

## MANAGING CANCER AND ITS INTERCURRENCES: THE FAMILY DECIDING TO SEEK EMERGENCY CARE FOR THE CHILD<sup>1</sup>

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*This study aimed to understand how the family of a child with cancer manages the illness and its intercurrences at home, and how it makes the decision of taking the child to an emergency care service. Oral History was used as the methodological strategy and data analysis was based on the "Family Management Style Framework". Participants were six mothers between 28 and 47 years old, who were experiencing their child's cancer treatment. The possible need for emergency care is incorporated into the family routine as a resource to manage the illness whenever it goes beyond the mother's capacity to keep control over the symptoms, which is permeated by suffering, derived from the uncertainties this creates. Helping the mother to develop skills to get stronger and reduce the suffering resulting from the situations that generate uncertainties and insecurities in her daily life with the child with cancer is a challenge.*

DESCRIPTORS: *pediatrics; family; oncology nursing; child*

## GERENCIA DEL CÁNCER Y DE SUS INTERCURRENCIAS: LA FAMILIA QUE DECIDE SOBRE LA BÚSQUEDA DE LA ATENCIÓN DE EMERGENCIA PARA EL NIÑO

*Este estudio buscó entender cómo hace la familia del niño con el cáncer para manejar la enfermedad y sus intercurrencias en la casa, y cómo hace la familia para tomar la decisión de llevar al niño a un servicio de emergencia. La historia oral fue utilizada como estrategia metodológica, y el análisis de los datos fue basada en el "Family Management Style Framework". Los participantes eran seis madres, con edad entre 28 y 47 años, que vivenciaban el tratamiento del cáncer de su niño. La posible necesidad de la atención de emergencia se incorpora dentro de la rutina de la familia como recurso para manejar la enfermedad siempre que vaya más allá de la capacidad de la madre en guardar el control sobre los síntomas, lo que es rodeado de sufrimiento, debido a las incertidumbres generadas por esa situación. Ayudar a la madre en el desarrollo de habilidades para se fortalecer y reducir el sufrimiento resultante de las situaciones que generan incertidumbres y inseguridades en su vida de cada día con el niño con el cáncer es un desafío.*

DESCRIPTORES: *pediatría; familia; enfermería oncológica; niño*

## MANEJANDO O CÁNCER E SUAS INTERCORRÊNCIAS: A FAMÍLIA DECIDIENDO PELA BUSCA AO ATENDIMENTO DE EMERGÊNCIAS PARA O FILHO

*Este trabalho objetivou compreender como a família da criança com câncer maneja a doença e suas intercorrências em casa e como decide levá-la para um atendimento de emergência. Para tanto, utilizou-se a História Oral como estratégia metodológica e a análise dos dados foi baseada no modelo teórico "Family Management Style Framework". Para isso, participaram seis mães, com idade entre 28 e 47 anos, que vivenciavam o tratamento de câncer do filho. A possível necessidade do atendimento de emergências é incorporada ao cotidiano da família como um recurso para manejar a doença quando esta vai além da capacidade da mãe de manter o controle sobre os sintomas, o que é permeado por sofrimento decorrente das incertezas que isto gera. Ajudar a mãe a desenvolver habilidades para se fortalecer, minimizando o sofrimento conseqüente das situações que causam incertezas e inseguranças em seu cotidiano com o filho com câncer é um desafio.*

DESCRIPTORES: *pediatria; família; enfermagem oncológica; criança*

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## INTRODUCTION

A significant number of children in Brazil have been struck by cancer, affecting their families and strengthening the disease's epidemiological importance, which has also given rise to studies about its diagnostic and therapeutic aspects.

The confirmation of the disease causes great suffering to parents. The family will have to live with the uncertainty of the prognosis and the consequences of an aggressive and painful treatment, producing feelings of anguish and negations that make them seek confirmation of the diagnosis<sup>(1-2)</sup>.

Despite technological advances in cancer treatment - through the arrival of new drugs, radiotherapy and surgeries - and the significant increase in the cure and survival percentages of children affected by this disease, treatment is still quite uncomfortable, invasive and threatening; it provokes a rapid and intense change in patients' lives and a disequilibrium in family routines and dynamics<sup>(3)</sup>. Families will have to face many difficulties during the entire treatment. They will have to seek ways of helping their child to overcome the situations of physical and emotional suffering caused by the disease and to deal with the problem of maintaining a healthy interaction among relatives<sup>(4)</sup>.

Families face problems deriving from treatment, as the aggressive therapy provokes several unwanted collateral effects, besides anguish, pain and suffering because they need to live with the possibilities of relapse, symptom exacerbation and death of the child.

Thus, cancer and its therapy can lead the child to emergency conditions. A cancer emergency can be defined as a clinical condition resulting from a structural or metabolic change caused by cancer or its treatment, requiring immediate medical interventions to prevent death or severe permanent damage<sup>(5-6)</sup>.

Literature presents the importance of getting to know the needs of family members who accompany their relatives at hospital emergency sectors. Reference is made to emergency sector environments, affirming that these are normally chaotic and that, on these occasions, administering situations that represent a risk to life and handling crises are priorities. Thanks to this particularity, the accompanying relatives' needs end up being neglected. It is also emphasized that family members

who accompany their relatives in the critical stage of a disease, at emergency units, should be considered as care units, and that there are as of yet few studies about their needs during this period<sup>(7)</sup>.

Parents' emotional burden when they experience emergency care for their child should not be forgotten, lacking information and communication to mitigate their emotions. Thus, nurses need ability to deal with parents and adequate communicative skills for each situation<sup>(8)</sup>.

This study aimed to understand how the families of children with cancer cope with the disease and its problems at home and how they make the decision to take them to emergency care.

## METHODOLOGY

To reach the study objective, a qualitative approach was used, with Oral History as the methodological strategy. This resource is used as a way of capturing the experiences of people who are willing to talk about aspects of their life, including the commitment to stick to the social context. It is applied to elaborate documents, files and studies about people's social life. Oral History departs from the premise about the past as something that continues into the present and whose historical process is not finished; moreover, it grants a meaning to the witnesses' and readers' social life, making them understand the historical sequence and identify themselves as part of it. In Oral History, the witness is considered a "collaborator", which implies a relationship of affinity between the interviewee and the interviewer<sup>(9)</sup>.

In this study, Thematic Oral History was used, which attempts to clarify or obtain the interviewee's opinion about a specific issue or preset theme. Objectivity is direct: it addressed external, objective, factual, thematic questions and its specific nature provides different characteristics<sup>(9)</sup>.

Getting to know people's actions while they experience certain situations makes it possible to anticipate some care actions, allowing for a more effective and active participation in care, including the possibility of intervention in case of risk<sup>(10)</sup>.

This research project was submitted to the Ethics Committee for Research Project Analysis at the University of São Paulo School of Medicine *Hospital das Clínicas*. Authorization was granted in August

2004. Initially, we requested the mothers' agreement to participate, in writing, through the Free and Informed Consent Term, which contained information about the research, that interviews would be recorded and that anonymity was guaranteed.

After their acceptance, interviews started and data were collected between October 2004 and March 2005. Six mothers participated, who accompanied their child's cancer treatment. The children were registered at a public hospital in São Paulo that is a referral center for child cancer treatment. Their ages ranged from 28 to 47 years. One mother was a widow and five were married. They accompanied the children during routine consultations, emergency care and chemotherapy and radiotherapy treatment.

These families were contacted while their child received care at the emergency unit. They were informed about the objective of the project and were asked to participate voluntarily. After they agreed, a day, time and place were set for holding the interview, always respecting the family's choice. Initially, we used an instrument with identification data and the following guiding questions: *Tell me: what is it like for you to live with a child suffering from cancer at home? What is it like for you to look for emergency care? How do you decide to come to the emergency sector? Who decides to come?*

Interviews were tape-recorded and took one hour on the average. Analysis involved three steps: 1) **Transcription**: is the rigorous transfer of the interview, after repeated careful listening to the entire contents, from tape to paper, including all of its lapses, errors, hesitations, repetitions, misunderstandings and the interviewer's questions; 2) **Textualization**: is the step when questions are removed and added to the answers, transferring the entire text to the collaborator, who assumes the first person as the only character. In this step, the narrative is reorganized so as to become clearer. Next, the "Vital Tone" is chosen, which is a phrase to introduce the narrative, as it represents its moral synthesis, and 3) **Transcreation**: during this step, the testimony is processed in a broader sense, by inverting the order of paragraphs; removing or adding words and phrases; using language instruments like punctuation, ellipsis and interjections, with a view to achieving a better understanding of the text.

This recreates the atmosphere of the interview, attempting to present the world of feelings provoked by this contact to the reader, which would

not happen if the testimony were reproduced word for word. The author infers in the text, which will be reworked several times and should comply with agreements reached with the collaborator. In this procedure, it is vital for the collaborator to legitimize the interview<sup>(9)</sup>.

After reading each testimony, we observed that the narratives expressed a peculiar meaning, perceiving points these histories had in common and which could be better explored with a view to a broader understanding of their contents.

Data analysis adopted the "Family Management Style Framework" (FMSF) as a theoretical model, which identifies cognitive and behavioral aspects that comprise the families' experiences in coping with their children's chronic disease. This model includes three conceptual components: **Definition of the Situation** divided in four conceptual themes: "Identity of the child", "View of the disease", "Ideas about the capacity to cope with the disease" and "Mutuality between parents". **Coping Behaviors**, divided in: "Parents' philosophy" and "Coping approach". **Perception of Consequences**, subdivided in: "Family focus" and "Expectations about the future"<sup>(11)</sup>.

## RESULTS AND DISCUSSION

Based on the theoretical model presented above, next, the results obtained from the mothers' testimonies are presented.

The first conceptual component of the model is the **Definition of the situation**, which refers to the meaning and the way parents see the child and the disease. These are key aspects for their definition of the situation, which influence the types of behaviors used to cope with the disease and incorporate it into the family routine<sup>(11)</sup>.

This component contains the **Child's identity**, in which the family, after the impact of the diagnosis, starts to perceive that the child will undergo a long treatment, which may cause consequences. In view of treatment reactions, children start to be seen as fragile and vulnerable to situations that used to be part of daily reality, and may present problems; hence, mothers start to define them as special and different from other children.

*... when you are familiar with the treatment routine of children with cancer, you know that there's nothing programmed*

*about them, they're like boxes of surprises and (...) they may need to come to the emergency care unit. (C1)*

The mothers start to perceive that the disease can affect the child's physical abilities and, consequently, psychosocial adjustment and, sometimes, even the family's.

*People came to visit us, I didn't like it when they kept on asking what my daughter had, why she was bald (...) I wanted them to know all that already. I lost many friends at that time, I didn't leave my house anymore. (C5)*

Another aspect to be taken into account is the **View of the disease**, which covers the parents' set of beliefs about the diagnosis, cause, severity, prognosis and course of the disease<sup>(11)</sup>.

The collaborators go back to the start of the disease trajectory, which was generally abrupt, without any known cause. From that point onwards, they start to elaborate definitions for the disease and spend a lot of their time trying to understand it. According to them, cancer is a destructive disease, with an aggressive treatment that entails a series of consequences for the child, creating suffering and, often, requiring frequent help from hospitals. The entire course of the disease is surrounded with uncertainties.

*I tell him that we cannot compare C. with us, he's different, (...) cancer is not like a flue ... (C3)*

Treatment is seen as extremely aggressive and able to impose additional clinical complications for the child. At the same time, it is seen as something necessary and a way of achieving cure.

*This treatment is like, really crazy, the chemo is terrible! But we have to do it. (C5)*

In this trajectory, the need to come to the emergency service represents uncertainty about treatment and the disease course as, for the mother, seeking emergency care represents that the disease is not under control and that treatment does not have effective results.

*... The impression I had whenever I had to bring her here (emergency unit - EU) was that treatment wasn't working. How could I trust treatment if she was at the EU and needed other resources? (C1)*

The adopted theoretical model also addresses **Ideas about the capacity to cope with the disease**, which refers to the interaction between the family's ideas about assessment of disease coping demands and its own abilities to perform these activities<sup>(11)</sup>.

*... I'm really scared of dealing with A. I guess that, because she's my daughter, I'm even afraid to touch her. I don't*

*take any measure with her when I'm on my own, I'm scared, it's as if I couldn't do anything. (C1)*

After the diagnosis, the children are put under surveillance and can no longer perform certain activities that used to be part of their routines. Particularly the mothers start a surveillance scheme of their sick child on a daily basis, seeking signs that something wrong may be happening and trying to avoid any kind of problem or accident.

*After he started chemotherapy, I started to value little changes he presented more. I was always looking for signs that could lead to a complication. (...) I do not usually let him alone for anything. (C3)*

Mothers living with children with cancer at home develop strategies to feel more secure to cope with the surprises of the disease. They use these strategies when they perceive that they are in a situation of minimal security to perform their role of delivering care and protecting their child. When beyond these limits, they turn to emergency care.

*If I perceive something different, my first reaction is to bring her to the EU, because I know that, when I arrive here, the doctors will examine her until they find what is causing the problem and start adequate treatment. (C2)*

Fear of the disease is more related to lack of knowledge than to the disease in itself<sup>(12)</sup>. In our study, one of the mothers expresses that the fact that she does not have knowledge about the treatment causes insecurity to stay at home with the child in case of any behavioral change, mentioning fear that the child may die. This makes her seek help through emergency care.

The search for information is one of the strategies mothers use to manage to perform their role with the desired responsibility level. Across treatment, parents and relatives accumulate experiences that make them more capable and secure for decision making in case of possible problems. When parents have the necessary information for care delivery to their child, they can provide care in a calmer way<sup>(13)</sup>.

*I know when she's fine or not based (...) on what her doctor says. (...), according to her, I know what to do and how to act with D., as I already know the whole treatment, it becomes easier to take care of her at home. (C4)*

Mothers also perceive their hospitalization experiences with the child and the symptoms perceived at home, besides conversations with other parents, as resources that facilitate decision making about managing the disease at home.

*(...) I perceived that her liver had grown, because one side of her belly was bigger than the other, which had already happened at the start of treatment, that's why I knew that it could be some problem related to the liver. (C2)*

The mother's assessment of disease coping demands also contains the need for physicians to obtain precise information about what happens with the child at home. The mother perceives she is committed and able to collect data about the child and present them to the medical team with precision.

*... I have to observe because, as the doctor herself says, I'm the one who spends more time with him and I have to perceive what's changing to be able to pass that information to the medical team and help in treatment. (C3)*

The children are fundamental resources in strategies to achieve this demand. Besides guarding them, the mothers also ask questions to obtain information about what may be happening, using strategies like: perceiving differences in their children and asking them questions to obtain further information about them. To the extent that parents become attentive to their children and aware of the symptoms they can present, or perceive changes in their general situation, such as temperature changes, they can decide about the actual need to seek additional medical help<sup>(14)</sup>.

*If I perceived that she was a bit sad, I undressed her, gave her a bath, asked if she was feeling well. I was talking and playing with her but, in fact, I was examining her body ... (C5)*

Another theme in this conceptual component is the **Parents' mutuality**, which addresses their perceptions in terms of how they share, complement or have discrepant view on how they define and manage the disease situation<sup>(11)</sup>.

One collaborator reports her experience in sharing the disease experience with her husband and highlights the importance of her husband's support when the child needs emergency care.

*Whenever we had to come her (emergency unit), she came playing and, this time, she was all sleepy and weak on my lap when we arrived. The guards at the reception desk did not want my husband to come in with me (...): I was desperate about seeing my daughter in those conditions, I didn't want to stay alone with her, I needed my husband's support at that time. (C2)*

The mothers' narratives point towards a discrepancy in how parents perceive and manage the disease, with different ideas, mainly when they decide to take the child to the emergency unit when they perceive that something may be wrong.

According to the mothers, their husbands are more tolerant to the symptoms appearing at home

and believe that the child can recover. The mothers, on the other hand, because they know the effects and risks of treatment better, do not accept to stay at home with their child because, as they feel insecure, they do not want to take the risk that something happens they cannot control alone.

*My husband does not always agree with me (...) I believe that, in his head, it's not very clear yet that the girl is ill. (C4)*

*I run to the doctor with my daughter at any time, my husband is calmer, he wants to postpone everything until tomorrow. (...) If it depends on him, he waits, he waits for a fever, waits for another, he thinks it will pass, that giving any medicine will solve the problem ... (C5)*

Mothers take care of the children, accompany treatment, carry out all care and master the information, besides making decisions about what will be done with their children.

*... when we have to come here, generally, I decide, because I remain in hospital with him and accompany him to the doctor, I know about everything. (C3)*

Another conceptual component of this model is **Coping behavior**, which refers to the principles supporting the family's behavior to cope with the disease and its ability to develop a routine to manage disease-related demands. It includes two conceptual themes: **Parents' philosophy** and **Coping approach**.

The **Parents' philosophy** corresponds to the principles their behaviors are based on, covering: objectives, priorities, values guiding the general approach and specific strategies to cope with the disease; **Coping approach**, related to the parents' assessment of the sphere through which they manage to develop a routine and strategies to cope with the disease and incorporate it into family life<sup>(11)</sup>.

In the light of their children's cancer, the mothers in this study assume a sense of responsibility with a view to providing the best care to their child together with the team. They live with uncertainties about when a new crisis can occur. Each day, they look for signs that can indicate some new complication that may emerge. They feel obliged to know the effects of treatment, so that they can know what it is and how to keep watch, in order to recognize all possible symptoms. Moreover, they attempt to anticipate possible complications, being ready to act at any time, if necessary. They see themselves as "key pieces" during the entire disease process. When the mother is faced with the impossibility of cure, she seeks the child's well-being and alleviating suffering becomes her main target.

In another study, the relatives mentioned that, as the disease advanced and the probability of death got near, care focused on avoiding or minimizing the child's pain<sup>(15)</sup>.

*She is receiving all medication intravenously and we are getting reasonable anesthesia; she has managed to be OK, but I want to establish analgesia with oral medication, so that we can go home. (C1)*

Some changes occur in family life, with a view to finding ways of coping with the disease. There is the fear that something will happen with the child without anybody noticing it.

Some of our collaborators mentioned they left their bags ready in case they had to take their children to the emergency unit; this routine decreases the stress of coping with the disease at home. To the extent that they incorporate the possibility of seeking emergency care, they feel more comfortable not to let the situation get worse at home. Emergency care is incorporated into the child's treatment.

It should also be emphasized that, even if emergency care is incorporated into the child's treatment as a possibility and reference for better coping during the course of the disease, it entails the meaning of possible worsening, lack of disease control and, consequently, fear, anxiety and uncertainties.

The last conceptual component is the **Perception of Consequences**, which refers to the dimension the disease occupies in family life, and its current and future reflection on the future of family life.

The conceptual theme **Family focus** comprises the parents' assessment of the balance between disease coping and other aspects of family life<sup>(11)</sup>.

The narratives present how the mother assesses the dimension or importance of the disease. Her own life is focused on the sick child, and she starts to live in function of him/her; she thinks about the family, other children, her husband, but the priority is her sick child. Mothers who used to go out to work gave up their job to be able to continue their child's treatment.

*I'm on leave from my job for over a year, almost exclusively taking care of my daughter. (C1)*

Mothers' whose children are not receiving treatment, but only undergoing examinations and control appointments, highlight that the results of routine tests become the focus in disease coping. This situation is accompanied by great expectation and uncertainties, as the possibility of a relapse or a metastasis is always near.

*Yesterday, she had to be hospitalized here at the emergency unit (...) a movie went through my head: the whole treatment just came back. (...) I always think she's cured, but I also know that this disease can come back. (C2)*

In the mothers' histories, the **Expectation about the future** is related to the fear of not managing to treat the children, which would result in their death. An important characteristic in their narratives is that the search for emergency care is related to the loss of control over the disease and the discovery of a new complication. This fact reminds them of the severity of the disease and their children's fragility to this enemy.

*When I decide to take her to hospital, I'm afraid that something may happen (...) afraid she'll die. (C4)*

Managing to stay at home with the child, without symptoms, behavioral changes and surprises is a sign that (s)he is well and that is the family's expectation.

## FINAL CONSIDERATIONS

The appearance of the disease makes the family open a space for flexibility, with room for new tasks, such as surveillance, and new events, such as the search for emergency care. Thus, coping with cancer at home involves activities like: monitoring the child's behavior, watching out for symptoms of the disease and regulating activities with a view to decreasing risks. Coping involves objectives that prioritize alertness to the disease and its signs, with a view to preserving the child's life with less suffering. The mothers become thoroughly responsible for the prevention of complications and for their children's well-being.

Several motives were mentioned for her decision to seek emergency care. No matter the motive, the final objective is always to guarantee rapid care for the child, with a view to minimizing the possibility of complications and preserving the child's life. She also looks for information about what is happening with the child and the reason for the problem. When seeking emergency care, she also attempts to guarantee that she acted correctly. Her competence to take care of the child needs to be acknowledged.

The mothers indicate that their daily experiences with the child at home are permeated by uncertainty related to doubts about the recurrence of

new symptoms, which can appear in function of treatment and the disease itself. Moreover, when symptoms appear, the mothers are frequently confronted with this uncertainty. Their doubts are related to how to deal with the symptoms and to their indecision about the right time to look for external help, such as emergency care.

Thus, the possible need for emergency care is incorporated into the family's daily reality as a resource to cope with the disease when it goes beyond the mothers' capacity to maintain the symptoms under control. However, they express the traumatic emotions they experience when they remember the incidents that occurred during their visits to the emergency unit.

Therefore, they use all possible efforts to treat their children at home. Nevertheless, when the symptoms continue or create mistrust about the possibility that something not visible may be happening, their first attitude is to go the emergency unit. They need to feel comfortable to stay at home and take care of the child.

Nurses' understanding of this intense cancer journey, permeated by the uncertainty presented in the mothers' narratives, affects care delivery to families. Understanding the mothers' perspective on specific events they experience with the child at home and the meaning she attributes to these events, relating them with the level of uncertainty they produce, can help to plan adequate interventions for each family.

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