Children with cancer nutrition at home

Authors
RITA ALEXANDRA FERNANDES PIRES (corresponding author): MSc, RN. Centro Hospitalar São João (São João Hospital Center). Ermesinde, Portugal.
Address: Rua Júlio Dinis, n.º 126, 4445-488. Ermesinde, Portugal.
E-mail: ritaafpires@gmail.com
MARIA MARGARIDA DA SILVA REIS DOS SANTOS FERREIRA: PhD, MSc, RN. Escola Superior de Enfermagem do Porto (Nursing School of Porto). CINTESIS – Center for Health Technology and Services Research). Porto, Portugal.
E-mail: mrs@esenf.pt
CÂNDIDA DA ASSUNÇÃO SANTOS PINTO: PhD, MSc, RN. Escola Superior de Enfermagem do Porto (Nursing School of Porto). Porto, Portugal.
E-mail: candidapinto@esenf.pt

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Summary
The children nutrition is one of the problems that parents have to manage at home, after treatment of an oncological disease. Nutritional commitment may prolong episodes of neutropenia and compromise the effectiveness of treatments. The goals of this study were: to identify the needs of parents/caregivers in the management of children/adolescents nutrition with cancer undergoing chemotherapy treatment, at home; to characterize parental strategies in the management of children's nutrition at home, after chemotherapy. A qualitative, exploratory, descriptive and cross-sectional study was developed with eleven parents of children with cancer, who underwent chemotherapy treatment, after returning home. Data were collected through a semi-structured interview and analyzed according to Bardin. From the analysis of content emerged the domain The Life at Home and the category Nutrition. Home Life for parents of the child with cancer presents several challenges, particularly in nutritional management, in the face of reduced food intake and the new rules imposed by the neutropenic diet. Thus, parents resort to several strategies to manage this problem: recourse to new practices in food confectionery; changes in the diet of the whole family; insistence/verbal pressure; distraction; reward after negotiation; supply a varied and nutritious diet; questioning/accepting the food preference; organic food. Despite appealing to the multiplicity of strategies, the subjects of this study require the need for more structured support so that at home, they can respond to the challenges they face in their daily lives.

KEYWORDS: PARENTS; CHILD; NEOPLASMS; DIET; NURSING.

Introduction
Nutrition is essential to promote the growth and development of children, and when they have an oncological disease, it is critical to improve energy levels, minimize morbidity and improve quality of life[1,2]. The relevance of diet has been proven, in the prevention and improvement of the treatment results of different types of cancers, through various modalities of action such as improvement of the immune system, prevention of obesity, among others[3].

However, malnutrition frequently occurs during treatment, being common in children with solid tumors such as sarcomas, neuroblastomas, Wilms tumor and brain tumors[4]. The highest prevalence rate (50%) occurs in children with neuroblastoma, estimated that about 30% of children with other solid tumors are at risk of malnutrition both at diagnosis and during treatments. Children with leukemia have a prevalence rate of malnutrition of about 5-10% at diagnosis and up to 5% during treatment[5]. Thus, it is imperative to promote an appropriate nutritional intake, consonant to the child needs.

Collateral effects of chemotherapy such as nausea, vomiting, anorexia, taste and smell changes, oral mucositis, constipation and pain are responsible for decreased food intake and consequently lead to changes in parental practices at the moment of the meals[2,6-9]. Despite the advances in symptom management, the difficulty in preserving adequate oral intake is a reality, and food should be a focus of attention for all health professionals. The nursing team should advise and report the importance of a balanced and adequate diet, and help parents to find strategies that minimize the commitment of nutritional intake.

Neutropenia and susceptibility to infection require the adoption of new practices in food preparation and selection. These changes associated with the disease and with the side effects of chemotherapy in the gastrointestinal system affect and lead to changes in the children diet.

As mentioned previously, children with cancer are prone to inadequate nutritional intake, both for disease and for chemotherapy[12]. Poor nutritional status reduces treatment tolerance, prolongs episodes of neutropenia, which increases the risk of

infection. On the other hand, these children present increased nutritional needs[11]. Therefore, children/adolescents should ingest a balanced diet with adequate amounts of protein and a variety of fruits and vegetables, without excess of vitamin supplements or extreme diets, which may interfere with cancer treatment[13]. Given the susceptibility to infection, they should avoid aliments more prone to high levels of bacteria's such as raw[14].

The reaction of children and adolescents to the disease differs. Adolescents and school-aged children are able to understand information about their illness. Typically, schoolchildren are more cooperative in the treatment and care process. Otherwise, adolescents consider the disease as a cause of loss of independence, which constrains their plans for the future. However, several factors affect the reactions of children and adolescents, such as temperament, previous experiences and the effects of illness in the family[10].

Adequate food intake is undoubtedly associated with improved health status. Thus, when returning home, after cancer treatment, food is a central concern for parents. They face the challenge of getting their child to eat well, striking the balance between their desires and the rules imposed by the treatment.

Adequate nutritional status is essential during and after chemotherapy treatment, to promote the growth and development of the child/adolescent; to increase tolerance to treatments and to contribute to the reduction of the risk of infection. In this sense, food assumes a centrality in the concerns of parents at home. This study aims to contribute to the identification of parents' difficulties in the nutritional managing of the child with cancer at home, in order to outline better support from health professionals.

This study aims to identify the needs of parents/caregivers in the management of home nutrition of children/adolescents with cancer undergoing chemotherapy treatment and characterize the strategies of parents in the management of children's nutrition after discharge from cancer treatments.

Research methods

The study is based on the qualitative paradigm, of exploratory, descriptive and transversal nature. The population was constituted by the parents of children with cancer undergoing chemotherapy treatment, in a specialized Hospital Center, located in the north of Portugal, after the return home. The non-probabilistic intentional sample was consisted of 11 parents. The participants were selected by the investigator according to the following inclusion criteria:

- Parents of children with cancer submitted to a chemotherapy treatment, independently of the number of cycles, in the Hospital Center.
- Parents of children with cancer 48 hours after returning home. It was considered that this time interval would be necessary, so that the participants would obtain a minimal perception about the experience of caring for the child at home, after completing chemotherapy treatment.
- Accepted to be in the study.

As exclusion criteria was defined: participants who don't speak Portuguese fluently.

For this study, the interview script was selected as a data collection instrument, and a semi-structured interview as technique, in order to acknowledge the experiences and needs of the parents of children with cancer.

The investigation obtained a positive consent from the Ethics Committee and the Board of Directors of the institution where it was held. The participants were contacted during the period their children were in hospital and signed an informed consent document.

Between January and June 2016, 10 interviews were conducted at the participants' homes, in a room at the Pediatric Oncology Day Hospital or other location, according to the wishes expressed by the parents. Mostly they took place in the presence of the children, being these entertained to draw or color drawings, provided by the investigator. They took place in one single session with the participation of one of the parents, in only one of the sessions both parents participated. The interviews lasted an average of 58 minutes and were recorded on audio support. They were later transcribed, respecting the language used by participants, including laughs, hesitations and silences, as suggested by Bardin[15].

As a technique to analyse the content, the thematic or categorical modality was chosen, which consists in a transformation of the text in registration units and categories, being this technique the most commonly used by the content analyses[15,16].

The ethical questions were considered from the beginning, in choosing the theme, the type of study, participants' selection, data collection and its interpretation.

With the aim of safeguarding the participants' anonymity and confidentiality, identification codes were used and were recognized by E1 to E10.

Findings

From the content analysis of the interviews emerged the domain "Life at Home" and the category "Nutrition" (figure 1).

The parents' concern about their children nutrition, managing the guidelines that were given to them, the child's wishes and daily difficulties were reported by all of the interviewees. The neutropenic diet is recommended by the multidisciplinary team, which causes several changes in the child's eating habits and sometimes to the whole family. In the discourse produced by the participants, it is possible to observe these concerns and changes:

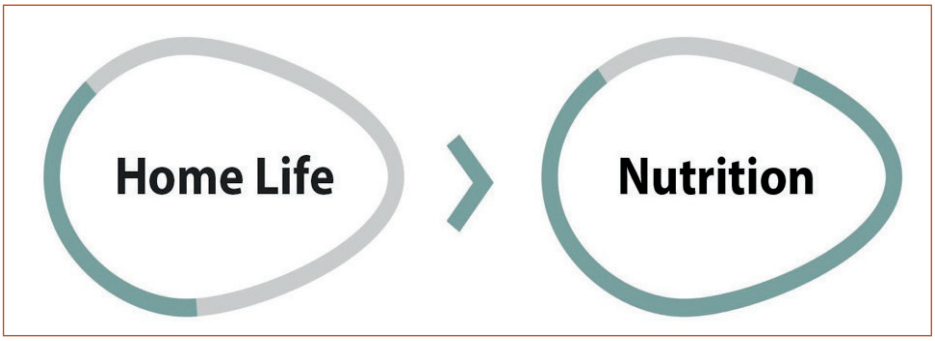

Figure 1. The domain "Life at Home" and the category "Nutrition"

… we are careful, now not so much, but from the beginning it was with the food, because for example the milks, had to be in small packages, the wafers, although still the milk continues, the wafers, I facilitate now. If there is a piece of rice left over, and if he asks us the next day, or sees us eating, I'll give him a little, but, formerly, I did not make it easier. The fruit, […] he does not eat it cooked, so what I do I wash it very well, I take out a thick bark and he eats a little bit (E3).

I buy fresh bread every day and she eats, […] [the yoghurts] I go to the supermarket, I choose... with the longest shelf life, go to the fridge, I see if the packaging is not broken, […] we disinfect the mango with vinegar, we peel and she eats. […] we also try to make a very varied diet, […] fortunately she likes a lot of coarse fruit, likes bananas, likes pomegranates, likes, for example, avocado […] (E4).

The management of the risk of infection associated with nutrition is a central concern, as expressed, in the following grafts:

… we spend a lot of vinegar because we disinfect everything. There is a bottle of our own whenever we open to him that never lefts to the other day […]. All very carefully indeed. An uncle kills a chicken, […] comes in an ark, only makes the trip, half an hour, arrives here prepare the chicken, all in individual bags, all frozen (E5).

… the spices before cooking or confection, […] the food, the vegetables, very well cooked. […] I do not give him anything that is made out, smoked, nothing. […] a person always has those care, to do everything homemade, even the cakes and everything, there is nothing bought (E6).

… we are doing our best to […] him not eat like that, things that are open, right? It has to be more stuffy, is not it? It is different from what a person was accustomed to, a radical change, no doubt. […] if you had enough to eat at noon, kept, put in the freezer or the fridge and at night ate […]. Now we cannot do that […]. The butter, juices have to be those little packages (E8).

The parents who participated in this study also mentioned the need to prepare and confection food at every meal as a new challenge. It is worth mentioning that one of the speakers says that currently facilitates, and does not always comply with all the recommendations.

One of the parents who participated in this study stated that their adolescent son was aware of and complied with the diet proposed by health professionals.

In addition to the restrictions of the neutropenic diet, one participant reported the need to manage the prescribed oral supplements:

… he drinks Fortimel® for breakfast, then in the afternoon he drinks milk, but he has to put the Fantomalt® (E10).

Nutritional issues raise constant doubts:

… his food at home, is where I sometimes have more doubts, […] we make soup, can I keep from noon to night? […] one thing I've been doing, is buying that crushed ham, already cut, is it the best option or is it not? […] can it be a box of familiar butter? […] or have to be those little ones for him? […] milk I know that it has to be those little packs […] at four o'clock I open the milk package, at six o'clock I want milk again, can it be from the same package? […] it is because I have already made both options […] I still often get caught up in the prospect that the nutritionist gave me and I already read it, I do not know how many times (E10).

The concern with diet is also expressed in the preference of organic food in order to promote adequate nutrition for their children, as it is said in the affirmations:

… since this happened we started to opt for organic products. Ah whatever he eats, whether of vegetables or meat, whatever is organic (E5).

We had to radically change habits that he had, which was to eat biscuits […] Heaps of junk […] We have to look for what is biological, which was produced through organic farming (E7).

However, food is associated with other problems, such as those resulting from the refusal of children, which is evident in the participants' discourse:

The difficulties, hmm, were more to see, even with […] the rejection of food (E1).

He says no… I put in the mouth and he is lying down […] before going to bed he drinks milk, he practically stays only with soup. It's only soup, eat the baby food in the morning at breakfast, at lunch it's a sacrifice to give him something, but that's it (E3).

Towards the difficulties they faced with the rejection of their children's food intake, parents used several strategies as changes in the diet of the whole family:

Everyone followed the food of R. in the same way, what he eats is what others eat, here at home (E5).

Some of the participants adopted another strategy such as questioning / accepting the child's food preference:

… I try to give her as much as she likes (E6).

I always ask him what he wants, because if he says he does not want to, I'll put him in the face … and he eat. Yesterday he said he wanted a fresh soup, he ate the fresh soup, then he said he wanted rice with gilthead, he ate rice with gilthead, but he just ate a little. But it was because I asked. […]. A person asks what he wants, […] That way he has no excuses (E9).

Parents who participated in the study verbalized that they insisted with the child to ingest refused food:

… [after chemotherapy treatment] returning home, is the start to give her food gradually, because she eats badly. First she does not eat, then begins to eat very little and this insistence on our part, to give her, little by little and very often … to stimulate her to eat, and then start eating, usually after a week, a week and a half (E2).

To see if she evolves, we are giving food hourly to see if she develops, otherwise with what she eats if we only give the snack, dinner and lunch we are plotted (E8).

Some of the participants reported that in addition to providing their child's favourite foods, they urged him to ingest refused foods by offering them throughout the day and night. In this sense, some parents, despite insisting, exert some verbal pressure on their children to feed, as expressed by one of the interviewees:

I'll put a yogurt in here and I'll give it to him one morning, but I'll give him a spoon, then he'll come, I'll give him another spoon, another spoon and I'll get it. Like milk today, I made simple milk, I got it, it started at 8 and it ended now, two hours, but I got it. It is like this in bits and threatening […] (E9).

One parent of this study said he resorted to distraction strategy:

He never stopped eating […]. Anything to distract him, as television or a game, anything. Everything is worth at this point. So the important for him is to eat and it is a fact that he never stops eating (E5).

Reward after negotiation is a strategy reported by one of the participants of this study:

One thing we cannot eliminate is bread, he continues to eat bread with butter, much less than what he ate, […] we have had results to give him fruit, like you want to eat bread, […] eat a banana first and I'll give it to you later (E7).

One of the participants mentioned that he chose to insert food in his meals, without saying to the child, with the intention that he ingested them, without being aware of his presence:

… the difficulties I have felt is in changing the diet habits, […] yesterday we did an incredible thing, the [mother] cooked shiitake mushrooms and mixed with grilled meat and cut everything and gave it. He barely felt! Incredible […] that is all brown and, […] and she insisted two or three times and the third time she ate and from there she began to eat. Oh man, it was a victory (E7).

Faced with the refusal of children to eat, parents resort to a multiplicity of strategies, as expressed in the following grafts:

… he rarely eats fruit, so yesterday I was grazing him a series of fruit and he ate it. If he does not eat later at night, but at least he has that whole fruit, I'm going to do like this […] I try at least to give him the soup. The soup has it all, so if it does not eat the main dish I do not care anymore (E3).

May the food not go, but will the soup. […] I put meat in the soup and everything. It is a way for him to eat a little more meat […]. we do one thing one time, another time to see if he goes to eat (E10).

Two participants in this study provided meals with foods that they say are important in fighting cancer:

… what he ate was soup with […] pumpkin seeds or sunflower seeds, no one remembers to put quinoa with seaweed […] The shakes I always made with beets, carrots, oranges and seeds. […] one thing I always kept was no dairy products, there is no sugar, no refined flour, no processed food. […] the grandmother only cooks with Monchique® water, because it is more alkaline […] I have always made several types of teas to detoxify […] since the dandelion, borututu, I have several (E5).

… we have tried to incorporate healthier things into his diet. […] we make soup daily and the soup is loaded with […] crucifers, which are a part of the veg-

etables that are very good for fighting cancer. The crucifers are broccoli, cauliflower, Brussels sprouts, all kinds of cabbage, arugula, watercress. […] very important seeds, because they have many vitamins and nutrients, magnesium, selenium, potassium […] nuts also have lots of vitamins and minerals (E7).

Discussion

The parents' concern about their children nutrition was visible in the participants' discourse analysis, we verified the preoccupation and the fulfillment in the choice, storage, preparation and confection of the food. The implementation of the neutropenic diet is a challenge for families, since it requires changing their eating habits. Participants emphasized the challenge of banning raw foods, which meant that their children would stop eating some fruit they appreciated. Other researchers[2,7], report similar difficulties in participants in their studies, who adhered to the neutropenic diet.

One of the study participants reported that currently facilitates, and does not always comply with all the recommendations, which corroborates the findings of Sari et al.[8] This may be due to the experience acquired by the parents over time, when they are aware of the most frequent adverse effects of their children to the treatments, and when the failure to comply may lead to a higher intake. Thus, parents have to learn to manage the fragile balance between strict compliance with the guidelines they have received, and the will of the child.

Another parent who participated in this study mentioned that his adolescent son knew and complied with the diet proposed, as Sari et al.[8] concluded in their study.

The need for management of nutritional supplements was reported by one of the participants. Nutritional support is a crucial tool in successful care for children undergoing chemotherapy[9]. These investigators concluded that 45% of the children undergoing chemotherapy had a loss of 10% of their weight and consequently met the criteria of malnutrition. To avoid these situations oral supplements are provided to promote a good nutritional status, however, these are not always well tolerated[2,9].

The father's speech, interviewed on the first homecoming, shows the need for more information about diet, since parents are still in a process of adaptation to the disease, and they already need to take care of the child. From the above, despite the written information that is read and reread, doubts remain, as it does not relate to all the problems / difficulties that have to be managed on a daily basis. Other researchers[2,8,19], also report the need for parents to provide more information about diet.

The choice of participants for biological products is now widely publicized as a cancer control / management measure. Participants in the study by Sari et al.[8], also referred to the demand for organic food as an option for better nutrition. The industrialization of food leads the consumer to eat carcinogenic aliments. The oncologist Khayat[20] recommends that the consumption of organic fruit and vegetables in the diet of cancer patients should be favored.

During the chemotherapy treatment, most children have decreased appetite and reduced food intake[9,19], which potentiates parents' difficulties in promoting adequate nutrition, causing worry and distress[9].

All these problems, and the inherent weight loss, cause stress in the parents[7]. In this study, food refusal was verbalized by all participants, noting that it was due to both gastrointestinal side effects and changes in dietary habits that lead to alterations in diet, suggested by health professionals.

Parents used various strategies to deal with feeding rejection such as modifying the diet of the whole family to follow the dietary changes experienced by the child is a benefit, helps in the implementation of the new diet, improves the family's quality of life, and leads to a better adherence by the child. When changing the dietary habits of the family does not occur according to the needs of the child, it impairs the adaptation to the disease and decreases adherence to the therapeutic plan.

In order to combat loss of appetite and lack of interest in food, parents can provide preferred aliments, question the child about what they want to eat and try to take their requests into account, not forgetting the counselling and constraints given by the health professionals[2,7,21].

Insisting with the child to ingest refused food without imposition and with encouraging words can be a relevant strategy at meal times[21,22]. As the participants verbalized.

However, the recourse to verbal pressure may lead to some conflict between the parents and the child, which may aggravate the situation. In fact, some parents report periods of tension and conflict during meals, referring to resort to verbal pressure with some frequency[7]. Parents' anguish when experiencing weight loss and reduced nutritional intake may have a negative impact on parent-child interactions during meals[7].

Distraction is a strategy used by many parents at meal times. The interaction with family, playing, stories, drawings and watching television appeals to children and their use facilitates the great challenge that parents face at meal time[2,21]. Playing is considered a therapeutic measure, which promotes child development, and physical and emotional recovery by minimizing the disease process. The playful facilitates the moment of the meals, leading the children to eat better[23]. However, distraction must be adequately performed to avoid that the child is more interested in the strategy than the food offered[21]. Distraction, according to the child's age and preferences, when used correctly, can be a relevant strategy in the nutrition of children.

The recourse to negotiation and

the reward towards the act of refusing food is a tactic with some success and lessening the distress of parents, who exchange the intake of food for something that children cherish. However, the frequency of its use may hinder the child's ability to understand limits and consequently become disobedient[22]. This strategy is also mentioned in the study by Sueiro et al.[17]

Blissett[24] argues that parents with their children's refusal to eat healthy foods should resort to rewarding negotiation strategy rather than imposition, since the former is more likely to succeed in achieving the goals.

Concealment of food makes it difficult for the child to know about it, being a strategy used by the parents[17], as a way to bring the food that is considered nutritionally adequate. However, exposure to food flavors enhances their acceptance[24].

Parents believe that nutrients are basic and essential elements for maintaining good health and strengthening the child's immune system, helping them cope with illness and aggressive treatment. Thus, they rely on several strategies to provide a diversified diet to overcome the food aversion that children develop during chemotherapy[2].

Parents should resort to positive strategies[7], because recourse to negative strategies may contribute to incorrect eating behaviors[24].

Nowadays, even in the media, information about the association of food with diseases, namely cancer, is published. Thus, eating habits can increase the risk of cancer, or otherwise help prevent it, or improve the response when facing a cancer.

Food should be diversified, avoiding fried, grilling and processed aliments[20,25]. These authors also mention the aliments that the participants mention because they have compounds with anticancer properties, and their consumption strengthens the immune system and prevents cell alteration. Regarding the type of water that children should ingest, there is no consensus. Some authors state that it should have an alkaline pH, close to 9.5, because there is currently a propensity for the pH of our body to be acidic[25]. Others point out that there is no scientific evidence to prove the benefits of alkaline water intake during cancer treatment, so its consumption should not be advised for both cancer prevention and treatment[26].

Conclusion

Being well fed is associated with good health. In this context, the preoccupation with the nutritional practices of children who have a chronic illness, like cancer, assumes a centrality in the daily life at home. In order to promote good ingestion, parents resort to different strategies: changing the diet of the whole family to follow the changes experienced by the child; the insistence on the consumption of food throughout the day; distraction; reward negotiation; providing a varied diet and more nutritious meals; questioning the food preference and providing the meal according to their request; verbal pressure to promote adequate food consumption; the use of organic food. Despite the multiplicity of such strategies, it becomes apparent that parents face issues related to food as a complex challenge.

The present research demonstrates the difficulty, the complexity of food management in children and the need for more structured support so that at home, they can respond to the challenges they face in their daily lives.

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