

## Parents' conceptions of their children's oncological condition and their chemotherapeutic treatment

Concepções dos pais acerca da doença oncológica e do tratamento quimioterápico de seus filhos  
Concepciones de los padres acerca de la enfermedad oncológica y del tratamiento quimioterápico de sus hijos

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**Abstract: Objective:** to assess and analyze the conceptions of fathers and mothers of children with cancer of their children's disease and their chemotherapeutic treatment according to the concepts of the Commonsense Model (CSM). **Method:** descriptive, qualitative study. Fourteen (14) parents of pediatric patients undergoing cancer treatment were interviewed. The data underwent content analysis and were analyzed according to the CSM. **Results:** the results were grouped into the following categories: Disease identity: conceptions of cancer; Duration: the length of time up to diagnosis and symptoms involved; Causes of the disease: the search for explanations; Consequences of the disease and treatment; Cure or control: perceptions of the prognosis as based on the CSM domains. **Conclusion:** negative conceptions relating to cancer and its treatment can cause uncertainties affecting the parents, compromise the use of resources to cope with the consequences of the disease, and reduce the expectations that the experience will have a positive outcome.

**Descriptors:** Neoplasms; Child; Adolescent; Parents

**Resumo: Objetivo:** analisar as concepções de pais e mães de crianças com câncer em relação à doença e ao tratamento quimioterápico de seus filhos, de acordo com os conceitos do Modelo do Senso Comum (MSC). **Método:** estudo descritivo, qualitativo. Foram entrevistados 14 pais de pacientes pediátricos em tratamento oncológico. Os dados foram submetidos à análise de conteúdo e analisados segundo o MSC. **Resultados:** os resultados foram reunidos nas categorias: Identidade da doença: concepções sobre o câncer; Duração: o tempo para o diagnóstico e

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os sintomas envolvidos; Causas da doença: a busca por explicações; Consequências da doença e do tratamento; Cura ou controle: percepções sobre o prognóstico, baseadas nos domínios do MSC. **Conclusão:** concepções negativas relacionadas ao câncer e seu tratamento podem gerar incertezas nos pais, comprometer a mobilização de recursos para lidar com os desdobramentos da doença e reduzir as expectativas de um desfecho positivo da experiência.

**Descritores:** Neoplasias; Criança; Adolescente; Pais

**Resumen: Objetivo:** analizar las concepciones de los padres de niños con cáncer respecto a la enfermedad y al tratamiento quimioterápico de sus hijos, según los conceptos del Modelo del Sentido Común (MSC). **Método:** estudio descriptivo, cualitativo. Fueron entrevistados 14 padres de niños en tratamiento oncológico. Los datos fueron sometidos al análisis de contenido y analizados según el MSC. **Resultados:** los resultados fueron reunidos en las categorías: Identidad de la enfermedad: concepciones sobre el cáncer; Duración: el tiempo para el diagnóstico y los síntomas involucrados; Causas de la enfermedad: la búsqueda por explicaciones; Consecuencias de la enfermedad y del tratamiento; Cura o control; percepciones sobre el pronóstico, basadas en los dominios del MSC. **Conclusión:** concepciones negativas relacionadas al cáncer y su tratamiento pueden generar incertidumbres, comprometer la movilización de recursos para lidiar con los desdoblamientos de la enfermedad y reducir las expectativas de un desfecho positivo de la experiencia.

**Descriptor:** Neoplasias; Niño; Adolescente; Padres

## Introduction

Child and adolescent cancer is the leading cause of death from diseases in the age group ranging from zero to 19 years, with an average of 12,600 cases diagnosed per year in Brazil.<sup>1</sup> The most common neoplasms in childhood are leukemias, mainly acute leukemias, tumors of the Central Nervous System (CNS), and lymphomas.<sup>2</sup>

Cancer has always been associated with the idea of death, pain, uncertainty, confusion and impotence, both for patients and their families.<sup>3</sup> When the disease affects a child, consequently, the impact is felt by the entire family and their social circle. There are inversions in family roles, changes in their daily activities, reformulation of life goals, expectations and hope for those involved. Some parents resort to unscientific explanations in order to understand the possible causes underlying their children's illness.<sup>3</sup>

An individual's conceptions are developed in various manners and can be influenced by their level of education, surroundings where they live, and their culture – hence, those

conceptions are changeable.<sup>4</sup> They can determine people's ability to grasp an idea or issue and to perceive a phenomenon, thereby establishing their own viewpoint.<sup>5</sup>

The literature points out that patients and their family members may believe that the occurrence of adverse effects during treatment is evidence of its effectiveness. Thus, greater damage and suffering would imply better responses and greater hope for survival. The absence of these side effects, secondary to therapy, causes uncertainties, anxiety and questioning as to the success of the treatment.<sup>6</sup>

Some parents of children undergoing chemotherapy understand that the drugs affect both good and bad cells and are aware that initially the symptoms are worse, but as treatment progresses, the patient may have the resources available to minimize these unpleasant effects. For others, however, treatment is seen as harmful and, instead of helping the patient, as causing limitations that are worse than the disease itself.<sup>6-7</sup>

The illness of a child due to cancer represents a threat and can cause representations of the disease that are influenced by individual beliefs. These beliefs can compromise the acceptance of the disease and treatment, behaviors and coping required by the situation being experienced.<sup>8</sup> This way of representing the disease is referred to as the Common Sense Model (CSM) or Self-Regulation of Health and Illness Behavior,<sup>8</sup> which is the framework adopted for this study.

According to the CSM, the perception of the disease can be understood by considering five dimensions: **identity** - expressed by abstract labels, such as the name of the disease and symptoms associated with it; **causes** - factors relating to the origin of the disease; **duration** - temporal duration or course of the disease over time (for example, acute, chronic, or cyclical); **consequences** - disease severity and its impact on physical, psychological and social functioning; and **control/cure** - possibility of cure or control of the disease.<sup>8</sup>

Starting from the above, one may ask: what are the conceptions of fathers and mothers of children and adolescents with cancer of the disease and treatment of their children? Having this question in mind, our objective was to assess and analyze parents' conceptions of children with cancer with regard to their disease and chemotherapeutic treatment according to the concepts of the Common Sense Model (CSM).

## Method

This is a descriptive, qualitative study, where speech was examined in the light of the CSM or Self-Regulation of Health and Illness Behavior Model. Data collection was performed at the chemotherapy outpatient clinic of a referral hospital for the treatment of child and adolescent cancer in São Paulo - SP, Brazil, from June through August 2016. Parents of children or adolescents receiving palliative chemotherapy or for whom there were no therapeutic possibilities left were excluded. Participants accepted to take part in the study out of convenience, and there were no refusals to participate.

Semi-structured, audio-recorded interviews were conducted, guided by a script previously prepared by the authors and based on the literature on the subject. The questions addressed not only the parents' conceptual comprehension of their children's disease, but also the action of chemotherapeutic agents on the child's body from the parents' perspective. Only one meeting with each participant was necessary. The statements obtained during the interviews were transcribed in full for a better understanding of the participants' speeches and then underwent procedures for deductive content analysis. Data collection was interrupted when the set of data obtained in the interviews proved to be redundant and sufficient for understanding the phenomenon being studied according to the structured matrix based on the CSM.<sup>9</sup>

The deductive modality is used when the analysis structure is operationalized as based on previous knowledge and concepts.<sup>9</sup> By using it, researchers aim to test pre-existing categories, concepts, models or hypotheses. Both inductive and deductive analysis are divided into three main phases: preparation, organization, and reporting of results. In the preparation phase, the empirical material was exhaustively read over in order to identify words, phrases and expressions that might respond to the objective of the study. Then, the data were organized according to a structured matrix based on the five dimensions present in the adopted theoretical model (CSM): **identity, causes, duration, consequences** and **control/cure**. Accordingly, only aspects fitting the five dimensions of the model were selected from the participants' testimonies, giving rise to the categories presented in the results. The study met the requirements of Resolution 466/12 of Brazil's National Health Council (*Conselho Nacional de Saúde*) and sent to the institution's Research Ethics Committee – registry number CAAE 56098216.4.0000.5479, having been approved according to document No. 1.561.355 issued on May 25, 2016.

## Results and discussion

The sample consisted of 14 parents, of whom 13 mothers (92.8%) and one father (7.2%), with an average age of 39.9 years, the majority of them had completed high school (71.4%) and were unemployed (78.5%). As for their professions, those in the labor market declared themselves as therapists, psychologists and seamstresses, each of which represented 7.1%. With regard to the children's diagnoses, the most prevalent were bone tumors and lymphoma, each accounting for 21.4% of cases, followed by leukemias, medulloblastoma and tumors of the central nervous system, each corresponding to 14.2%. Other types of tumors such as sarcoma and germinoma were also found, totalling 14.6%. The deductive analysis results, summarized in categories, are presented below:

### Disease identity: conceptions of cancer

In the interviews, the participants reported their perception of their children's diagnosis relying on their previous knowledge about the disease. Based on preconceptions, parents used the following terms to characterize cancer: *scare, monster, darn disease, terrible, malignant, hopeless, synonymous with death, terrible, devastating and aggressive*. Therefore, the disease, whether it has a good or a bad prognosis, is perceived to be associated with stigmatized names.

*Cancer is a scare! We come from a very small town, when [my child] was diagnosed with a tumor in the head, we think the worst. I still make jokes about it, I say it's the bottom of the well and deep down in there, there is a drain that goes even a little bit further down. But when you find out [the disease is there] in time, there is a cure. (E1)*

*When I found out he had the illness [child], it was a very difficult day, I was very angry with God for letting this happen and, honestly, for me, cancer is synonymous with death; when I knew [about it], I thought of all the bad things that could happen, nothing positive [at all]. I have always been very afraid [of it]. Where I come from, in Pernambuco [State], not even the word cancer would be spoken. (E5)*

Cancer is a stigmatized disease, permeated with negative conceptions and often associated with lethality. A Brazilian study showed impressions of the lay population on cancer and pointed out the terms most associated with the disease, such as death, pain and suffering.<sup>10</sup>

Hence, as described in another study with fathers and mothers of children with cancer on their knowledge and attitudes towards their children's disease, it was observed that the difficulties related to the parents' search for information about the their children's disease and symptoms were directly linked to negative conceptions and the stigma attached to the disease in society.<sup>3</sup> Many parents avoided even mentioning the word cancer, as this referred to the

negative experiences associated with the disease, whether due to previous concepts or the loss of family members afflicted with oncological diseases.

In addition to the stigma of the disease, there is also a patronizing pattern in the doctor-patient relationship in Brazilian society. This, in turn, imposes barriers on most parents, preventing them from speaking openly about the disease and its treatment, since they fully trust the scientific knowledge and decisions made by the medical team.<sup>10</sup>

The conceptions of fathers and mothers of the disease and its treatment proved to be permeated with myths and stigmas, which should be clarified by health care professionals, especially those in nursing. Stigma can have a silencing effect and affect the individuals' behavior and their way of life, in addition to making it difficult for them to cope with diagnosis and treatment.<sup>10-11</sup> It is necessary that, at the moment of diagnosis, the multidisciplinary team be prepared to address any conceptions, doubts and questions that they consider important and thus clarify the family members' concerns and questions. It is important that the meaning of the word cancer be explained and that it be emphasized that the family had no participation or fault in the development of the disease.<sup>11-12</sup>

### **Duration: the length of time up to diagnosis and symptoms involved**

After analyzing the parents' speeches, it was possible to notice that both the children and the parents realized that something was not right and that due to the signs and symptoms presented, they decided to then seek the health care service.

*It took him a while to find out what he [teenager] had, it was a struggle; after the tests, the doctors thought it was a "bubo", it had started as a lump on the neck, he had an ultrasound and a CAT-scan performed, and that such "bubo" was from an infection that had not yet appeared, the exams gave normal results, until he had a biopsy [whose result] was a lymphoma in his neck, a malignant tumor. (E9)*

*He was diagnosed in January, we spent two months presenting to the emergency room and nobody [was able to] find out what he [child] had, he*

*was always diagnosed with an infection, but no doctor really observed the symptoms he had, blood was coming out of his nose, low platelets, bruises, continuous fever, joint pain, all of these accompanied by a throat infection and low immunity. His testicles increased [in size], he had recurrent infections and pallor. (E6)*

Early diagnosis of childhood cancer is a challenge for medicine.<sup>13</sup> Most of the time, the association of symptoms with the disease is not apparent. Thus, most pediatric patients arrive at specialized institutions with an advanced stage of the disease due to the difficulty of doctors in recognizing nonspecific symptoms, in addition to the parent's lack of information and fear of diagnosis. Most times, the signs and symptoms of childhood cancer, since they are not specific, can be confused with those of other common childhood diseases.<sup>14</sup> The factors related to the difficulties in elucidating the diagnosis, added to the long way leading to the disease being finally found out and beginning of treatment can influence the prognosis, compromising both survival and the possibilities of curing the disease.<sup>15</sup>

In view of this, one can perceive the inadequacy in maintaining the flow of care, already mentioned in the literature, which highlights the support given to assessing the effectiveness of health care services such as ensuring access to them and meeting the population's needs. In this context, the nurse should seek to have an attentive outlook and qualified listening skills for children presenting with signs and symptoms that are suggestive of cancer, thereby favoring an early diagnosis of this disease.<sup>15</sup>

### **Causes of the disease: the search for explanations**

The interviewees showed in their reports that they found no causal links to their children's disease as they took into consideration prenatal care, successful birth and way of life prior to their illness. On the other hand, other participants showed that they did not want to even consider how the pathology had developed, since the pressure imposed by the situation already causes too high a level of stress and an avalanche of emotions that is exhausting enough *per se*.

*He was always healthy, he was born perfect, had a peaceful pregnancy, uneventful prenatal [care]. (E13)*

*I don't even like to think about it, I try not to [and] avoid getting into that subject, because I always need to be strong so that I can be with him, if I get into this matter of what it is and why it happened, I freak out, so I prefer to live one day at a time, and I don't like to talk about it. (E6)*

Oncological diseases, even though they affect adults and children alike, seem to cause greater impact on society when children and adolescents are afflicted, as identified in the testimonials.

*It is a cruel disease, regardless of age, if for an adult it is already difficult, imagine for a child, a child does not know how to deal with what is happening [to then], and the treatment is quite trying [and causes] considerable suffering. (E13)*

The child potentially has a larger number of years of life ahead of them and is therefore considered a fragile being. The idea of illness and death being experienced and faced in childhood is something that contradicts the natural order of events. The sorrow due to an existing malignant disease in children or adolescents can be experienced more intensely. Furthermore, it can lead parents to reflect about and question why illness is directly affecting their children and their family.<sup>3,16</sup>

When asked about their perception of what caused their children's cancer, the participants reported:

*[they] had a disease that was "related" to chicken pox he [child] had, I don't remember remember what it's called, and that was the beginning of everything, we are now hopeless. (E6)*

*he [God] is the one who let all this happen, but there will still be life, to make us stronger. I see this as a process, not as some penalty [or] punishment, I see this as proof that God gave us a mission to overcome, because we can overcome it. (E13)*

By means of their reports, the parents explained situations such as radiation absorption during pregnancy, mistreated diseases, exposure to chemicals or vaccines, associated with the weakening of the immune system, thus facilitating the onset of the disease. Some have even established a connection between cancer and past sports trauma. It is clear that the parents tried to establish causality both from a biomedical and a supernatural perspective. A study on a similar theme pointed out that parents based their reasoning on a fatalistic view in an attempt to understand the reasons for their children's illness, i.e. based on God's will, either to test the faith of these individuals or to show them his sovereignty and control over adverse situations.<sup>17</sup> The results corroborate findings reported by other studies in the literature,<sup>4,6</sup> according to which illness does not seem to be something that can be controlled by humans and that can be interpreted as a mission to be accomplished, as proof of faith.

Such supernatural interpretation of the facts can alleviate the guilt the parents feel for their child's illness: should the divine have control over events, then there should be fewer chances of intervention and feelings of guilt. On the other hand, they can trigger feelings of guilt related to non-compliance with rules of faith and represent some sort of punishment for spiritual misconduct.<sup>18</sup> The strictly biomedical view is known to be based on the resolution of the disease alone, exclusively by remedying its causes; a supernatural or miraculous view, in turn, might lead parents to conceive of misconceptions of illness and therapy, which might have repercussions on their coping and adapting to all events contrary to their expectations.<sup>12,18</sup> The search for a logical explanation for and causes of the disease is unconscious, given that families seek to understand the reasons why they need to go through such painful events. For parents, the illness is characterized by their children experiencing intense suffering and accompanying uncertainties, which oscillate between the fear of death and the hope for a cure.<sup>15</sup>

### **Consequences of illness and treatment**

After accepting the diagnosis and moving from the avoidance phase to the phase of coping with the disease, parents envision the possibility of a cure for the disease and tend to accept treatment better.

*When we come to a place that has the resources, we feel reassured and understand what is happening, the treatment that will be performed and its consequences, things start to get lighter. (E3)*

The main treatment for childhood cancer is chemotherapy, a pharmacological treatment that aims to interfere with the ability of cells to grow and reproduce. It can be used either alone or in conjunction with other therapies, such as radiation or surgery.<sup>4</sup> Some of the participants appeared to understand the effects of chemotherapy on their children's bodies, as expressed in the following excerpts:

*I think it [chemotherapy] acts on both good and bad cells, [regarding] the chemotherapy he is getting today, I was told it is more specific, it acts on the most resistant cells. (E4)*

*it destroys [both] the bad cells, that are cancer cells, and the good cells too. Each organism responds in their own way, mine in one way, yours in another, hers in [yet] another. (E1)*

*I know she feels bad, but it is good for her, it is the medicine that is going to make the tumor shrink so that there can be a cure as soon as possible. (E2)*

Chemotherapy can be quite effective in treating certain types of cancer, but as some participants did know, chemotherapeutic agents do not differentiate normal healthy cells from cancer cells, which can lead to many adverse effects during treatment, which vary depending on the drug used. The most common symptoms and adverse events in children and adolescents are: nausea, vomiting, fatigue, alopecia, bleeding, immunosuppression, anorexia, among others.<sup>4</sup>

In the interviews, it can be seen that the treatment phase and the consequences it brings are not only felt by the child, but by the whole family because they experience a major change in their daily life.

*It is an intensive, exhausting treatment, we arrive here early and leave only at night, it has changed our daily life routine. (E8)*

*He used to be a teenager who would ride a bicycle, play soccer and fly a kite, he has stopped [doing all those], so you realize that the person is not well, he would stay [indoors] at home all day long, playing video games, lying in bed and [would still be] in great pain, when he got a little better he would go flying kites on the street, but at night time, it seemed that he would come back home [feeling] much worse. (E11)*

One notes that the interviewees showed divergent understanding about chemotherapy. In their perspective, if on the one hand the treatment can be good, on the other hand it can just as well be bad, as described in the following excerpts:

*I know she feels bad, but it is good for her, it is the medicine that is going to make the tumor shrink so that there can be a cure as soon as possible. (E2)*

*[for] every disease you take a medicine and the tendency is [for it to] decrease and for the person to get stronger, [with] cancer it is the opposite, the medicine has a very bad reaction, it kills [both] bad and good cells. (E3)*

*it destroys everything that is good and bad, it is a good poison, because it puts an end to all that is good, but it is treating bad things, it destroys the child, but [such a thing] is required, this is the cure, there is no other way. (E7)*

The participants showed that they understood the drugs' action on tumor cells and also pointed out the symptoms and adverse events caused by such medications to the healthy cells in their child's body:

*It's bad, there can be nothing good in that which it does; for example, you take [he takes] MTX today [Methotrexate] if he doesn't get it all out [of his*

*system] in a few days, it will harm his kidney, liver, all of his organs, how can that be good for you, can you explain that to me? It kills bad cells and it kills good cells. (E12)*

*Chemotherapy has greatly decreased [his tumor], and in the meantime, [he] no longer has felt any pain. He only had one complication, he spent six days without [being able to] eat because of chemotherapy, he had a hard time eating and drinking water, he got very weak and dehydrated, he was sick. (E11)*

The literature points out that many patients and family members associate the symptoms with the effective action of chemotherapy, that is, the more intense the symptoms felt, the greater the possible effects chemotherapy is having on the body and, consequently, the better the response to treatment.<sup>6</sup> Chemotherapy is characterized as a treatment that brings pain and suffering, but at the same time, it materializes the battle against the disease and functions as an instrument which helps parents to believe in their child's clinical improvement and possible cure.<sup>6-7</sup>

### **Cure or control: perceptions of prognosis**

The concept of healing is often associated with spirituality, given that a diagnosis such as that of cancer causes feelings of loss and early mourning on the part of family members. The inability to deal with the situations imposed by the disease diminishes hope. In this way, spirituality has been studied and shown to be an important resource from an individual's perspective amid adverse situations: it serves as a form of support and helps lower anxiety rates, decrease stress, and increase hope and satisfaction with the treatment results.<sup>18</sup>

*After my son started taking it, he was transformed, from his condition as he arrived at the hospital to [his condition] now, wow, he was transformed. It is a miracle, I thank this holy medicine that seems to do so much harm, but [instead] does him well. (E9)*

*After I came here and my daughter started [her] treatment, I saw that cancer can indeed be cured, nowadays we have very advanced technology, and first [there is] God, then [there are] the doctors. There where doctors*

*can't get their hands on, God touches and heals, for me cancer does have a cure, but I wouldn't believe [this] before. (E4)*

*Today I believe in cure. I have always had Faith in God, but when you go through problems, faith ends up getting bigger. (E6)*

*We have an effective treatment, a treatment that has been showing results, [on which] research has been increasingly growing [in numbers], but there is still no definitive solution. Our faith is very great. (E13)*

Spirituality can be described as support that increases the the link between hope and th ability to cope with the disease. It is faith that promotes such support in the face of events. For some parents, spiritual beliefs and practices were first adopted due to a stressful situation (their children's cancer diagnosis), which modified their experience associated with suffering. This changed the way the seek for and find solace, comfort and hope.<sup>19</sup> Thus, spirituality manifests itself as an important coping strategy during the course of the disease, allowing the search for the meaning and purpose of life/cure of patients. Many family members consider spirituality to be an important resource during cancer treatment, without ever minimizing the importance of continuing conventional therapy.<sup>18-19</sup>

## **Final considerations**

According to the conceptions held by fathers and mothers of their children's illness – and interpreted in the light of CSM –, cancer is deemed as a threat that causes fear, anxiety and other emotions, against which denial appears as a short-term coping strategy that provides but temporary relief. However, long-term denial or non-acceptance of the disease makes it difficult to develop emotions any further, which can have a negative impact on these parents becoming ready to deal with the challenges imposed by the disease and its treatment. For the participants, the disease and the treatment were ambivalent, i.e. simultaneously permeated with fear and hope for improvement and a cure. Chemotherapeutic treatment stood out as a necessary evil, whose benefits tended to outweigh its adverse events.

Despite the limitations to the study, especially concerning data collection at one single center, its results describe the parents' conceptions of their children's disease. Armed with such pieces of information, these professionals will be able to create educational strategies to clarify possible myths and stigmas attached to the disease and its therapy, especially those influenced by the social representations of cancer lethality, which results in limits to the hope and investment of these parents' internal and external resources. Thus, the role of professionals in an individualized approach and according to the particularities of the disease, the child and their family is crucial in tackling doubts, clarifying any questions regarding the treatment and strengthening the bonds and outcome prospects relative to the disease. This study still has the potential to pave the way for future research encompassing the influence exerted by cultural variations over those conceptions, myths and stigmas linked to childhood cancer, and to raise awareness as to the need for further research on a theme that is still poorly explored in the literature.

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Drafting of the paper and critical review

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