



Childhood cancer: maternal perceptions and strategies for coping with diagnosis

Marcela Rosa L. R. Beltrão,¹ Maria Gorete L. Vasconcelos,² Cleide Maria Pontes,³ Maria Clara Albuquerque⁴

Abstract

Objective: To investigate maternal perceptions of childhood cancer and strategies for coping in a pediatric unit in Recife, Brazil.

Methods: This descriptive exploratory study was conducted using qualitative methods. The reports of 10 patients' mothers were analyzed according to a saturation sampling technique. The investigation was conducted in a pediatric oncology unit of the Instituto Materno-Infantil Professor Fernando Figueira. Fieldwork was carried out from March to May 2006 using observation techniques and recorded interviews to respond to three guiding questions. Content analysis and thematic coding were used, and recurrent themes were extracted from the categories identified.

Results: Mothers' ages ranged from 22 to 39 years, and two had only one child. The following themes stood out in the analysis of maternal perceptions of the moment that they were living: attitudes and feelings when the disease was diagnosed; information as support for coping; and social support.

Conclusions: Maternal perceptions of childhood cancer revealed a shocking, painful and despairing experience, as well as a sensation of loss that made life meaningless. The sources of family support were individual religious beliefs, family members, healthcare team and friends.

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Introduction

The number of cases of cancer has increased significantly all over the world, particularly since last century, and cancer has now become one of the most important public health problems worldwide.¹ The incidence of malignant neoplasias in childhood ranges from 1 to 4% of all cancers in population studies.² Cancer used to be classified as an acute disease with an invariably fatal progression, and was one of the most frequent causes of death in Brazil. Today it is classified as a chronic disease with chances of cure in most cases.³ Therefore, 70% of the children that have cancer can be cured when an early diagnosis is made and treatment is provided at specialized centers, where scientific and technological advances led to evident improvements.⁴

Studies in the literature point out that the moment when parents receive the diagnosis is stressing, tense and full of uncertainties, and may lead to painful experiences in the lives of family members.⁵ Families have to live with the disease and its meanings, as well as with concerns about the future and fear of death,⁶ which causes significant changes in family dynamics and relationships and affects dimensions that are external to the family.⁷ Chemotherapy protocols establish a great variety of medical procedures, but often do not provide guidelines about how to deal with patients and family members at the time when they learn the diagnosis or to help them cope with the situation.⁵ Coping requires constant changes in behavioral and cognitive efforts, and generates internal and external demands that usually exceed personal resources.⁸

1. Mestre, Universidade Federal de Pernambuco (UFPE), Recife, PE, Brazil.

2. Doutorado, Escola de Enfermagem de Ribeirão Preto, Universidade de São Paulo (USP), Ribeirão Preto, SP, Brazil.

3. Doutorado, UFPE, Recife, PE, Brazil.

4. Pós-Doutorado, Universidade Complutense de Madrid, Madrid, Spain.

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Families and children with chronic diseases, such as cancer, deserve special attention to deal with not only biological, but also psychological, social,⁹ economic⁷ and spiritual¹⁰ dimensions. Moreover, the family, together with friends and the hospital team, becomes part of the social network that supports therapy.¹⁰

Healthcare services, in their search for excellence, have adopted new paradigms that take into consideration the child's as well as the family's needs and, therefore, expand health-care provision.¹¹ Therefore, understanding how families deal with childhood disease may lead to changes in healthcare for the child-family dyad.⁵ The quality of care provided demands that systematic strategies be adopted to promote the health of all. Such strategies should take into consideration feelings, previous experiences and opinions,¹² and should also aim at the establishment of a healthy therapeutic relationship, so that decisions are clearly and honestly shared by the child, the family and the healthcare team.¹³

The constructs used as the theoretical basis of this qualitative study, whose purpose was to investigate maternal perceptions of childhood cancer and coping strategies, were care focused on the family¹⁴ and social support.¹⁰

Methods

This descriptive, exploratory and qualitative study was designed to investigate a reality that cannot be quantified because it is made up of meanings, motives, aspirations, beliefs, values and attitudes.¹⁵ Therefore, the reports of 10 patients' mothers were analyzed according to a saturation sampling method.¹⁶

The investigation was conducted in a pediatric oncology unit of Instituto Materno Infantil Professor Fernando Figueira (IMIP), a nonprofit and nongovernmental organization in Recife, Brazil.¹⁷

Fieldwork was carried out from March to May 2006 using observation techniques and recorded interviews to respond to three guiding questions: How did you feel when you found out that your child had cancer? What did it mean to you to participate in the social admission process? What has helped you to cope with this experience?

Inclusion criteria were: to be a patient's mother and the child's guardian; have not previously known the diagnosis; and having participated in the social admission process. The social admission process was a meeting with the healthcare team, composed by a physician, a psychologist, a social worker and a nurse, in which families obtained information and explanations about the disease. Exclusion criteria were: to be the mother of a child that had a neoplasia and was followed up in an outpatient service without any initial therapeutic intervention; and death of the child during the fieldwork phase. The protocol was approved by the Ethics Committee of the institution where the study was conducted, and participation was voluntary after the mothers received information

about the purposes of the study. To preserve anonymity, the mothers were identified by names of flowers.

The interviews were transcribed on the same day that they were made. The reports underwent content analysis, a set of techniques to analyze communications,¹⁸ and theme analysis to extract recurrent themes from the group of categories identified. This process consisted of classification of constitutive elements of a set by differentiation and regrouping according to analogy.¹⁸ Therefore, the categories of less amplitude became indicators of broader categories,¹⁹ without moving away from the initially attributed meanings.

Results and discussion

Mother's ages ranged from 22 to 39 years; eight were Catholic and two were Evangelical; and six came from cities other than the state capital. Four were married, four had a live-in partner, and two were separated. Three mothers were illiterate. Four had jobs, four were housewives, and two worked in subsistence agriculture. Four families lived on minimum wages, and two had no income. The children's ages ranged from 8 months to 12 years, and two had no siblings.

Three themes were identified in maternal perceptions: attitudes and feelings at the moment when they learned about the disease diagnosis; information as a support for coping; and social support.

Attitudes and feelings when the disease diagnosis was learned

Maternal discourses about the time when they learned about the diagnosis had an intense emotional component. They described the situation as an odd, shocking, painful, traumatic and despairing experience, which led them to say, for example: "(...) the worst sensation I have ever had. Yes, excruciating, horrible! The news was like an electric discharge; if I could die at that moment, I would have died. You never expect it to happen! We believe we are immune to such things" (Angelica). For Iris it was: "(...) a very strong pain. Life has no meaning, I don't feel like doing anything, like playing, dressing up, nothing!"

Sadness and doubts were associated with treatment outcomes: "(...) not knowing whether during the treatment she (daughter) will really achieve her goal" (Angelica). The moment of diagnoses revealed that: "The pain is the same as the pain of loss" (Dahlia).

Studies in the literature indicate that the path followed by family members is a difficult and complex experience that involves uncertainty, multiple feelings, and physical and psychological limitations.¹⁰

At the same time, the disease carries stigma and preconceptions, and is even seen as a synonym of death, as can be seen in the following excerpt: "This disease has no cure, it is hopeless! It is the disease that saws off the bones, the arms! 'That one is going to die!' (said by a neighbor according to

Hydrangea).” Dahlia explained: “People are scared. They think they are going to catch it. Is this disease transmissible?”

Sources other than the family, such as neighbors, friends or strangers, may be causes of stress¹³ when they make biased comments or look weirdly at the child. Therefore, it is evident that the family needs emotional support and guidance to become stronger and to cope with these experiences.

The meanings of cancer are reinterpreted along time through knowledge built on references, which may be continuously reformulated and restructured in each interactive process.

One aspect that should be mentioned in Gardenia’s discourse was the fear to lose her son: “I was afraid, I thought I was going to lose him. I wished a thousand times it were me, not him.” In this situation, cancer is often associated with death and fear.²⁰

Angelica interpreted the fear associated with the fact of having only one child as follows: “(...) the pain of the loss, when you have only one child; if you have more children, it is easier. God forbid, if you happen to lose him, there are others to take his place, to calm you down. But what if you have only one?”

Most mothers and children came from cities other than the state capital because our unit is a reference center for the treatment of childhood cancer, and, therefore, they missed other members of the family and were homesick, as Rosa reported while crying: “I have a 3-year-old son, it’s going to be 2 months that I’m here, I haven’t seen him, I miss him!”

The long duration and the perceptions about treatment led some mothers to say: “(...) I live far from here, I have to spend more time here than at home. I am here, but I’m thinking of my home” (Magnolia).

Several times the conflicts due to the multiple roles played by women in society, as mothers, wives, housewives, and workers, affect and intensify their emotional distress.²¹ When they are informal workers, they are not able to keep their jobs if they have to be absent to take care of their sick children, and are often dismissed.²² This situation was clear in Gerbera’s report. She is a housekeeper and lost her job because of the many times she did not go to work to stay with her daughter during hospitalization. She clearly states that: “(...) then I thought the lady I worked for would dismiss me, because she really threatened to do it”.

In other cases the negative experiences lived before the disease were perceived as threatening because of impotence and fear of the unknown²³: “I was very nervous because my grandmother died of this (disease), I despaired because I thought that it had no cure” (Rosa). Previous experiences may intensify or alleviate the emotional impact felt by the parents. However, nothing can prepare a parent for the fact that their child has a serious and threatening disease such as cancer.⁵

Information as support for coping

The social admission process described above was an important moment to receive the family. The value of the information²⁴ received on that occasion was stressed by some mothers: “(...) told you the whole truth, explained everything well, as it should be, what was going to happen, how to treat it. I understood many things that she (doctor) said, explained, and that I was not sure about. (...) there was a chance of cure, and that gave me faith, I believed in it!” (Magnolia). Rosa explained: “I thought it was good to participate because then the mother and the father become aware of what the child has, in case something happens!”

The diagnosis of a serious disease in the child is a stressing factor for healthcare workers that have to tell parents about it. Parents were satisfied when the conversation about the diagnosis was frank and open, and when the workers that provided it respected their privacy, allowed them time to express their emotions and answered their questions.¹³

The approach and type of communication used during this initial meeting were easy to understand, according to Hydrangea, who had never gone to school: “After that moment (social admission meeting) I was happier because they explained it very well... I did not understand it before, I don’t know how to read. And after that conversation, I know more, see?”

Information provided at the time of admission may have given families the opportunity to prepare to participate in the care of the child together with the healthcare team. Family members need to understand and participate in the situation to ensure protection to the child²⁵: “(...) the doctor called me and explained everything very well, that I have to take good care of him (son)” (Daisy). Violet said: “(...) it was good because I know what he (son) has, what he can eat, what he cannot eat. There, it all helps!” Complications that may appear during the long course of cancer have to be managed by constant follow-up by the healthcare team.

At the same time, learning about the diagnosis was a difficult and delicate moment for other families. The truth of the information about the diagnosis triggered ambiguous reactions, and one mother reported great distress: “That moment was very difficult, I was so stunned that I did not even pay attention to what she (doctor) was saying” (Dahlia).

The amount and content of the information triggered various emotional reactions that complicated understanding of what the healthcare team said. It should not be expected that all information is recalled, and it takes some time for it to be effectively assimilated. Discussions should be repeated so that information and reactions can be processed; such discussions will be opportunities for the team to give parents further information and explanations about a disease of such nature.¹³ “(...) I had so many things in my head” (Daisy).

Each family perceives information in a very particular way, and there is not a single model that applies to all.⁹ For

example, to mention a high percentage of cure may mean happiness and hope for some family members, but others may understand it as a death sentence. Some reports show how it was understood: "I learned in detail that he has only an 80% chance of getting cured" (Iris). All the findings in the analysis of this theme should be investigated qualitatively, and the views of the healthcare worker that is prepared to give the diagnosis to the family should be considered.

Social support

Several types of support¹⁰ were identified and characterized among children with cancer and their families: family, other families in which someone had cancer, friends made before and after the disease, hospital and healthcare workers, religious and financial support.

The first support mentioned by mothers and considered the most important to cope with the disease was the belief in God. Cure, comfort, security, and strength from spiritual faith were reported by some mothers. According to Dahlia, support was: "(...) in the force of God, and I am overcoming this situation, I can bear it. I leave it all in His hands, and He resolves everything. Be it whatever God wishes!" Violet said: "I prayed to God for strength, that He helped me, that my son may overcome it. Everyday I beg Him to give my son health, that he gets well!"

These reports are in agreement with findings in the literature that show that religion helps to overcome the fear of death, losses or suffering, and that people feel that the meaning of life is born again.²⁶

At the same time, a study reported that family was the first support option because they share difficult moments and responsibilities, give each other words of comfort and have compassion, and that distance is not a barrier.²⁷ The following report confirms it: "My mother is here with me. People in my family call everyday to get news, and my husband calls too" (Dahlia). One mother recognized that "(...) the aunts, who are the same as mothers, suffer a lot and are suffering to this day with me" (Gerbera). Although several types of support relieve suffering, the one obtained from family is also a way to keep the family united.¹⁰

A significant fact revealed that, even in face of marital problems, parents become closer to provide care to the child, which leads to family reorganization and reestablishment of forces. This may be seen in the following report: "The father is closer now, he comes to the hospital, we are more united. He was a little distant, we live together, are married, but he has a life out there, he works, travels, has other women out there. (...) We are going to grow, one will support the other" (Angelica).

Closer marital relations⁵ are an important resource to join forces and take care of children, as well as to bear and share the overload of the disease and provide comfort to family

members. Mothers should have a good relationship with their partners to overcome fear and suffering.⁹

However, Rosa, who came from a town far from the hospital, could only be visited by her husband when he got a leave from his job. "My husband comes whenever he can!" When the family does not have a support network at the time of disease and hospitalization, difficulties are added to those of everyday life.²⁸ Therefore, the less support, the more difficult and painful the experience.

Another source of support to face the situation arose from everyday contact with other people in the hospital and the friendships made there. The contact between patients' mothers is close, and their heavy load is shared and minimized: "(...) when we talk, we understand the case better, and it becomes easier. (...) if you have no one to talk to, it becomes too heavy!" (Violet). According to Hydrangea: "Friends (the other mothers) also give you advice, they have already experienced the same case, they overcame it, it helps a lot. (...) they say: 'What is the matter with you?' We are sad, then another mother helps, gives advice, it is a kind of relief." Sharing experiences also helps coping: "(...) I see worse cases, they (other mothers) are fighting. This gives me strength!" (Iris).

A study with mothers of premature newborns²¹ showed that their stay in the hospital made it easier to make them participate, to make new friends, and to share experiences, thus reducing suffering.

In a special way, equity, professionalism, dedication and attention from the healthcare team was one more form of support, and was confirmed by the following reports: "You (healthcare team) do not treat us with indifference; you treat everyone the same, it gives us greater strength" (Gardenia). "(...) the doctors treated us well, the doctors made great efforts. The people in the social service prepare us to go home, make all efforts to make it possible" (Magnolia).

The child and the family should receive clear and well defined information about the disease, treatment, and side effects, as well as about their place in society.²⁹ The healthcare team that is friendly and helpful becomes heroic,³⁰ which may positively affect the adaptation of the family to the disease. Moreover, an adequate three-way relationship (child, family and healthcare team) facilitates understanding of the extension and severity of the disease, promotes adherence to treatment, and spurs confidence among all those involved.⁹

The qualitative analysis of the reality of families led to the conclusion that a diagnosis of childhood cancer is a shocking, painful and despairing experience according to maternal perceptions. Social support to the family was found in individual religious beliefs, family members, healthcare team and friends. This support network helped cope with the disease and its biological, psychological and social effects.

This study suggests that further studies should be conducted with different participants, contexts and situation because no universal reality exists in this area of investigation.

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Correspondence:

Marcela Rosa Lins Rodrigues Beltrão
 Rua José Bonifácio, 1356/604, Bloco C, Madalena
 CEP 50710-000 – Recife, PE – Brazil
 Tel.: +55 (81) 9962.337, +55 (81) 3229.1285
 E-mail: marcelarlins@hotmail.com