

Assessment of Nutritional Problems in Pediatric Patients with Cancer and the Information Needs of Their Parents: A Parental Perspective

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ABSTRACT

Objective: The majority of problems and symptoms occur in the gastrointestinal system in children with cancer. Parents have difficulty in coping with the nutritional problems and changing routines of children and need support in this respect. This study aimed to assess the nutritional problems of children with cancer and the information needs of their parents.

Methods: This descriptive study was performed among children with cancer aged 3–18 years and their parents ($n = 69$). The data were collected through a data collection form developed by the researchers based on the literature. **Results:** The most prominent nutritional problems experienced by children were loss of appetite (85.5%), nausea (84.1%), vomiting (81.2%), fatigue (79.7%), and mucositis (66.7%). According to the parents, the factors causing these nutritional problems in

children were physiological factors (100%) and the foods given to children in the hospital (65.2%). The parents mostly needed information about food–drug interactions (58.0%), food–disease interactions (52.2%), foods that children with neutropenia should avoid or should eat (neutropenic diet) (46.4%), and frequency of nutritional intake (36.2%). **Conclusions:** This study has shown that most children experience at least one nutritional problem, and the parents need comprehensive and regular information about nutrition. Pediatric oncology nurses have a significant responsibility in the evaluation, education, and monitoring of these children.

Key words: Childhood cancer, education, nursing, nutrition, symptoms

Introduction

Cancer is the second most common cause of death among children. An estimated 1190 cancer deaths are expected to occur among children 0–14 years of age in 2017.^[1]

Cancer and its treatment cause physical, psychosocial, and neurocognitive problems and symptoms in children that

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affect several body systems.^[2] The majority of problems and symptoms occur in the gastrointestinal system (GIS). Children diagnosed with cancer often experience symptoms such as taste change, pain, nausea/vomiting, constipation, and diarrhea.^[3] The treatments may cause symptoms that lead to deterioration in diet and undernourishment by stimulating the vomiting center; disrupting the oral mucosa membrane; and causing aversion to food, early satiety, malabsorption, and impairment in bowel motility. Problems and symptoms of the GIS track include dry mouth due to a reduction in saliva production, changes in taste, difficulties in swallowing, irritation of GIS, nausea, and vomiting.^[3-6]

Pöder *et al.*^[7] indicated that one of the most frequently experienced problems during cancer treatment is associated with malnutrition. Malnutrition is frequently seen in childhood cancers due to the tumors, treatment-related factors, and long-term changes in eating habits. Since children have more nutritional requirements for growth and development, they are more vulnerable to malnutrition than are adults. The incidence of malnutrition in pediatric oncology patients is between 6% and 50%.^[8-10]

Malnutrition in children diagnosed with cancer may be affected by factors such as the hospital environment, moving away from a familiar environment, changes in routines, an inability to adapt to a diet, inadequate information about issues other than the disease, and treatment. Parents need to be informed on issues about diet and nutrition, including what foods should be consumed by children and how foods should be prepared during the treatment process. A lack of information causes anxiety in families.^[5,10,11] Nutrition is especially important for children with cancer to get the proper nutrients they need. The nutritional needs of children with cancer vary from child to child and implementation of a proper nutritional regimen before, during, and after treatment can help a child feel better and stay healthy. The dietary regimen for children with cancer should meet the needs of the children. A diet should include the major food groups with high nutritional qualities and include healthy and natural food. Furthermore, foods should be prepared properly (e.g., hygienically), especially when a child's white blood cell count is low.^[12]

To enhance the supportive care of children with cancer and their parents, it is essential to determine the information needs and experiences of parents regarding the nutritional regimen. Along with changing treatment protocols and clinical approaches, the nutritional problems seen in children will change. By determining parents' perception of children's nutritional problems and information requirements, the quality of care will increase. This study is important in terms of providing up-to-date information in the literature, as it assesses the nutritional problems of

children with cancer and information needs of parents from the parental perspective.

This research aimed to assess (a) the nutritional problems and causes of these problems in children with cancer from the parents' perspective and (b) the nutritional information needs of the parents.

Methods

Design and sample

A quantitative descriptive study design was used to describe parents' perceptions of the nutritional problems experienced by their children with cancer and their own nutritional information needs. A study was conducted in the pediatric hematology and oncology clinic of a university hospital located in Ankara, Turkey, between February 15, 2014, and July 31, 2015. A sample selection was not conducted; therefore, all participants who met the inclusion criteria were included in the study.

The participants included parents who had a child (a) between 3 and 18 years of age, (b) hospitalized during treatment, (c) treated for cancer for at least 1 month, (d) able to take oral nutrition, (e) who spoke and understood Turkish, and (f) who agreed to participate in the study. Because verbal expression ability is not fully developed in children under 3 years of age,^[13] parents may not be able to effectively assess children's nutritional problems and related factors. For this reason, we have included children 3–18 years old in the study. In the study period, a total of 73 parents were contacted during the research process. One parent who spoke no Turkish, another two who did not agree to participate in the research, and one child who received total parenteral nutrition were excluded from the sample. Thus, the research sample comprised of 69 parents (participation rate was 94.5%).

The hematology and oncology ward has a 24-bed capacity, and nine registered nurses work in the ward. Children (aged 0–18 years) are monitored mostly for diagnoses of leukemia, lymphoma (Hodgkin's lymphoma, non-Hodgkin's lymphoma), bone tumors, Wilms tumor, and intracranial mass. Nurses provide verbal information to the parents in the ward about the diet for neutropenic children. The oral health care of the children is monitored on a regular basis. There is no special symptom assessment and management protocol in the ward. A neutropenic diet is administered to children if their absolute neutrophil count is lower than 1500/mm³. All patients are informed about a neutropenic diet at the beginning of their therapy.

Procedure

After obtaining approval to approach participants from the hospital and ethics committee, a research assistant visited

parents in the ward and informed them of the purpose and procedure of the study. Among parents who agreed to participate, a data collection form was administered by the researchers through face-to-face interviews. Nutritional symptoms, the perceived causes of problems, and nutritional information needs of the parents were collected from parent reports. In addition, data related to diagnosis and treatment were obtained from medical records. The forms were completed in approximately 30 min.

Ethical consideration

Written permission from the hospital and ethics approval was received from G. U.'s Ethics Committee for Noninvasive Clinical Trials (Ref. No. 25901600-1927). In addition, verbal and written consent was obtained from the parents.

Measurement/instrument

Data were collected using a data collection form developed by the researchers based on the literature,^[5,6,14,15] and the forms were also reviewed by five experts, of whom two were associated professors in nursing and three had a master's degree in pediatric nursing. The overall validity of the questionnaire ranged from 0.70 to 1.00, and the majority of the questions were at the high level. In addition, based on the experts' feedback, the choice of "other" was added to each question, and examples were added for the physical causes of the nutritional problems children experienced.

The data collection form comprised of four sections: (1) Descriptive data about the child and parents (eight items on age, gender, educational status, income level, etc.), (2) data about the disease and treatment of the child (six items on the child's diagnosis, age at diagnosis, duration of treatment, etc.), (3) data on the child's nutritional problems (ten items about stomatitis, diarrhea, constipation, nausea, vomiting, causes, etc.), and (4) data about the information needs of the parents (ten items on the education received about nutrition, information needs, food hygiene, food preparation, child's diet, etc.). The data about the causes of the nutritional problems children experienced were collected using open-ended questions.

Data analysis

The data were evaluated using the SPSS 16.0 software package (SPSS for Windows, Version 16.0. Chicago, SPSS Inc. Chicago, IL, USA). The frequencies, percentages, averages, minimums, maximums, and standard deviations were calculated for the individuals that were included in the study. The open-ended questions were evaluated, and the answers grouped by two nurses specialized in pediatric nursing separately and simultaneously. The internal consistency was examined between specialists' evaluations.

The agreement between the specialists was evaluated using the kappa test. The agreement between the specialists was substantial ($\kappa = 0.748, P = 0.001$).

The Kappa result was interpreted as follows: values of ≤ 0 indicated no agreement, 0.01–0.20 indicated none to slight, 0.21–0.40 indicated fair, 0.41–0.60 indicated moderate, 0.61–0.80 indicated substantial, and 0.81–1.00 indicated almost perfect agreement.^[16] The alpha level was set as < 0.05 for the statistical tests.

Results

Descriptive information about the children and parents, including data about the disease and treatment, is shown in Table 1. Although not indicated in the table, the majority of children (60.9%) only received chemotherapy. Data

Table 1: Descriptive information about the children and families (n=69)

Variables	n (%)
Child's age (years)	9.71±4.94 (3-19)
Mother's age (years)	36.46±6.17 (23-50)
Father's age (years)	39.95±5.73 (28-54)
Child's gender	
Male	45 (65.2)
Female	24 (34.8)
Child's education	
Not at school age	26 (37.7)
Break school	24 (34.8)
Not continuing school	4 (5.8)
Continue to school	15 (21.7)
Family income*	
Expenses more than income	11 (15.9)
Income is equal to expenses	52 (75.4)
Income more than expenses	6 (8.7)
Data about the disease, treatment, and nutrition (n=69)	
Variables	n (%)
Age at diagnosis (years)	8.91±5.12 (0.4-17.5)
Treatment duration (years)	0.78±1.01 (0.1-6.50)
Hospitalization duration (days)	16.97±26.16 (1-120)
Diagnosis of child	
Leukemia	31 (44.9)
Solid tumor	18 (26.1)
Central nervous system	11 (15.9)
Lymphoma	8 (11.6)
Others	1 (1.4)
Treatment**	
CT	67 (97.1)
RT	17 (24.6)
Surgery	19 (27.5)
HSCT	5 (7.2)
Nutrition type	
Normal diet	42 (60.9)
Neutropenic diet	27 (39.1)

*Assessment about family income is made according to the parents' expressions, **The percentage of each item is taken out of n=69 and some children may receive more than one treatment. SD: Standard deviation, HSCT: Hematopoietic stem cell transplantation, CT: Chemotherapy, RT: Radiotherapy

were mostly collected from mothers (85.7%). The parents stated that the most prominent nutritional problems that their children experienced were loss of appetite (85.5%), nausea (84.1%), vomiting (81.2%), fatigue (79.7%), and mucositis (66.7%) [Table 2].

According to the parents, the factors causing the nutritional problems in children were as follows: physiological factors (100%) (related to the adverse effects of diagnosis and treatment), the foods given in the hospital (65.2%) (insufficiently hygienic foods, foods with unpleasant flavors or smells, and inappropriate portion sizes and presentation of foods for children), hospital environment (31.9%) (being in the hospital, alteration in meal routines, and overcrowded patient rooms with unpleasant smells), and emotional factors (13.0%) (feelings of being under stress; separation from home environment; and missing their parents, siblings, and friends) [Table 2].

The parents mostly needed information about food–drug interactions (58.0%), food–disease interactions (52.2%), foods that children with neutropenia should avoid or eat (neutropenic diet) (46.4%), and frequency of nutrition (36.2%) [Table 3]. Furthermore, parents stated that the education they received at the initiation of treatment was not sufficient, and they needed a more comprehensive and regular education. While not indicated in the table, 81.2% of the parents stated that, at the time of diagnosis, they received information about the nutrition of their child from a nurse (56.5%).

Discussion

Several physical and psychosocial problems and symptoms at the beginning of the disease, during, and even after treatment were observed in children with cancer, related to the disease and the treatment protocols.^[6,8,17] The disease and its treatment lead to changes in the daily routines of children, especially in nutrition, eating habits, and appetite. Parents experience difficulties in coping with the changing routines and nutritional problems of their children and need to be supported.^[7]

This research aimed to assess the nutritional problems of children, the causes of these problems, and the information needs of their parents from the parents' perspective. Previous research has demonstrated that children experience critical nutritional problems because of the treatment's damage to their organs and body systems.^[18-20] This research showed that all the children experience at least one nutritional problem, and the most frequent problems were loss of appetite (85.5%), nausea (84.1%), vomiting (81.2%), fatigue (79.7%), and mucositis (66.7%). Robinson *et al.*^[19] demonstrated that symptoms such as nausea/vomiting or decline in oral intake (90%), mucositis (57%), and pain (76%) showed

Table 2: Children's nutritional problems and causes thereof from parents perspective (n=69)

Problems*	Prevalence, n (%)**
Appetite loss	59 (85.5)
Nausea	58 (84.1)
Vomiting	56 (81.2)
Fatigue/weakness	55 (79.7)
Mucositis	46 (66.7)
Constipation	32 (46.4)
Diarrhea	27 (39.1)
Pain	27 (39.1)
Taste alteration	21 (30.4)

The causes children's nutritional problems

Causes†	Prevalence, n (%)
Physiological factors‡	69 (100)
Factors related to hospital foods‡	45 (65.2)
Factors related to hospital environment‡	22 (31.9)
Emotional factors‡	9 (13.0)

*Assessment about nutritional problems is made according to the parents' expressions, **The percentage of each item is taken out of n=69, †Assessment about causes of nutritional problems is made according to the parents' expressions, ‡Explanations of the causes indicated in each item are given in the findings section

Table 3: The information needs of the parents (n=69)

Topics about information need*	n (%)**
Food/drug interactions	40 (58.0)
Food/illness interactions	36 (52.2)
What nutrients should/should not be eaten	32 (46.4)
Mealtime frequency	25 (36.2)
Mealtime	24 (34.8)
Food preparation and cooking	20 (29.0)
Food cleaning	19 (27.5)
Child's diet	16 (23.2)
Food preservation	15 (21.7)
Other†	14 (20.3)

*Assessment about needed information is made according to the parents' expressions, **The percentage of each item is taken out of n=69, †Intervention about appetite loss (n=3), information about compliance to diet (n=5), information resources after discharge (n=6)

higher rates than did other symptoms. The results obtained by Tah *et al.*^[21] suggested that the loss of appetite (89.2%), vomiting (81.1%), and nausea (54.1%) were the most frequent problems of children diagnosed with a solid tumor. In addition, Hedén *et al.*^[22] stated that pain, feeling sad, and nausea are initially the most distressing symptoms according to parents. Dupuis *et al.*^[23] found that the most prevalent symptoms were mood swings (85%) and fatigue (80%), while nutritional problems such as nausea (69%) and loss of appetite (68%) were relatively less prevalent than were others. It is thought that the diagnosis of the child, type and duration of the treatment, and the child's individual characteristics are the source of the differences in symptoms and symptom frequency documented in previous research.

In addition to physical factors such as diagnosis and treatment, emotional and environmental factors play a

role in the development of nutritional problems in these children.^[7,10] In this research, parents stated that the problems children experienced were due to factors such as the unpleasant smell, inappropriate portion size, and presentation of the foods given in the hospital; being in hospital; and separation from their family, friends, and home. Similarly, Ruland *et al.*^[6] showed that children who are hospitalized for a long time were emotionally affected due to changes in their routines, longing for their social environment (school, family, friends, etc.), and reluctance to stay in the hospital. Nurses stated in Skolin *et al.*^[24] that displeasure with the meals given in the hospital is one of the basic reasons for a loss of appetite in children. Previous research showed that parents stated that the meals in the hospital were not appetizing and were not properly prepared for children with cancer or their age group in general.^[10,25] As evidenced in much previous research, psychosocial factors can negatively affect the nutrition of children.^[25-27] Hospitalization is a main stress source for children with cancer because of changes in their daily routines and can affect them in many different ways. Nutritional problems are one of them. From this perspective, it is important in nursing care that the meals (flavor, taste, portion size, smell, etc.) and hospital environment (noise, light, odor, etc.) are arranged in accordance with the characteristics of the children's age group and particular emotional needs.

The study provides evidence that the parents feel uncertain about their children's nutrition and the proper selection of foods for their children. A neutropenic diet is implemented in most of the wards, even though its effect in preventing infections has not yet been supported. On the other hand, diet initiation time and food selection vary from one institution to another.^[28,29] Another point to remember is the negative effect of some foods on treatment due to their interactions with chemotherapeutic agents and their effect on absorption.^[30-33] Parents often experience uncertainty and doubt about nutrition during this process.^[5,11] This research documented that parents need information on food–drug and food–disease interactions, neutropenic diets, food preparation, and when a neutropenic diet should be started. Pöder *et al.*^[7] showed that parents needed to be supported and informed about nutritional issues for their children. In other research conducted by Arslan *et al.*,^[34] 40% of the parents stated that they needed information about the disease and nutrition. Even though parents were informed about nutrition at the onset of the children's disease, they needed regular and repetitive education due to the challenges caused by the disease. Health-care teams should provide comprehensive education to children and their families at the start of treatment. Regular education

on nutritional issues might reduce the concerns of children and families as well as the nutritional problems of children.

Strength and Limitations

Our examination of the nutritional problems, their causes, and parents' information needs about children's nutrition while children are being treated for cancer adds to the current literature on children with cancer. However, the study has several limitations. The research was conducted only in one center; therefore, the results cannot be generalized. The data about the nutritional problems, the causes of these problems, and information needs were based solely on the statements of parents. The thoughts, beliefs, and needs related to nutrition described by the parents might vary by individual, community, or culture. In this research, the relationship between the problems and the factors affecting causes of these problems has not been examined. Further research with a larger sample size is needed to examine these factors.

Conclusions and Implications

The results of this research indicate that loss of appetite, nausea, and vomiting are the most frequent problems according to parents' views. In addition, parents stated that the basic causes of nutritional problems are physiological and related to the foods given in the hospital. Parents who received education about nutrition after the diagnosis reported that this education was not sufficient and that they needed more comprehensive education covering several other matters.

Pediatric oncology nurses have a significant responsibility in terms of evaluation, education, and monitoring of these children and their parents. Educating parents, who experience uncertainty, on symptoms and their management, nutrition of children, and other related matters is one of the most important issues during nursing care of children undergoing cancer treatment. Importantly, children and their parents should be provided with information about nutritional concerns from the beginning of treatment. Furthermore, nurses should provide regular oral and written 24 h educational support and counseling using technological education materials for parents at the hospital and at home.

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Conflicts of interest

There are no conflicts of interest.

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