ORIGINAL ARTICLE

MATERNAL PERCEPTIONS OF COPING WITH CHILDHOOD CANCER

PERCEPÇÕES MATERNAS ACERCA DO ENFRENTAMENTO DIANTE DO CÂNCER INFANTIL

PERCEpciones MATERNAs ACERCa Del ENFRENTamiento DEL CÁncER INFANTIL

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ABSTRACT

Objective: to understand the perceptions of mothers on coping with childhood cancer. Method: descriptive exploratory study with a qualitative approach. During the month of March 2012, nine mothers of children with cancer were interviewed while they were accompanying their children in a support center for children with cancer in the city of João Pessoa, Paraíba, Brazil. The technique of Collective Subject Discourse (CSD) was used for organization and interpretation of the data. The study was approved by the Research Ethics Committee, protocol No. 094/11. Results: the mothers revealed the major difficulties experienced during the illnesses of their children, emphasizing the influence of family support and divine strength as allowing them to be able to face such a situation. Conclusion: it was possible to identify and understand the circumstances relevant to the emotional condition of the mothers, which are indispensable in subsidizing the care provided by health professionals. Descriptors: Neoplasms; Child; Pediatric Nursing; Oncology Nursing.

RESUMO

Objetivo: compreender a percepção de mães acerca do enfrentamento diante do câncer infantil. Método: estudo exploratório descritivo, com abordagem qualitativa. Durante o mês de março de 2012, foram entrevistadas nove mães de crianças com câncer, as quais se encontravam acompanhando seus filhos em uma casa de apoio para crianças com neoplasias na cidade de João Pessoa/PB. A análise dos dados ocorreu à luz do Discurso do Sujeito Coletivo (DSC). O estudo teve o projeto aprovado pelo Comitê de Ética em Pesquisa, protocolo nº 094/11. Resultados: as mães revelaram as principais dificuldades vivenciadas durante o processo de adoecimento do seu filho, enfatizando o apoio familiar e a força divina para conseguirem enfrentar tal situação. Conclusão: foi possível identificar e compreender os aspectos inerentes às condições emocionais das mães, as quais são indispensáveis para subsidiar a assistência prestada pelos profissionais de saúde. Descriptors: Neoplasias; Criança; Enfermagem Pediátrica; Enfermagem Oncológica.

ABSTRACT

RESUMEN

Objetivo: comprender la percepción de las madres sobre el enfrentamiento del cáncer infantil. Método: estudio exploratorio, descritivo, de abordaje cualitativo. Durante marzo de 2012, fueron entrevistadas nueve madres de niños con cáncer, las cuales se encontraban acompañando a sus hijos en una residencia de apoyo para niños con neoplasias en la ciudad de Joao Pessoa/PB. El análisis de datos se realizó según el Discurso del Sujeto Colectivo (DSC). El proyecto del estudio fue aprobado por el Comité de Ética en Investigación, protocolo nº 094/11. Resultados: las madres revelaron las mayores dificultades experimentadas durante el proceso del padecimiento de sus hijos, enfatizando el apoyo familiar y la fuerza divina para conseguir hacer frente a tales situaciones. Conclusión: fue posible identificar e comprender los aspectos inherentes a las condiciones emocionales de las madres, indispensables para ayudar en la atención prestada por los profesionales de salud. Descriptors: Neoplasias; Niño; Enfermería Pediátrica; Enfermería Oncológica.

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INTRODUCTION

Childhood cancer, which is any cancer that affects all those under 19 years of age, until a few decades ago was considered an acute disease, with no possibility of healing, and which led to death. However, with scientific progress in all areas of pediatrics, childhood cancer has been changing regarding its epidemiological characteristics and it is currently considered a chronic disease. The incidence of chronic diseases in children, such as cancer, has increased and this may be related to reductions in the number of deaths due to preventable diseases. Factors contributing to this decline may include current policies for health promotion and prevention, the development of new vaccines and effective antibiotics, medications for mental and neurological disorders, and due to advances in intensive care and pediatric surgery, resulting in an improved quality of treatment.

Childhood cancer, when it is diagnosed and treated early, has an increasingly greater chance of being cured. Unlike cancer in adults, there is no clear association between pediatric cancer and certain risk factors or behaviors. It is known that cancers in children and adolescents have lower latency periods, often grow quickly and are more invasive; however, they respond better to treatment and most cases are considered to have good prognoses. The advent of chemotherapy has made the possibility of a cure for cancer no longer unattainable. Currently, 75% of children affected by cancer survive beyond five years after diagnosis.

Cancer, like any serious illness, triggers a series of stressful experiences that are full of suffering for the child and the family, as it involves prolonged treatment, requiring substantial care and lifestyle changes. The stressors are not only derived from the progression of the disease, but also from the chronic condition, considering the social, emotional, affective, cultural and spiritual aspects. These factors can lead to depression, isolation, hopelessness, inferiority and inadequacy, with an increased risk of psychiatric problems and spiritual suffering. Therefore, support for the affected child and his or her family is essential to provide them with skills and resources necessary to deal with these difficulties.

The process of diagnosis and treatment of childhood cancer, which is usually long and emotionally painful, consequently causes problems in the lives of the affected children and their families. It is noteworthy that in most cases, since the beginning of treatment, it is the mother who attends routine hospital visits and hospitalizations, provides care, and manages medication schedules, among other duties. Therefore, when diagnosed, there is a great emotional and psychological impact on the mother and child binomial.

Considering these aspects, the feelings of the mothers of children diagnosed with cancer are of interest for enhancing the establishment of healthy therapeutic relationships, with shared decision making, between the child, family and health staff, in a clear and honest manner. Understanding the challenges of the disease can inform changes in the work process aimed at children and their families. This raises the importance of valuing the discourse of the mothers of children with cancer regarding coping strategies, in order to aid professionals in developing humane approaches of support.

OBJECTIVE

- Understand the perceptions of mothers on coping with childhood cancer.

METHOD

A descriptive exploratory study was carried out with a qualitative approach. The research site was a Non-Governmental Organization (NGO) that works as a support center for children with cancer in the city of João Pessoa, Paraíba, Brazil. The same unit is a philanthropic organization that has existed since 2005 through the initiative of professionals in the field of health and some volunteers. The goal of the unit is to improve the quality of life of children and adolescents with cancer from all over the State of Paraíba that are treated in João Pessoa. The NGO provides food, hygiene, physical rest, ambulatory care, food baskets, as well as affection, attention, and many other services to support the children and their families.

The study was conducted with nine mothers who were accompanied by their children in the aforementioned institution. In qualitative research, the critical factor is not the number of subjects involved, but the intensity with which the phenomenon occurs. Therefore, there was no minimum number of participants required for the study. The inclusion criteria used were a minimum age of 18 years and subjects must have been accompanying a child with cancer at the NGO. The exclusion criterion was having trouble communicating verbally.

It is noteworthy that the researchers respected the legal and ethical aspects of the research involving humans, recommended by
It was observed that most participants had an understanding of the disease and its treatment, as they reported having received information from health professionals, especially from those working in specialized units.

The mothers also reported that, on numerous occasions, their children had undergone multiple diagnostic hypotheses, due to childhood cancer being confused with other diseases. The final diagnoses of cancer were almost always late with the disease being in an advanced stage and many times without the possibility of a cure. This is consistent with the findings of previous studies. They also emphasized the importance of staying informed, and that they sought to learn about the disease using the media such as television, the radio, newspapers, and mostly on the Internet.

Question 1 asked “Could you tell me about being a mother of a child with cancer?” From the responses of the participants, only one Central Idea emerged, which emphasizes the sadness and the support in God that allowed them to be able to face the disease (Figure 1).

RESULTS AND DISCUSSION

The participants were mothers with ages ranging between 18 and 50 years with jobs related to domestic work and a family income of one to three minimum wages.

<table>
<thead>
<tr>
<th>CENTRAL IDEA 1</th>
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<tbody>
<tr>
<td>I felt sad, but I am now prepared to tackle the disease</td>
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<tr>
<td>COLLECTIVE SUBJECT DISCOURSE</td>
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<tr>
<td>I could not believe it, no mother would want this. I cried a lot, felt sorry, I never thought about having a sick child. I was very shaken, as any mother would be. For me, I saw the dying hour, I thought he had a lump that had no cure. I was very upset and I was hospitalized several times. At first I suffered a lot, but then God helped me and gave me strength, I know that today I can fight the disease. I'm prepared for anything, because God gives me comfort and I believe this is an important learning experience in my life.</td>
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Figure 1. Central Idea 1 and the collective subject discourse of the research participants in response to question 1.

Given the CSD of the study participants expressed in Central Idea 1, it is noteworthy that the time of the diagnosis is one of much anguish, stress, and tension, loaded with great sadness and uncertainty, permeated by intense emotional components described as a desperate experience, which was demonstrated by crying and feelings of impotence and/or incapacity.

Thus, the time from diagnosis and onwards in coping with the disease can lead to a painful process in the families’ lives. At this time, they have to deal with a new reality with many meanings, besides the concerns about treatment and the fear of death, which leads to unveiling changes in family relationships.

In this context, the moment of cancer diagnosis has a great impact on the mother, as described in the CSD, as it is the event that is perceived as a threat to the integrity of her child, thus demonstrating feelings of incapacity. This makes the disease process an occurrence of much suffering and pain, in which the possibility of loss seems to cause an interruption in the mother and child binomial. The feelings of significant impotence by the mother at the time of diagnosis present because, from the time of pregnancy, great expectations for the child have been generated, hoping that no complications ever occur. Therefore, when the disease is identified in her child, the feeling is that her dreams for the normal development of the child are disrupted.

Another important point perceived in the discourse is the non-acceptance of the cancer at the time of diagnosis, since the disease...
Maternal perceptions of coping with... 

Central Idea 1: My family helps me, giving strength and love. 

My mother, my brothers and sisters, my grandparents, and all of my family talk a lot, giving me strength, support and love. They pray for him and for me.

Figure 2. Central Idea 1 and the collective subject discourse of the research participants in response to question 2.

The CSD shows that the family is important at this time because it gives strength and love. The family of the patient with cancer is considered the main source of support for the patient and especially for the binomial, which are considered a unit of attention. The disease should be treated as a family problem.

With the appearance of the oncological disease, family relationships can be altered, as these are affected by the way each individual deals with living with the disease and its meanings, especially considering the stigma of death that it carries, causing a negative impact on peoples’ lives. The oncological disease can trigger previously existing (apparently fixed), or hitherto non-existent malfunctions in families, but it can also be a factor of cohesion between people.

Spirituality is presented as the foothold on the meaning of life for the family. The disease, causing suffering for the family, pushes families to life’s limits, producing the need for a relationship with the divine. In these circumstances, the CSD shows that spirituality provides a source of support, because it promotes access to social networks and introduces forms of assistance, especially in stages of anguish. Such support appears from religiosity, especially in the form of prayers, searching for some comfort through faith, which is intended to relieve the suffering and focus attention on hope. Such an attitude enables the family to find strength and comfort. Furthermore, it assists in decision making and overcoming discouragement, thus improving quality of life.

Question 3 asked “How do you cope with the situation?” The CSD of the participants involved in the study reveals, according to Central Idea 1, that they look for support and strength based on spirituality, placing their suffering in the presence of God, in which they find acceptance. Faith of the study participants reportedly resulted in the expression of feelings of hope.

Figure 3: Central Idea 1 and the collective subject discourse of the research participants in response to question 3.

Spirituality is part of human nature, which must be discovered from experience and individual discoveries. This includes a personal search for a meaning and a purpose in life. It deals with transcendence, where the inner essence of the person is to be found. Therefore, having a connection with oneself and with the environment, where God is an integrating factor of a human being, is essential for the welfare of the person.

Another aspect that emerges from the CSD of the study participants is the search to try...
to understand the concerns that afflict her sick child, in order to offer him or her better attention and care. In this context, mothers look to communicate with their children, to understand their suffering as sick people, in order to offer them better attention and care. For the study participants, feeling that they are being good mothers in the situation of the
disease is vital, and it keeps the mother in a position to control the process, involving having the competence to meet the demands of the child throughout the process.21

Question 4 asked “What do you hope for, from now on?” The CSD revealed only one Central Idea, which emphasizes faith (Figure 4).

![Central Idea](Figure 4: Central Idea 1 and the collective subject discourse of the research participants in response to question 4. From the CSD analysis regarding Central Idea 1, it was possible to observe that spirituality and religiosity are key factors for mothers in coping with the disease. In this perspective, the interviewees revealed the search for mechanisms to deal with the process of their child’s illness, such as the faith that they placed in God.

The presence of spirituality and feelings of faith and hope coming from a higher power, a divine being, is posited as a mechanism to boost the anguish and uncertainty associated with the treatment and to provide the means to handle the situation.13 According to the literature, through this mechanism, some mothers have found relief from the anguish.22

The faith that mothers have in God is a condition that contributes to their maintenance of hope during the diagnosis and treatment. This relieves their distress and allows them to perceive meaning in their lives.

It can be observed in the CSD that the acceptance of the disease by mothers occurs mainly as they gain knowledge regarding how to tackle the illnesses of their children, the increased care required by the children, and as they develop the ability to react in the face of obstacles. It is noteworthy that the denial experienced from the moment of diagnosis is perceived in the first Central Idea until the other moments of confrontation, revealing that mothers go through different stages of grief: denial of illness, anger, bargaining, depression and acceptance.23 The sick person and/or their family do not always go through all of the stages nor do they experience each one on its own.24

Based on the results of the present study, it can be observed that, during the course of the disease, the mother will get closer and closer to reality in her acceptance of the

CONCLUSION

The present discourse allowed us to understand aspects inherent to the chronic cancer condition faced by mothers of affected children, which are indispensable in subsidizing the care provided by the health team and by nurses, in particular.

The moment of diagnosis and the course of treatment cause a great impact on the mother, when she finds herself powerless against the possibility of the loss of her child, which makes her experience intense anxiety, in addition to insecurity and fear. The mothers expressed feelings of sadness at such situations, causing them to confront the duality of thoughts about the recovery or death of their child. Even though mothers said that they felt prepared to tackle the disease, they still become fearful at the prospect of death.
The mother puts all her hope in the support coming from God, then clinging onto spirituality as an attempt to increase her faith and hope in finding a cure for her child. At this moment, she becomes in touch with “herself” in order to minimize the suffering. Thus, the spirituality of her “being” and support in the divine motivates her to have more hope, thus assisting in her acceptance of the disease and treatment. Despite all the suffering inherent to the chronic condition, it is in the hope of healing that she gains the strength to face such difficulties.

Given these considerations, it is essential that the health care team, especially nurses, can understand such moments lived by the binomial, to be able to provide care in a humane and comprehensive manner. This is essential for the continuity of the treatment. In this context, nurses should develop actions in their work environments that allow the mother to discuss and develop strategies for dealing with such suffering, since it largely dictates the good emotional condition of the child during the course of treatment. Furthermore, it is up to the nurse to open lines of communication and have the sensitivity to listen to the demands of the binomial in order to improve care.

In a humanized perspective, the hospital environment allows the creation of mechanisms that can assist the mother, during the monitoring of her child, in expressing her suffering while providing continuous knowledge of her emotional state. This can assist in making the care of the mother’s emotional well-being a basic condition, unveiling a look at the child in his or her uniqueness and not solely due to the disease.

This study may serve as a reference for support and an instrument for reflection that improves understanding of optimal strategies to assist the mother of a child with cancer. In addition, this may contribute to the creation of new research on the subject.

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