

# CHILDHOOD CANCER: CAREGIVERS' PERCEPTION REGARDING NUTRITION, FAMILY DYNAMICS AND EMOTIONS

*Câncer infantil: percepções de cuidadoras sobre alimentação, dinâmica familiar e emocional*

*Cáncer infantil: percepciones de cuidadoras sobre alimentación, dinámica familiar y emocional*

Original Article

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## ABSTRACT

Objective: To know caregivers' perception regarding nutrition, family dynamics and emotions of children and adolescents with cancer. **Methods:** Qualitative descriptive research conducted between March and May 2013 in a reference pediatric center for diagnosis and treatment of cancer in infants and young children in Fortaleza, Ceará. The nonprobability, random and convenience sample included 24 caregivers of children with cancer. Information was collected using semi-structured interviews and focus group, and was later submitted to content analysis. **Results:** The following categories were defined: "Family dynamics and its emotional implications", "Concern about healthy eating" and "Food myths". The content reveals caregivers concerned about changes in family dynamics due to the constant absence from home to devote to the sick child. The main problem faced was the sick child's refusal to eat, and nutrition emerged as an act of love, care and cure. Mothers reported cultural aspects that interfere in the planning of their family's diet, particularly the myths. **Conclusion:** From the point of view of the caregiving mothers interviewed, the cancer diagnosis has important consequences that generate changes in the nutrition, family dynamics and emotions, which require the adaptation of the sick child and the family.

**Descriptors:** Cancer; Child Care; Feeding.

## RESUMO

**Objetivo:** Conhecer a percepção de cuidadoras sobre alimentação, dinâmica familiar e emocional de crianças e adolescentes com câncer. **Métodos:** Pesquisa descritiva, com abordagem qualitativa das informações, realizada entre março e maio de 2013 em um centro pediátrico de referência no diagnóstico e tratamento do câncer infantojuvenil, em Fortaleza/CE. Foram selecionadas, por amostragem não probabilística, aleatória e por conveniência, 24 cuidadoras de crianças com câncer. Coletaram-se informações por entrevista semiestruturada e grupo focal; posteriormente, realizou-se a análise de conteúdo. **Resultados:** Definiram-se as seguintes categorias: "Dinâmica familiar e suas implicações emocionais", "Preocupação com a alimentação saudável" e "Mitos alimentares". Os conteúdos expõem cuidadoras preocupadas com as mudanças na dinâmica familiar devido à sua ausência constante do lar para dedicarem-se à criança doente. O principal problema enfrentado foi a recusa alimentar da criança doente, pois dele emerge a alimentação como ato de amor, cuidado e cura. As mães referiram aspectos culturais que interferem na organização da dieta de sua família, especificamente os mitos. **Conclusão:** Na percepção das mães cuidadoras entrevistadas, existem importantes repercussões do diagnóstico de câncer que geram modificações na alimentação, dinâmica familiar e emocional, demandando adaptação da criança doente e de sua família.

**Descritores:** Câncer; Cuidado da Criança; Alimentação.

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## RESUMEN

**Objetivo:** Conocer la percepción de cuidadoras sobre la alimentación, la dinámica familiar y emocional de niños y adolescentes con cáncer. **Métodos:** Investigación descriptiva de abordaje cualitativa de las informaciones realizada entre marzo y mayo de 2013 en un centro de pediatría de referencia en el diagnóstico y tratamiento del cáncer infanto-juvenil de Fortaleza, Ceará. Fueron elegidas 24 cuidadoras de niños con cáncer a través de un muestreo no probabilístico, aleatorio y por conveniencia. Se recogieron informaciones a través de entrevista semiestructurada y grupo focal; a posteriori se realizó el análisis de contenido. **Resultados:** Se definieron las siguientes categorías: “Dinámica familiar y sus implicaciones emocionales”, “Preocupación con la alimentación saludable” y “Mitos alimentarios”. Los contenidos muestran cuidadoras preocupadas con los cambios de la dinámica familiar debido a la ausencia constante del hogar para dedicarse al niño enfermo. El principal problema afrontado ha sido la recusa alimentaria del niño enfermo pues de él emerge la alimentación como un acto de amor, cuidado y cura. Las madres refirieron los aspectos culturales que interfieren en la organización de la dieta de su familia, en especial los mitos. **Conclusión:** En la percepción de las madres cuidadoras entrevistadas hay importantes repercusiones del diagnóstico de cáncer que generan modificaciones de la alimentación, la dinámica familiar y emocional necesitando adaptación del niño enfermo y su familia.

**Descriptor:** Neoplasias; Cuidado del Niño; Alimentación.

## INTRODUCTION

Health Promotion constitutes one of the strategies of the health sector aimed to support actions to influence the determinants and conditioning factors of the population's health by empowering people as well as groups, organizations and the community so that they become actors in this process within an intersectoral perspective<sup>(1)</sup>.

Considering the range of actions aimed at health promotion in the context of cancer in children and adolescents, there is a need to understand the impact of this disease on the life of the person and family and how, through empowerment, intersectoral support actions can be developed.

In this context, it is essential to understand that cancer in children and adolescents is rare and accounts for 3% of all malignant tumors diagnosed in Brazil, being the first cause of death by disease in this age group, surpassed only by accidents. In 2015, there were more than 11,000 estimated new cases of cancer in children and adolescents up to 19 years old<sup>(2)</sup>.

Pediatric cancer patients are considered, since diagnosis, a nutritional risk, both because of the metabolic changes that cancer causes and due to the antineoplastic therapy. They are also more susceptible to the development of nutritional deficiencies directly associated with poor quality of life and response to treatment, leading to increased morbidity and mortality<sup>(3)</sup>.

It is, therefore, a serious and debilitating disease, and the care dedicated to the patient causes – in addition to physical side effects – changes in the family dynamics, involving psychosocial and financial aspects and causing inconvenience not only because of the disease itself, but also because of caregivers' work overload, which generates an imbalance in the social and family life<sup>(4)</sup>.

The family can be defined as “[...] an affective union institution of daily communion of activities and sharing of situations in which its members are responsible for mutual care in their daily lives”<sup>(5)</sup>. This aspect is taken into consideration by the current paradigms of child care, which recommend the presence and participation of parents in hospital care<sup>(6)</sup>. In the hospital context, the family/child and health care team partnership is permeated with the knowledge of all people involved in the process, which can contribute to the family empowerment within the care process<sup>(7)</sup>. In general, it is the mother who embodies the family's presence in this perspective of care, which favors the verbalization of their perception regarding this process.

Understanding the meaning given to nutrition by the caregivers of patients following antineoplastic therapy, their perceptions of the affection involved in this care as well as the family changes due to the diagnosis of cancer can contribute to the provision of a more qualified health care by professionals working with pediatric oncology, particularly the nutritionist.

The aim of this study was to understand the perception of caregivers regarding feeding, family dynamics and emotions of children and adolescents with cancer.

## METHODS

This is a qualitative descriptive study that seeks – through words – to seize the perceptions of human beings belonging to particular groups about a particular social process, allowing thus the creation of new concepts<sup>(8)</sup>.

The research took place between March and May 2013 in a reference pediatric center for the diagnosis and treatment of cancer in children and adolescents located in the city of Fortaleza, Ceará.

The selection of subjects was carried out using a nonprobability random and convenience sampling<sup>(9)</sup> according to the availability of participation. Eligibility included caregivers of children and adolescents undergoing cancer treatment for at least one month in the center. Caregivers of patients treated in the outpatient centers for early diagnosis (pre-treatment) and follow-up (post-treatment) were not included.

The number of participants was determined through theoretical saturation of the sample<sup>(10)</sup>, which occurs when no new data appear from the researcher's point of view. Thus, the study included 24 caregivers of children and adolescents undergoing cancer treatment in the aforementioned hospital.

Data were collected using the focus group (FG) technique, which stimulate discussion between participants on a specific theme using guiding questions<sup>(11)</sup>. There were 3 FG, each being composed of one moderator (the researcher), one collaborator (observer), and an average of eight participants. It took place through the use of a FG questionnaire and an observation script with an interval of one week between them in order to ensure the heterogeneity of the sample. The FG had an average duration of 40 minutes and took place in a waiting room of easy access at a little busy time in order to ensure the silence and tranquility necessary for the proceedings.

At the beginning of each FG, the characterization of the identification data of caregivers was performed through semi-structured interviews conducted by the researcher addressing the variables gender, age, place of birth, address, occupation, education level and family income – the data were recorded on a structured instrument designed for use in the present study.

Adaptation of the FG was carried out using six guiding questions. What has changed in your family after your child's illness? Do you think that food can interfere with the treatment of your child? Once your child started treatment, what are your main concerns about his/her nutrition? Has anything changed in your child's nutrition after treatment? What are your main concerns in relation to nutrition during treatment? What are your main doubts about your child's nutrition? The reports of the participants were recorded using a smartphone after prior authorization and their attitudes were registered by the observer.

The analysis of these documents was made using the thematic analysis of content, following its steps<sup>(8)</sup> and highlighting the emerging meanings in the material according to the research objectives. From the analytical and interpretative process of the issue addressed in the present study, four thematic categories were identified: "Family

dynamics and its emotional implications," "Concern about healthy eating", "food myths" and "Difficulties in eating".

The project was approved by the Research Ethics Committee of the University of Fortaleza – UNIFOR (Opinion No. 189.263) and the *Hospital Infantil Albert Sabin – HIAS* (Albert Sabin Infant Hospital) (Opinion No. 215.264), following the National Health Council resolution No. 466/2012. Participants signed the free informed consent form and gave their written authorization prior to recording. Secrecy of the material was guaranteed. Noteworthy, participants are identified as interviewees using the letter "I" followed by a number – I1, I2, I3, and so on – in order to ensure their anonymity

## RESULTS AND DISCUSSION

### Characterization of participants

The study included 24 women – mothers and caregivers of children and adolescents admitted to a hospital ward and to the Intensive Care Unit (ICU). In all, there were 15 domestic workers, 3 housewives, 2 agricultural workers, 1 seamstress, 1 painter, 1 general services assistant and 1 independent seller. All women had left work after their children started the treatment. Fourteen had secondary education (5 of them incomplete and 9 had primary education) and only 1 completed. One participant reported being illiterate. Family income ranged from less than one minimum wage (11 participants) to 1-2 minimum wages (13 participants). Noteworthy is the prevalence of low income and low education of caregivers coupled with the need to interrupt their work activity due to the care of the child.

The contact with the caregivers led to understand that coping with the disease involves a number of subjective aspects and generates a chain of emotional conflicts, with numerous implications for the organization of the family unit. These aspects are intrinsically correlated to nourishing. In addition, although most of the guiding questions used in the FG address nutrition issues, family issues were present at several times of the discussion and became inseparable from the central theme of the present study.

During the process of analyzing the information, the following categories were defined: "Family dynamics and its emotional implications," "Concern about healthy eating"; "Food Myths" and "Difficulties in eating".

### Family dynamics and its emotional implications

The treatment of children and adolescents with cancer is a challenge for both the family and health professionals involved in the process. The diagnosis of cancer causes abrupt changes in the family dynamics of the individual,

interfering with life routine and generating a high degree of anxiety in response to the disease<sup>(7,12)</sup>.

During cancer treatment, caregivers are urged to adapt to a new family, social and professional routine and deal with a series of stressful events such as fears, expectations, medications, hospitalizations and side effects<sup>(13)</sup>. Many families, due to the overload of activities, which is higher in low-income families, end up experiencing situations of conflict between relatives<sup>(14)</sup>.

The child's disease causes great suffering to the caregiving mother, as she has to be away from home and from other children and loved ones, especially during periods of hospitalization, as recorded in the following report:

*Everything's changed. All her routine changed. (11)*

Mothers generally become primary caregivers; they leave the job and the rest of the family and focus on the care of the sick child at the expense of their husbands and other children. They have several responsibilities in their daily lives (administration of medications, interurrences, decisions, among others). It is a new life situation, with the father acting as a provider and the mother taking the main responsibilities related to the treatment, as highlighted in the following report:

*As soon as I heard of the disease, I left everything behind, I moved from the countryside and came to live here with him. And we live here [in the hospital]. My husband stayed there. It is difficult... (12)*

By analyzing the daily life of informal caregivers of patients undergoing chemotherapy, researchers<sup>(15,16)</sup> found a higher prevalence of female caregivers. Such findings may be explained by the fact that women have historically played the role of taking care of the family, especially the children<sup>(17)</sup>. A similar reality was found among the mothers participating in the present study, as all of them left work and dedicated exclusively to the treatment of their children and mostly came from municipalities in the countryside, where they had left their families.

### Concern about healthy eating

The diagnosis of cancer is a painful and shocking experience for the mother. After the confirmation of the disease, the family members experience feelings of fear, apprehension and doubts regarding the multidisciplinary procedures related to the treatment<sup>(18,19)</sup>. Some reports illustrate this situation:

*At the same moment that the doctor disclosed the diagnosis, I started breathing again after a brief cardiac arrest... "Come back because you are a mother!" (sic). So I said: "Yes, what is bad for him? What can he eat?". I wanted to know what I could do. (13)*

Thus, the category "Concern about healthy eating" emerges and shows that cancer treatment affects the patient's nutrition right at the time he needs to eat better. Therefore, nutrition becomes essential in the care and treatment. It can be noticed through the participant's reports that the concern about nutrition is present from the time of diagnosis:

*In the first consultations I sought the nutritionist to get a menu. So, I always follow it. (...) I always try to check what I should give. (14)*

*At the same moment that the doctor disclosed the diagnosis (...) I said: "What is bad for him? What can he eat?" (...) I soon checked the following: what is good, what is allowed, what is not allowed and when he can eat. (15)*

The experience of a disease like cancer involves various adaptations, both in the patient's life and in the whole family. In addition to re-evaluating pre-existing concepts and give new meanings to life, the inclusion of habits that had been little appreciated so far becomes recurrent right after diagnosis, at the beginning of treatment and throughout the whole process. The link between healthy food and those that are good for health was evident in the report of caregivers. In addition, these foods appeared as non-processed ones. The caregivers reported healthy eating as follows:

*Fresh food. Strong food. Beans cooked right away, meat, vegetables... Home cooked food, healthy food. (16)*

*He has always eaten very well at home, in terms of fruit, vegetables, juice... He sometimes and only drank soda on the weekend, but never Coca-Cola. (18)*

Proper nutrition is related to food considered good for health, such as fruits, vegetables, beans and meat. However, eating well presupposes the exclusion of all foods considered harmful, which are usually banned from the diet in order to prevent harms to general health:

*It changed [nutrition]. Pork, sardines, shrimp... These things they say it is allergenic (sic). Chocolate, instant noodles, she has always been crazy about it... I removed the coloring chemicals. I removed the mortadella, which she ate a lot... Sausage, mango. (14)*

*He does not eat sugar; the sugar he consumes is either brown sugar or honey. I literally cut gluten, things like that. He does not consume food preservatives such as canned food, sausage. (120)*

In general, caregivers presented knowledge about healthy eating based on a constant dichotomy in which foods are classified as good or bad, right or wrong, healthy or unhealthy, and, because of that, they “may or may not” be consumed. This perception appears in the following report:

*One says that beet with carrot is not allowed. Then I asked the nutritionist, who said no, he can eat it. If someone says something, we get afraid to give them. Pineapple is not allowed, then you are afraid of giving pineapple. Some say, “Oh, woman, this is bad”, “Oh, woman, this is good, the defenses increase a lot” “Oh, woman, this is not allowed, it breaks down defenses”. So we have doubts about what is and what is not allowed. (I18)*

This division of food into good and bad may be due to increased concern about the compliance with a proper diet, which causes a pressure on individuals, leading them to categorize the food based on their previous knowledge. On the other hand, it may simply be a result of cultural roots and simplistic discourses disseminated by healthcare professionals in the society, which advocate the exclusion of harmful food<sup>(20)</sup>.

The trend is that this concern about the nutrition of the individual with cancer remains even after treatment in order to promote the prevention of disease and maintenance of quality of life<sup>(19)</sup>, as several studies emphasize the protective effect of a diet rich in fruits and vegetables and low in saturated fats on cancer onset<sup>(21)</sup>. The caregivers questioned the probable relationship between poor diet and cancer onset:

*Well, it is because I think that because he eats “junk food” (sic) he got the disease. He did not eat well, he missed the proteins needed in his body... That is what I think... [He] just wanted to eat “junk food”. (I16)*

However, there were reports against this idea:

*I think that food does not interfere. She is 1 year and 6 months old. She only eats soup and porridge. (I8)*

The causes of cancer in children are not well known. In this age group, malignant neoplasms appear to be mostly of embryonic origin and generally affect the cells of the blood system and supporting tissues<sup>(22)</sup>. Therefore, the questions presented by the caregivers and the need for professional clarification to minimize this concern should be highlighted.

### Food myths

The reports show that although the food meets the physiological needs, it is not merely consumed for nutritional

reasons. Nutrition is subjected to several biological, social and cultural factors. Historically, the act of eating has been permeated by beliefs and representations that underlie the years and coexist in parallel with the advances of science. Thus, the traditional dietary knowledge is transmitted across generations<sup>(23)</sup>.

The reports on the changes in the patient’s nutrition after treatment make it clear that they are underlain by stigmas and myths related to nutrition:

*A friend of mine turned yellow. That’s why my sister called me saying that carrot is bad. (...) Then, she keeps calling me saying that carrots with beetroots are bad. It is a myth. It’s because she has given a lot of carrot to the boy and the palm of his hand turned yellow. (I12)*

Myths are stories that are part of the culture of a people and they are used to explain incomprehensible phenomena<sup>(23)</sup>. The reports of caregivers reveal that, during the health-disease process, some food customarily consumed and that once were associated with the maintenance of health and well-being are not recommended anymore in situations of an organism’s fragility. For most participants in this study, foods such as mango, pork, seafood and some types of fish are associated with a worsening of the health status and therefore should be avoided:

*My child eats mango. I don’t think it’s allergenic (sic), is it? (I16)*

A situation similar to that found in the present study was observed in a study conducted with women in a traditional community of Mato Grosso do Sul<sup>(24)</sup> in which food considered strong – or with more “nutrients” – such as pork are associated with the strengthening of the “healthy organism” and relapse of the “sick organism”, which would not be prepared to receive a “strong” and “hot” food.

Such “forbidden foods” would be associated with “allergy”. Thus, it is noticed in the reports of most participants the fear in relation to the so called “allergenic” foods, which would be harmful to the treatment:

*I think allergenic foods make it worse. Pork, shrimp... (I22)*

*But, these other things help... Vegetables, fruit... They are not bad. (I24)*

An “allergenic” food is one that “is not good” and, therefore is offensive in some states of the organism and can be consumed only by people with a perfect health status. Widespread in the North, Northeast and Midwest regions of

the country, the so called “allergenic” foods are related to the harmful effects that food have on the blood<sup>(25)</sup>.

### Difficulties in eating

When asked about the changes in nutrition after the beginning of the treatment, the caregivers’ reports revealed that anorexia and the consequent reduction in intake during chemotherapy cycles are the main factors responsible for the change in the dietary pattern of patients. Such poor appetite, which according to caregivers is caused by nausea and vomiting, is a major concern:

*He spent one week in hospital and he ate nothing on the following week. Five months vomiting. It is difficult, he is just three years old, he still does not understand much. And if you force him to eat is worse, he will surely puke (vomit). It is very difficult. (114)*

In fact, chemotherapy and radiation therapy cause a number of side effects of great impact on food intake. However, the metabolic changes caused by the disease may also be responsible for such occurrences, a fact that has not been reported by the study participants. Chemotherapeutic agents particularly induce vomiting, anorexia, diarrhea and constipation, which may impair the absorption of nutrients<sup>(3)</sup>. The presence of these effects weakens the organism and interferes with food intake, increasing the risk of nutritional and immunological impairment, promoting a reduction in the quality of life, decreasing the response to treatment and affecting negatively the general state of the patient’s health<sup>(21)</sup>.

The difficulty in eating is one of the most frequent complaints of parents of children – including the healthy ones – since the introduction of complementary feeding. They often show concerns and anxieties in relation to child development.

Malnutrition is a frequent finding among cancer patients and appears as one of the main concerns of health professionals; however, the main caregivers’ concern is the child’s immunity:

*We realize that the defenses... The strengthening of the organism depends on nutrition (...). Food really strengthens it. If he does not eat, he will be weak, get fever and with poor defenses. (118)*

*A well-nourished child is far less likely to have poor defenses (...). You have to look for the type of food that will not affect his defenses. I believe that food is 50%. (15)*

It is also observed in several reports that the reduction of food consumption and number of meals is exacerbated during periods of hospitalization:

*My [son] almost didn’t get hospitalized in the first cycle. Now, the relapse medication is stronger, then he stops eating. He spent two weeks without eating, he only vomited and did not eat, so he may get weak and chemotherapy may knock him down. (17)*

This reduction may be directly related to their own physiological condition, the side effects of chemotherapy, changes in eating habits and dissatisfaction with the meals offered in the hospital<sup>(26)</sup>. Although there is a concern with the nutritional state of patients, little attention is given to the verification of dietary compliance. In the present research, there were no reports on the association between low acceptance of food served in the hospital and dissatisfaction with the quality of food served.

### FINAL CONSIDERATIONS

Having a child or an adolescent undergoing cancer treatment generates big changes in the family dynamics of the caregivers, who are compelled to adapt to a new health care routine, leaving behind their affective circle and their social relationships. The diagnosis of cancer, in addition to being a painful experience for the caregiver, raises fear and apprehension in relation to chemotherapy and nutrition of the child and adolescent during this period.

Nutrition is seen as an important part of anticancer therapy and it is essential for a successful treatment. Given that, at the beginning of the treatment, the family generally changes old eating habits by excluding processed and “allergenic” foods considered harmful from the diet and increasing the consumption of foods considered healthy, such as fruits and vegetables. However, for the caregivers, the challenge is to find ways to overcome the patient’s difficulty in eating.

In this scenario, it is noted that caregivers and patients themselves need to be routinely counseled by health professionals on the appropriate consumption of food. These professionals have a key role in the treatment of children and adolescents with cancer and should also be aware of the subjective issues inherent to this process.

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