Mothers' Perception on Recreational Activities in the Treatment of Childhood Cancer

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Abstract

This study aims to understand the perception of mothers of children with cancer from playing. This was a qualitative study, carried February and April 2016. Six mothers were interviewed, who accompanied their children during treatment at a non-governmental organization (NGO) that functions as a support house for children and adolescents with cancer. From the organization of the empirical material, two categories emerged: The mothers’ perception on the playful during the oncological treatment and the spirituality adopted by the mothers after the discovery of the diagnosis. The conclusion is that playfulness fulfills a therapeutic function assisting the child in his/her development, providing joy and pleasure. Mothers, on the other hand, find in faith the strength not to lose hope in the continuity in the caring process. Thus, it is evident that mothers seek the best for the child’s well-being, in an attempt to minimize the suffering generated by the experienced situation.

Introduction

Childhood cancer can be understood as a group of chronic non-communicable diseases that affect children and adolescents from zero to 19 years old, which has in common the appearance of modified

Keywords

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cells that multiply quickly and disorderly in some organ, interfering in its operation. In childhood, the most common types of cancer are leukemia, brain tumors, lymphomas, kidney tumors, sarcomas, among others [1].

The National Cancer Institute (INCA) shows that, in Brazil, cancer represents the first cause of death from illness among children and adolescents from one to 19 years. Of them, there is estimative that around 70% can be cured if the diagnosis is early and the disease is treated in specialized centers. This is because, although childhood and juvenile cancers have a short latency period, high rates of proliferation and a greater invasive character, it presents better responses to treatment since early discovered [2-3].

The cancer diagnosis, like any serious illness, triggers a series of stressful and painful experiences for both the child as his/her family. It involves a prolonged and painful treatment, needs care and changes, which in turn, come not only from the progression of the disease, but from the chronic condition, considering the social, emotional, affective, cultural and spiritual aspects, causing problems in the life of the child and his/her family [4].

In that context, it is essential for the child to have support from parents or relatives to face the difficulties inherent to the disease and to the treatment, since that support favors the adaptation and adherence to the selected therapy [1]. In that sense, it is important to be attentive to not only the child and his/her diagnosis, but also the people who live with him/her, his/her caregivers, especially the mothers [5].

The mother is usually the primary caregiver and, in many cases, the only one, since she is the family member who cares for her child full time, which causes them a physical and emotional overload and marital difficulties. The mother of a child with cancer expresses her feelings as fear of confirming the diagnosis, of the uncertainty of treatment, of not knowing how the child will react to the treatment and, if, at the end, her child will be cured or not [6-5]. In most cases, after beginning the treatment, the mother is responsible for taking on the routine of hospital visits, hospitalizations, care, medication schedules, among other intercurrences [4].

Given the exposed, when a child has cancer, it is necessary to establish strategies that ease the suffering of the child, and, therefore, of his/her mother as well. This is possible from playful activities, such as playing [7]. A study [8] states that play is the most important activity in the child's life and assumes various forms of contribution to child development and is crucial for his/her motor, emotional, mental and social development, defended by the Declaration of the Rights of the Child of the United Nations and the Child and Adolescent Statute [8].

In that perspective, play appears as a possibility to express feelings, preferences, fears and habits; a moment of relaxation, mediation between the family world and new or threatening situations; and of unknown, amusing or unpleasant experiences. In that sense, recreational activities are seen as a therapeutic space capable of promoting not only the continuity of child development, but also the possibility of the child to understand better that specific moment of his/her life [7].

Based on those considerations, play is an important strategy to minimize the suffering and stress experienced by the child during the treatment and, thus, to promote a significant improvement in the quality of life of the child and the mother, because it allows the mother to see her child improvement. Therefore, this study had as guiding question: What is the perception of mothers regarding recreational activities in the treatment of childhood cancer? Therefore, the objective was to understand the mothers’ perception on recreational activities in the treatment of childhood cancer.
Method

This is a qualitative field study, in which the research scenario was a non-governmental organization (NGO) that functions as a support house for children and adolescents with cancer in the city of João Pessoa/PB. It is a non-profit civil association founded in 1997.

That institution welcomes children with cancer from all over the state of Paraíba and treated in João Pessoa/PB and their respective caregivers, and counts on the participation of health professionals and some volunteers, aiming to offer quality of life during the course of their treatment. The NGO also offers food, hygiene, physical rest, outpatient care, food baskets, in addition to caring, attention and many other actions to support the child and his/her family.

The total number of participants was defined during the process of data collection, not being stipulated a priori. It followed the sufficiency criteria, since the qualitative research, as explicitly stated by Minayo [9], values the quality in which the phenomenon occurs and not the quantity. Considering that the empirical material enables organizing a comprehensive representation of the investigated problem, the total study sample consisted of six mothers.

For the purpose of eligibility of empirical data, the following inclusion criteria were adopted: being a mother aged eighteen years old or more and having been accompanying a child with cancer to the NGO for at least six months, in order to be able to report more accurately the importance of playful activities during the treatment of her child, as well as participate in playful activities offered in the routine of the mentioned association to her child. As exclusion criterion: having problems to communicate verbally.

Data collection took place between February and April 2016. At the beginning of the collection, the Informed Consent Form (ICF) was presented to the mothers, highlighting the objectives, justification and methodological procedures for their subsequent signature.

In order to maintain the anonymity of the participants, the statements were identified using flowers names (Rose, Arum Lily, Sunflower, Lily, Daisy, Tulip). Flowers symbolize nature in its greatest splendor, reflecting everything that is passive and feminine, symbol of harmony and life cycle.

As a way to make the collection of empirical material possible, the semi-structured interview technique was used, through the digital recording system, containing a structured script with the following guiding questions for the study: “What is your experience during your child's playfulness with the treatment at the Support House?”, “What strategies to cope with the illness of your child do you use?”. There was a qualitative analysis of the empirical data from the statements, in light of the relevant literature.

As for the structuring of the empirical data, one sought to make them feasible and to contemplate them in their particularities, using Bardin’s categorical content analysis. This is a set of techniques of communication analysis that aims to obtain systematic procedures and objectives of content description and messages indicators, which enable inducing information on categories of production of such messages [10].

It is important to emphasize that this research is linked to the project entitled Experiences of Children, Adolescents with Cancer and their Families at a Support House, approved by the Research Ethics Committee of the Federal University of Paraíba (UFPB) under protocol No. 1.286.4436 and CAAE: 49111315.8.0000.5183. The ethical principles contained in Resolution No. 466/12 of the National Health Council were respected.

Results

The study sample consisted of six mothers, three mothers of female children and three of mothers of
male children. One mother is married, one widow, one divorced, and three are single. Most of them (four) are from the urban zone and are teacher, housewife and farmer. Regarding religiosity, five are Catholic and one evangelical, but always believing that faith brings relief and give strength for continuity of care. As for length of stay in the support house, the shortest time is six months, and the longest, nine years. It is noteworthy that all mothers have more than one child.

From the organization and analysis of empirical material, the following categories emerged: Mothers’ perception on recreational activities during the treatment of childhood cancer and Coping Strategies employed by mothers on the discovery of the childhood cancer diagnosis. Those categories express the essence of the phenomenon studied and are described below.

Mothers’ perception on recreational activities during the treatment of childhood cancer
In this thematic category, the child and his/her family involuntarily enter into a context different from their reality. The mother, for assuming the role of primary caregiver of the child, observes that the games correspond to a fundamental activity, acting positively during the period of treatment and coping with the disease.

Given the explicit discourses, the use of play activities minimizes the physical, psychological, social and spiritual stress of the child. The following discourses of the mothers show that the developed activities contribute to an improvement in the child’s behavior, since the confirmation of the diagnosis and the beginning of the treatment can cause, in most cases, behavioral changes such as fear, anguish, aggression.

I noticed that with the games he was changing more the behavior. At the beginning of the treatment, he went through a phase when he was very aggressive and I saw that with the jokes he improved, getting calmer.

Arum Lily.

I see the games as fundamental. I see motivation and joy in them. The games played show a change both in their behavior as in their treatment.

Rose.

In that perspective, it is plausible to observe in the following reports the main feelings of the mothers during moments of playfulness with their children are joy and contentment, since the benefits of recreational activities are noticed both in the

Play is essential. They spend so many days stuck in the hospital and the jokes help a lot to disappear. They get distracted.

Lily.

Play is important because they are distracted mainly at the beginning of treatment, because it is very tense and them playing helps to improve.

Sunflower.

Play is essential. I think it is very important to face the treatment [...]. They get distracted, forget a little of what they are living.

Tulip.

My daughter is very cooperative. She learns easy, tells everything she learns, and that is a form of relief for me.

Daisy.

In that context, the following discourse reports the mother’s perception on how the play promotes a follow-up of the construction of a moral education, providing a feeling of hope during the treatment period, given that playful care favors the child’s growth and development.

I notice her change during the games, I think they are very important for the treatment.

Arum Lily.
children as in their relatives, who feel stimulated to continue to fight against cancer.

**Sometimes she stays there quietly in the corner, it is so bad and when I see her getting distracted, joking, for me it’s very good [...].**

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**[...] I see jokes as a positive form for her. They are great, she has fun, she likes it so much and I get happy.**

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**Play is essential. I think it is very important to face the treatment [...] I am very happy**

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The faith itself. The key word is Faith. I have been to church very little, because I spend most of my time here.

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For facing it, only God and Our Lady in the front, much faith. And you have to love your son very much, because it is very difficult to face it.

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Thus, the daily reality of mothers caring for children with cancer has the need for adaptation strategies, such as spirituality and religiosity, since they are present in people's lives in the most difficult moments and this can be evidenced in the following reports:

**Faith in God, without it we have nothing. I just know that I have never imagined that I would have so much strength. But, thank God I had patience and I was strong**

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**Faith is very important. I gave it to God and He gave me the strength to help him.**

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**Faith in God, without it we have nothing. I just know that I have never imagined that I would have so much strength. But, thank God I had patience and I was strong**

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**Faith is very important. I gave it to God and He gave me the strength to help him.**

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Religious practices aim to alleviate and solve problems. The mother has spirituality and religion as promoters of comfort, strength and faith and try to pass that experience to her children, whom she finds support to follow in the fight against cancer.

**Faith in God and kneel and ask God for strength. And her willpower. We realize that she wants to live, she plans for her life. She prays for her and her little friends. It gives us a lot of strength.**

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**Faith in God and kneel and ask God for strength. And her willpower. We realize that she wants to live, she plans for her life. She prays for her and her little friends. It gives us a lot of strength.**

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However, faced with a discouraging prognosis, mothers experience a dilemma especially related to the uncertainty of their child’s future. Fear, in-
security and despair become part of the maternal universe and, from that perspective, spiritual assistance brings benefits that allow mothers to face that new reality with less anxiety, giving them strength in the continuity of the process of caring for the child.

Discussion

In view of the situation experienced by the mother who has a child with cancer, in addition to the child with cancer, the family is impacted by the alterations not only from the disease but also from hospitalizations and treatment. The family, especially the mother, is the child’s primary social support network and provides most of the structure and support needed to deal with the difficulties of falling ill. That family support directly influences the way the child is going to deal with his/her illness, thus being essential to have a careful look at how the family will experience the entire process of the child’s illness [11].

Nevertheless, experiencing the disease becomes a disturbing context, because the sick child needs almost exclusive dedication, becoming the focus of attention by their caregivers. The mother, in the face of that moment of pain and uncertainty, feels as if she has failed in her natural instinct for protection, and suffers with doubts regarding illness and treatment, as well as for fear of something going wrong or even the clinical condition getting worse. In the uncertainty of the prognosis, the fear of death, depression and anxiety begins. [12].

As a result, the child has difficulty to accept his/her existential condition, since such condition arouses a feeling of revolt, which makes him/her feel different from other children, in the face of the physical changes that occur in his/her body, for the transformations are particularly troublesome in the presence of the limitations imposed by the disease [13]. Therefore, for the mothers participating in this study, recreational activities are fundamental, since they improve the children’s quality of life, since they get distracted and rescue the child being.

In that way, the sickness and hospitalization of a child with cancer represent ruptures in his/her daily lives. The child happens to be in a limited place, where hospital routines and the environment itself diminish the repertoire of activities he/she used to perform, which can interrupt his/her natural development. Moreover, due to the child’s own health condition, he/she is instructed to avoid certain actions and contact with other patients, which reduces the child’s interaction with people and, sometimes, causes fear in the face of illness and treatment [14].

Childhood is a phase of life when children tend to occupy most of their time playing, a fundamental action to maintain their physical and mental health and can include objects and occur individually or in a group. The ludic presents as a strategy that can minimize the discomforts caused by hospitalization and help in coping with the disease, besides being a resource that facilitates the nursing intervention, and should be incorporated as a care phase for children with cancer [14].

According to the statements of this study, when accompanying her son, the mother says that such playing process contributes positively during the treatment, which provides motivation and joy. Thus, play is a child’s need and means for him/her the way to develop in all aspects, whether physical, emotional, cognitive or social. Maintaining recreational activities for children with cancer is recognized as an important tool for the improvement and positive coping with disease and treatment. Besides being a promoter of the child’s development, playing is also a source of pleasure for the child, it is when, for a few moments, he/she forgets his/her difficulties of illness and treatment and enters in the fantasy world [15].

Thus, the rediscovery of the pleasure of playing provides benefits for the child’s biopsychosocial development and for his/her families, who, when
perceiving the child reacting and playing, also feel stimulated to continue in the fight against cancer [15]. From this point of view, the results of this study show the contentment of mothers in the face of the games performed with their child, during the period when they are at a support house. For them, when seeing their children relaxed, they feel a relief and a decrease in suffering, because, at that moment, they perceive a well-being in the child.

In that perspective, in the search for strategies to minimize the suffering of the child and his/her relatives, especially the mother, faith also appears as a source of support to face the presence of childhood cancer. Experiencing a child in cancer treatment, so exhausting, ends up being ameliorated through the confidence that the miracle of the cure can occur [16].

Mothers believe there are sovereign forces capable of healing their child through faith or spirituality and religious practices. That attitude is demonstrated through prayers, attributing to God the hope that the lived experience will get better. Religiousness and faith are present in people's lives, especially in the most difficult moments [17-18]. In the course of the study, the reports evidenced that mothers carry that faith with them and try to pass on to their children, since it gives them strength to follow in the walk.

Spirituality encompasses a broader concept of personal character in which there is a relationship with the divine and may or may not lead to religious practices, while religiosity refers to an organized system of practices and beliefs in a sacred and transcendent force that commands the universe [19]. In that sense, spirituality, inherent to the human being, refers to the human search for meaning in life, through a relationship with oneself, with others and with the Divine [20].

Nonetheless, religion and spirituality appear as sources of comfort and hope for caregivers in the face of a challenging moment, and have demonstrated to be a means of helping in the better acceptance of the chronic condition of the child with cancer [16]. Faith and spirituality have been recognized as important internal coping resources as well as social support strategies. A study carried out in the state of São Paulo highlighted that the use of faith decreased the anxiety, stress and feelings of depression presented by patients and relatives [19].

Therefore, the mother feels confident and finds the strength to face, along with her child, that process of becoming ill, since religious belief constitutes a structured symbolic system in which human attitudes, values and practices of love, affection and empathy are capable of assuming an ideological function and promoting the fortification of the maternal and child bond. Thus, it is through the spiritual dimension that the mother feels protected, welcomed and able to face the adversities of her child's illness, finding in faith and in the religiosity the necessary support to proceed with the treatment of the child, accept the situations experienced and overcome the obstacles [17, 21].

In view of the exposed, religious practices shall be respected in therapeutic settings, in order to allow a better psychological adaptation of the mother, minimizing the effects of stressful events and reducing depressive feelings that may arise due to the child's health-illness process [17, 20]. In this way, the caring process follows from the child to his/her accompanying mother, and needs spiritual and religious support during that period of adaptation.

**Conclusion**

The children, in front of the revelation, temporarily stop performing their activities and start to live another routine, based on hospitalization, chemotherapy sessions, and exams, among others. It reduces the contact with family and colleagues. Through the promotion of play, the child becomes safer and finds in the games a way to improve and cope with the disease and treatment.
When analyzing the statements of the mothers participating in this research, the impact of the discovery of the diagnosis of childhood cancer causes them a swirl of feelings, prevailing impotence, fear, insecurity and hopelessness.

The mother, for assuming the role of primary caregiver, does her best to protect the child from the complications that may arise during the therapeutic treatment, because, when noticing there is a threat to her child’s life, she is more exposed to stressful situations, relinquishes of personal attachments and often turns away from the rest of the family to devote herself to the child at such a delicate time.

As a result, the mothers feel more fragile and seek in faith strategies to adapt and react in an attempt to have the necessary control and not to lose hope in the continuity in the caring process.

The study presented some limitations, such as a reduced number of participants, which did not allow a greater generalization and comparison of the results, in a more detailed way, in order to comprehend, in a broader way, the perception of mothers in the presented context.

However, mothers of children with cancer need support from a multidisciplinary team, especially professionals who use recreational activities as a way to minimize the suffering, given that the cancer diagnosis has a great impact on their lives. In order to do that, it is necessary to carry out new studies to raise the knowledge about the perception of mothers on the playfulness faced with the confrontation of childhood cancer, as an important therapeutic function, generating joy and pleasure for the child and the mother, who sees her child reacting and feels stimulated to contribute to the child’s well-being.

Given the exposed, recreational activities are important to support the practice of palliative care, aimed at children with cancer and accompanying mothers, who need continuous support throughout the experienced situation.

References


