; Aykanat and Gozen, 2014; Tosun and Tufekci, 2015). Determining the needs and psychosocial problems of parents about themselves and their children is important in terms of providing data to family-centered care practices of

nurses working with children clinically and academically. Therefore, the present study was performed to determine psychosocial problems and unmet care needs perceived by parents whose children stay in hospital.

Methods

Study Design

The study has a descriptive design.

Study Setting and Sampling

The study was carried out on parents of 124 children receiving treatment between June and August in 2018 in pediatric diseases clinics of a university hospital in the Black Sea Region of Turkey. No sampling method was used. One hundred and twenty-four parents with children receiving treatment in hospital in the study period, being the primary caregivers of their children, not having any mental disabilities, able to communicate verbally and accepting to participate in the study were included in the study. Before conduction of the study, the sample size was determined by using G-power program as described in the literature. It was found to be 124 individuals so that the study should have the confidence interval of 95% and power of 80% (Beyazit, 2017). The data collection process was completed when the determined number was reached.

Data Collection

Data collection was performed by using Descriptive Characteristics Form for Parents and Children and Research Information Form. The forms were administered to illiterate parents at face-to-face interviews and literate parents were asked to fill in the forms individually.

Descriptive Characteristics Form for Parents and Children: This form, created by the researchers, is composed of 11 questions about sociodemographic characteristics of the parents and children included in the study (age, gender, education etc.).

Research Information Form: This form was developed by the researchers in light of the literature (Inal and Akgun, 2003; Gultekin and Baran, 2005; Erdim et al., 2006; Basbakkal et al., 2010) to determine psychosocial problems of and care offered to parents and their children receiving treatment in hospital as perceived by the parents.

Data Analysis

Data gathered were analyzed with SPSS 20.0 and descriptive statistics (frequencies, mean values and percentages).

Ethical Considerations

Ethical approval was obtained from the ethical committee of a university for clinical research and written permission was taken from the directorate of the university hospital.

Results

The mean age of the parents was 33,46±8,18 years. Of all the parents, 51,6% had primary education, 56,5% were living in a small town and 42% had two children. The mean length of hospital stay in the children was 13.25±23.87 days. Of all the children, 57,3% were aged 0-6 years, 61,3% were male, 53,2% had stayed in hospital before, 91,1% did not have an accompanying disease and 59,7% had a chronic disease diagnosed (Table 1).

Based on the distribution of the children by their diseases diagnosed, 41.9% had hematological-oncological diseases (Figure 1).

Table 1. The Distribution of Descriptive Characteristics of the Parents and Children

Characteristics of Parents		Number	%
Mean age (yrs.)= 33,46±8,18 (Min. 18- Max. 61)			
Gender	Female	112	90,3
	Male	12	9,7
Education	Illiterate	6	4,8
	Primary education	64	51,6
	High school	32	25,8
	University	22	17,8
Place of living	City	43	34,6
	Small town	70	56,5
	Village	11	8,9
Number of Children	One	35	28,2
	Two	52	42,0
	Three or more	37	29,8
Characteristics of Children			
Mean length of hospital stay (day)= 13,25±23,87 (Min. 1- Max. 150)			
Age (yrs.)	0-6	71	57,3
	7-12	32	25,8
	13-18	21	16,9
Gender	Female	48	38,7
	Male	76	61,3
Prior hospital stay	Yes	66	53,2
	No	58	46,8
Having an accompanying disease	Yes	11	8,9
	No	113	91,1
Having a chronic disease	Yes	74	59,7
	No	50	40,3

%; Percent

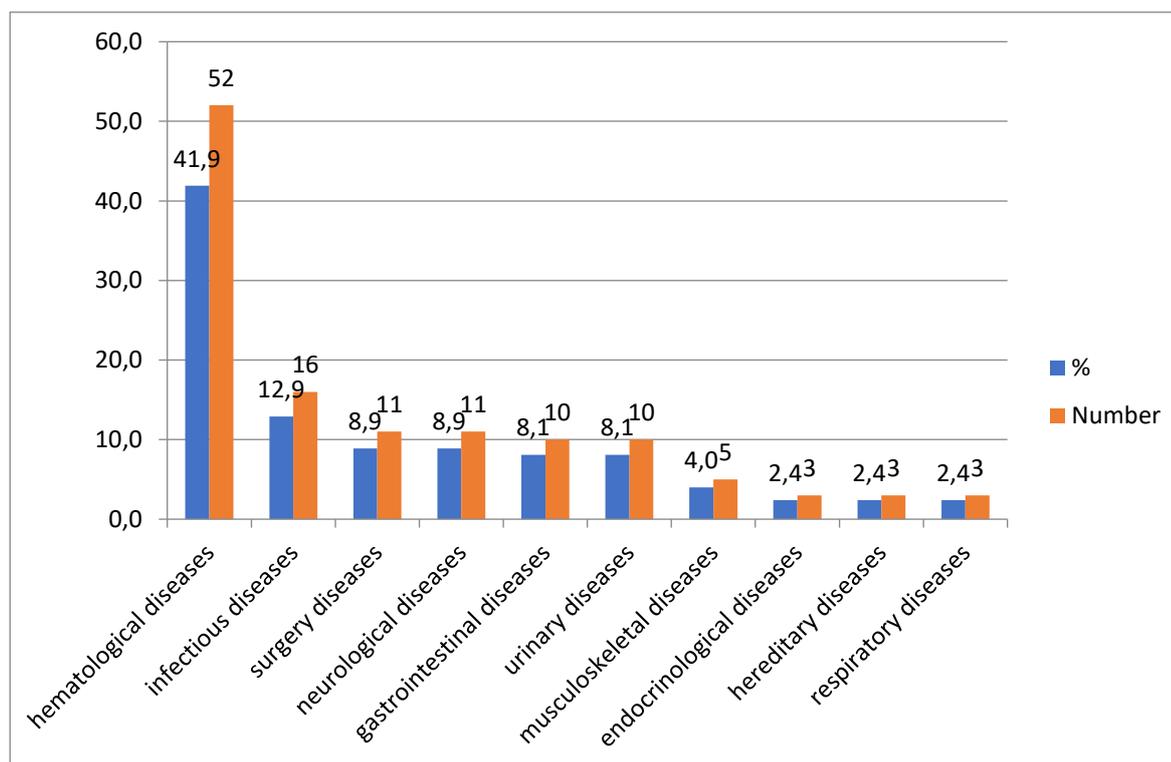


Figure 1. The Distribution of the Children by their Diagnosis

Table 2. The Distribution of the Psychosocial Problems of Hospitalized Children and the Parents as Perceived by the Parents

Perceived Psychosocial Problems of the Parents	YES		NO	
	Number	%	Number	%
Anxiety	81	65,3	43	34,7
Unhappiness	77	62,1	47	37,9
Continuously wanting to cry	57	46,0	67	54,0
Fear	57	46,0	67	54,0
Despair	50	40,3	74	59,7
Anger	34	27,4	90	72,6
Loneliness	28	22,6	96	77,4
Hopelessness	16	12,9	108	87,1
Wanting to rebel	13	10,5	111	89,5
Psychosocial problems of children as perceived by their Parents				
Anxiety	57	46,0	67	54,0
Problems with eating habits	53	42,7	71	57,3
Continuously crying	52	41,9	72	58,1
Fear	50	40,3	74	59,7
Dependency on parents	43	34,7	81	65,3
Unhappiness	40	32,3	84	67,7
Problems with sleeping habits	38	30,6	86	69,4
Aggressiveness	35	28,2	89	71,8
Anger	35	28,2	89	71,8
Becoming introverted	25	20,2	99	79,8
Acting like a baby	23	18,5	101	81,5
Rejecting treatment	21	16,9	103	83,1
Problems with urination /defecation	15	12,1	109	87,9
Difficulty in communication	11	8,9	113	91,1

#: Percent

Table 3. The Distribution of Care Services Offered to Hospitalized Children and their Parents as Perceived by the Parents

Care Services offered to the Parents	YES		NO	
	Number	%	Number	%
Offering adequate and accurate information	85	68.5	39	31.5
Smiling	64	51.6	60	48.4
Accessibility of the nurse	54	43.5	70	56.5
Receiving consent before procedures	51	41.1	73	58.9
Effective Listening	41	33.1	83	66.9
Allowing parents to express their opinions	40	32.3	84	67.7
Effective communication	35	28.2	89	71.8
Care Services offered to the Children				
Offering adequate and accurate information	67	54.0	57	46.0
Smiling	56	45.2	68	54.8
Creating a safe environment	45	36.3	79	63.7
Receiving consent before procedures	34	27.4	90	72.6
Establishing eye-contact	32	25.8	92	74.2
Allowing the children to express their opinions	28	22.6	96	77.4
Effective listening	22	17.7	102	82.3
Playing a game	13	10.5	111	89.5

#: Percent

Of all the parents, whose children stayed in hospital, 65,3% reported feeling anxious, 62,1% reported feeling unhappy, 46% reported having fears and wanting to cry continuously, 40,3% reported experiencing despair, 27,4% reported having anger, 22,6% reported feeling lonely, 12,9% reported experiencing hopelessness and 10,5% reported wanting to rebel (Table 2).

As perceived by the parents, out of all the children, 46% had anxiety, 42,7% had problems with their eating habits, 41,9% continuously cried, 40,3% had fears, 34,7% became dependent on their parents and 32,3% were unhappy. In addition, of all the children, 30,6% had problems with their sleeping habits, 28,2% displayed aggressiveness and anger, 20,2% became introverted, 18,5% acted like a baby, 16,9% rejected treatment, 12,1% experienced changes in urination/defecation and 8,9% had communication problems (Table 2).

In addition to psychosocial problems, whether the care services for parents and children were fulfilled was examined. Although more than 50% of the parents gave a positive feedback about fulfillment of care services, 31,5% of the parents revealed that the nurses did not provide them with adequate and accurate information and 48,4% of the parents revealed the nurses did not smile. In addition, 56,5% of the parents reported the nurses were not accessible, 58,9% of the parents reported their informed consent

was not taken before procedures, 66,9% of the parents reported not being listened effectively, 67,7% of the parents reported not being allowed to express their opinions and 71,8% of the parents reported an effective communication was not established with them (Table 3).

Concerning fulfillment of care services for children as perceived by the parents, although 54% of the children were given adequate and accurate information, 54,8% of the children were not smiled at. Furthermore, a safe environment was not created for 63,7% of the children, informed consent was not obtained from 72,6% of the children, 74,2% of the children were not allowed to express their opinions, 82,3% of the children were not listened effectively and health professionals did not play a game with 89,5% of the children (Table 3).

Discussion

It has been reported in the literature that family-centered care practices are very important in terms of meeting the needs of families, giving the most appropriate service to their expectations and speeding up the recovery process by reducing the anxiety of the children and their family (Ahhmann, 2001; Ocakçı, 2006; Cooper et al., 2007; Dunst et al., 2007; Davidson et al., 2017). Researches with hospitalized children and their parents will make easier planning of family-centered care practices. The present study

was performed to determine care needs concerning psychosocial problems perceived by parents whose children stay in hospital.

More than half of the parents reported that they felt anxious and unhappy. Nearly half of the parents continuously wanted to cry, had fears and experienced despair (Table 2). Parents may face many stressors including inability to fulfill their roles and needs during hospital stay of their children (Beyazit, 2017). Some care needs and unclear disease processes due to hospitalization of their children may cause parents to experience some psychosocial problems such as anxiety, restlessness and unhappiness (Cakan and Sezer, 2010). In a study by Erdim et al., 84,2% of the parents with hospitalized children reported feeling anxious about diseases of their children during hospital stay (Erdim et al., 2006). However, a very low rate of these parents (20%) received support for their problems. This may lead the parents to have despair. Gonener and Pek also showed that parents became anxious when they heard their children were hospitalized and when their children stayed in hospital (Gonener and Pek, 2009). Similarly, Günay et al. reported that mothers whose children stayed in hospital had high state and trait anxiety levels (Gunay et al., 2017) and that their children's becoming ill and staying in hospital was an important source of fear for the mothers.

As reported by the parents, about half of the children were anxious, had disrupted eating habits, were continuously crying and had fears (Table 2). It has been pointed out in the literature that children have different moods about and respond differently to staying in hospital (Gonener and Gorak, 2009; Basbakkal et al., 2010; Atay et al., 2011; Celebi et al., 2015; Gunduz et al., 2016; Akkavak and Karabudak, 2019). Staying in a different environment, different devices and tools, painful interventions, disease symptoms and presence of crying children may result in several psychosocial problems in children (Celebi et al., 2015). Atay et al. reported that diseases and resultant hospitalizations cause psychosocial stress which has a negative effect on child development (Atay et al., 2011). In Basbakkal et al.'s study, hospitalized children were found to have sleeping and nutrition problems, inability to adjust to the new environment and people and bed-wetting and fears (Basbakkal et al., 2010). In Gonener and Gorak's study, 88,3% of the hospitalized children were anxious about their hospitalization and diseases. In addition, the children thought they would be separated from their friends, die, and suffocate when

they wore an oxygen mask, which caused them to have a fear (Gonener and Gorak, 2009).

In the present study, unmet care needs of hospitalized children and their parents were examined. About half of the parents revealed that they were not offered adequate and accurate information and that health professionals did not have a smiling face. More than half of the parents reported that they could not access health professionals, were not asked to give informed consent before procedures, were not listened to and communicated with effectively and were not allowed to express what they thought (Table 3). Satisfaction of hospitalized patients and families is an important element of the quality of care given (Lye, 2010). Family-centered care should be adopted to maintain the quality of care. This allows parents to actively get involved in care of their children and making decisions about their children and have adequate information about their children (Aykanat and Gozen, 2014). Based on evidence in their study, Sener and Karaca drew the conclusion that mothers expected nurses to be friendly and to provide emotional support concerning their problems and anxiety (Sener and Karaca, 2017). In Arıkan et al.'s study, more than half of the family caregivers in pediatrics clinics (56,9%) reported that nurses were the first to refer to when they had problems and more frequently expected nurses to smile, have tolerance and show interest (Arıkan et al., 2007). Tosun and Tüfekci reported that most of the parents with children receiving treatment in hospital were requested to give their consent and that most of the mothers actively participated in decision-making about procedures, could ask questions to nurses, share their anxiety about their children and fulfill their needs (Tosun and Tufekci, 2015). However, Erdim et al. found in their study that 80% of the mothers with hospitalized children could not receive support from health professionals (Erdim et al., 2006). In addition, Boztepe and Cavusoglu discovered that mothers did not have adequate information about care for their children, could not get involved in decisions concerning their children, could not ask questions about treatment of their children and could not share their anxiety with nurses (Boztepe and Cavusoglu, 2009). Arıkan et al. found that parents whose needs in hospital were not fulfilled got significantly low scores for satisfaction with technical skills and emotional needs (Arıkan et al., 2014). In the present study, more than half of the children were diagnosed with a hematological-oncological disease. The high rate of the parents with unfulfilled care needs suggests their care needs increased depending on

diagnoses of their children. The findings also showed that the parents needed psychosocial care involving in-depth acting and motivation in addition to standard nursing approaches (Table 3).

In the current study, nearly half of the parents reported that nurses did not give sufficient and correct information to their children and most of the parents revealed that nurses did not smile at their children, create a safe environment for their children, obtain informed consent from their children, make an eye contact with their children, let their children talk about their opinions, listen to the children effectively or play with the children (Table 3). Akkavak and Karabudak found that most of the children staying in hospital were afraid of nurses, confused and curious and excited due to lack of information. Also, some children revealed that they were not given information, which caused them to feel uncomfortable and depressed, and get confused about what to do since their curiosity was not satisfied (Akkavak and Karabudak, 2019). Providing hospitalized children with necessary care can not only support child development but also contribute to solution of psychosocial problems (Atay et al., 2011). Interventions directed towards fulfilling children's needs and active involvement of families in the care process are important to offer this care (Er, 2006). Nurses' smiling, being tolerant, communicating with children face-to-face during hospital stay can reduce negative effects of the hospital environment on children (Teksoz and Ocakçı, 2014). Several studies have also attracted attention to the role of nurses' positive interactions in psychosocial adaptation of children during their treatment (Coyne, 2006; Pena and Cibanal, 2011). Furthermore, it has been reported that parents want health professionals to play with their children in hospital and that games have positive effects on both children and their parents (Arslan et al., 2013; Teksoz and Ocakçı, 2014).

Conclusion

In light of the results of this study, which was performed to determine psychosocial problems and unmet care needs perceived by parents of children staying in hospital, the following conclusions were reached:

- Psychosocially, the parents experienced anxiety, unhappiness, fear and despair and continuously wanted to cry and the children had anxiety, fear and nutritional problems and continuously cried as perceived by their parents.
- The parents' needs for adequate and accurate information, smiling and accessible health

professionals, informed consent, effective listening, opportunities to express their opinions and effective communication were not fulfilled sufficiently; unmet care needs of children as perceived by the parents were concerned with provision of adequate and accurate information, smiling, safe environment, informed consent before procedures, eye-contact, opportunities to express their opinions, effective listening and playing games.

Based on the abovementioned conclusions, the following recommendations can be made:

- Nurses should implement primary, secondary and tertiary measurements against psychosocial problems likely to appear in children receiving treatment in hospital and their parents,
- Inservice training programs should be planned to improve psychosocial care, creative activities and verbal and nonverbal communication skills of nurses working with children having health problems.
- Needs-centered care should be provided for children and their parents, who should be involved in care-giving processes.

Ethics committee approval: Ethics committee approval was received for this study from Ondokuz Mayıs University Clinical Research Ethics Committee.

Peer-review: Externally peer-reviewed.

Author Contributions: Concept -OSO; Design OSO, ET, II, MA; Supervision OSO, ET, II, MA; Materials- OSO, ET; Data Collection and/or Processing- II, MA; Analysis and/or Interpretation- OSO, ET; Literature Review- OSO, ET, II; Writing- OSO, ET; Critical Review- OSO, ET, II, MA.

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