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FEELINGS AND LIVING OF FAMILIES OF CHILDREN WITH CANCER IN THE AMAZON CONTEXT

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ABSTRACT

Objective: To describe the feelings and experiences of relatives of children with cancer in the Amazon context in a reference hospital in oncology in the city of Belém-Pará-Brazil. **Methodology:** Exploratory study of a descriptive nature with a qualitative approach, carried out in a Reference Hospital in Pediatric Oncology in Belém do Pará, family participants of children hospitalized with cancer. A semi-structured interview was used, through the methodological reference of the family evaluation of the Calgary Model. From there six categories were raised and discussed. **Results:** The impact that the families suffer, caused by the diagnosis of cancer in the child, has been evidenced, repercussions in the activities of life, work, intra-family relations, suffering, and doubts. It is still evident that the lack of qualified professionals in this type of assistance also has repercussions on the family. **Conclusion:** The family evaluation allowed to identify that the majority of the families participating in the study were nuclear. One characterized as extended family and the overload as to the care that falls on the primary caregiver-mother. The child and his / her family need to be qualified and systematized assistance in order to enable paths that foster feelings of hope, confidence, and confidence regarding the treatment and consequently with a satisfactory prognosis.

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INTRODUCTION

Cancer is the name given to a group of different diseases with different causes, Manifestations, treatment, and prognoses, has in common the disordered (malignant) growth of cells that invade the tissues and organs, and can spread to other regions of the body, a phenomenon this so-called metastasis. (BRUNNER & SUDDARTH'S, 2009). Several factors contribute to the fact that cancer has a differentiating

characteristic of other chronic diseases, as well as the physiological issue. It also has a substantial psychological impact on the individual and family. Triggering feelings such as fear, anxiety, anguish, doubts, and anger - a disease that remains strongly stigmatized, surrounded by mysteries and uncertainties, having a negative impact on the lives of the people involved - not only for its social and economic repercussion, but also for the agony that the patient and his family come to experience. (RIBEIRO & SOUZA, 2012). Chronic diseases such as cancer, even in the face of technological evolution with significant evidence of cure, remains a disease of unknown causes and with inefficient

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treatments. Nowadays, new research shows that oncological disease is a treatable chronic disease. In the vast majority of cases, it has a cure, especially in early diagnosis (SALES *et al.*, 2012). In Brazil and the world, pediatric and juvenile cancer is considered a public health problem due to the high mortality rate, responsible for about 13% of all causes of death in the world. (BRASIL, 2009). By 2020 It estimates that the number of new cases per year will be around 15 million. In Brazil, cancer mortality represents 13.7%, leaving only circulatory diseases, with a percentage reaching 27.9%. Deaths from external causes appear next, with 12.4% (BRASIL, 2008). The most common tumors in childhood and adolescence are leukemias (affecting white blood cells), central nervous system and lymphomas (lymphatic system). They also affect children and adolescents neuroblastoma (peripheral nervous system cell tumor, often of abdominal location), Wilms tumor (type of renal tumor), retinoblastoma (affects the retina, fundus of the eye), germ cell tumor (of the cells that go originate the ovaries or testicles), osteosarcoma (bone tumor), and sarcomas (INCA, 2014). Childhood cancer imposes on the child and his or her family various expectancies that modify their lives in every way, undergoing several transformations regardless of age and their capacity for cognitive comprehension (SOUZA *et al.*, 2012).

Identifying the family system, that is, the family as a complex phenomenon, which demands support among its members, to confront a particular disease situation, can be the first step towards raising awareness and reflection on the importance and care of the family for the nursing (ANGELO, 1999). In pediatric oncology nursing, the child is the target of care. However, family members should be partners in making decisions about child care. The nurse is in a unique position to influence the care and well-being of the child and his / her family but should focus on the child as a focus of care. In this case, when the focus of care is the child, it is critical that the professional knows the family, their expectations about their participation, in order to evaluate and plan care that supports the mother, father or other significant members in the family childcare (SANTOS; FIGUEIREDO, 2013). Nursing work with family members requires the professional's ability to identify the complexity of the established relationships within the families, through interactions between their members and theirs with the community. In this sense, they make the information obtained from the family context more efficient for care planning (FILIZOLA; RIBEIRO; PAVARINI, 2003). The family context, at different moments, is altered as a result of embarrassing and at the same time challenging situations, as in the case of the families of the children when they receive the diagnosis of cancer, causing sudden and drastic changes in the routine life of these families. Often, this process begins with the diagnosis, followed later to the treatment, and can reach an improbable outcome, being "cure or death." In this perspective, the objective of this research is to describe the feelings and experiences of family members of children with cancer in the Amazonian context in a reference hospital in oncology in the city of Belém-Pará-Brazil.

MATERIALS AND METHODS

This research is an exploratory study of descriptive nature with a qualitative approach. Thus, the qualitative approach allows the assessment of the structure of the development and functioning of the family to be studied. We used as a theoretical-methodological reference the Calgary Family

Assessment Model (MCAF), proposed by Wright and Leahey (WRIGHT; LEAHEY, 2012). The Calgary Family Assessment Model favors evaluating a family effectively and acquiring knowledge and intervention skills. It is a multidimensional structure and has been recognized worldwide and adopted in nursing colleges in countries such as Australia, Great Britain, the United States, Canada, and Brazil. It bases on a theoretical foundation that involves not only the concept of systems but also cybernetics, communication, and change, being constituted by three main categories: structural, developmental and functional. (WRIGHT; LEAHEY, 2012). The study was carried out in the city of Belém, State of Pará, at a Reference Hospital for Pediatric Oncology in the Northern Region. Participants were 05 (five) families of children diagnosed with cancer under treatment in the inpatient department, in order to explore in depth the experience of the family of the child with cancer, at a time when hospitalization is necessary. As inclusion criterion were family of children diagnosed with cancer treated in the pediatric hospitalization unit and that the present companion was a member of the family. In the exclusion were families of children hospitalized in a semi-critical state, febrile neutropenia or under precautionary measures (isolation) or that the companion was not a member of the family.

For the collection of subjective data, we used the interview with semi-structured questions related to the Wright and Leahey family assessment instrument (WRIGHT; LEAHEY, 2012), adapted according to the research study object. After the selection of the families that fit the inclusion criteria, the invitation to participate in the research was carried out, as well as the objectives of the study. Thus, the term of Free and Informed Consent (TCLE) was presented and read aloud by following the resolution 466/12, participants signed and received a copy. The interviews were recorded with the consent of the interviewees and transcribed in full, for further analysis of the information. Already the data of the instrument of evaluation of the structure and the technical file of the family of WRIGHT; LEAHEY (were noted during their application). This study used the Calgary Family Assessment Model (MCAF) to analyze the data into three categories: structural, development and functional. From the statements, we identified relevant points that allowed to analyze the data. Then, we established the connection between the themes Family, Childhood Cancer, Nursing and the Calgary Model, making the theoretical basis through studies already carried out according to the theme. Six (6) categories were collected, which subsidized the study in the presentation of the results and favored the discussion of the same according to the reports of the relatives. This research project complied with the Resolution 466/12/2012 of the National Health Council of the Ministry of Health, and it was submitted for evaluation and approval to the Federal University of Pará (UFPA), with approval under No. 53021915.0.0000.0018 and later to the Committee (CEP) of the institution where the study was carried out. To guarantee the protection of the anonymity of the subjects, we use fictitious names and codification of the family, randomly chosen without this representing personal or ideological similarities, as children use names of children's characters according to the will of each child.

RESULTS AND DISCUSSION

On the whole, the families that participated in this study through the accompanying family presented during their

reports similar characteristics and situations which will be evidenced according to the evaluator's perception. To this end, six (6) categories were established.

The participation of the health professional during the reception from the perspective of the family member

The understanding of the family as a unit is directly related by the interrelationships among its members, in a specific context of organization, structure, and functionality, being united by consanguinity, interest, or only affective ties, that coexist in a historical, cultural and political context (FIGUEIREDO & MARTINS, 2010). In this perspective, the family member distinguishes between the professions and can identify in which aspects he or she received help, whether for a referral, a comfort, a word of hope or for help in the process of adaptation to peaceful coexistence. We can observe in the following reports:

Family 1 - (...) *the standard nurse there was the one who arranged for me to go to Xinguara, when I went to Canaa it did not solve from there because it is from another municipality, that's where I came here, she left me there, it helped me a lot, I stayed there fighting, until I got here.*

Family 3 - *The psychologist soon when we stayed here she answered us and did not know what was going to happen yet, and the first thing she told me was: it will be all right, trust in God and never lose hope that will be all right.*

It is important to emphasize the importance of the nurse's role in dealing with the needs of children undergoing chemotherapeutic treatment. And of their relatives / caregivers, as well as knowing, interpreting and acting on the feelings manifested by the changes resulting from the adverse reactions triggered by antineoplastic agents, thus directing the conduct to a care that meets the biological and psychological needs of these children and their families (SOUZA *et al.*, 2012).

Family 1 - *My sister, there only the Nurse Patricia who was the one who took me, she is there from the village where we live at the health post, she is the standard Nurse from there? Then she set me up to go to Xinguara with Frozen 1.*

Family 4 - *Her mother, my sister, was determined to take her daughter from the hospital, take her away, and then the nurses and the doctor asked and explained to her. She wanted to take it because the doctor said that the chemotherapy was powerful and that she could go to the ICU and she was terrified.*

Family 5 - *In Viseu, there is no one and no professional to support us. Here is the whole structure of the hospital, the support of Dr. Alayde pediatric oncologist and the entire multi-professional team, in fact, a large team (social worker, psychologists, technicians all this set from here hospital), from outside there is nobody because whenever something happens, we seek a professional from here.*

It is essential that the health team, especially the nurse, as well as the multidisciplinary team, come closer to this family, with the intention of listening to it, of knowing it. Also, above all, that this family can expose its difficulties, exchange knowledge and that these professionals can help them with their needs in order to be able to consider their problems and

their satisfaction, thus favoring a relationship of trust (MARTINS, FERANDES & GONÇALVES, 2012).

Experiencing the division of tasks in the daily life of their lives

The companions were unanimous in reporting that the daily tasks of families' daily duties are the responsibility of everyone, including parents, grandparents, siblings, children and often uncles, a fact exemplified in the following lines.

Family 1 *My son Antoniel takes over the duties and responsibilities there and when he is not there he is the father who takes care of everything there, but in this case, he is usually my son even though his father spends most of his time outside. Because then, as I cannot do to be here in the hospital, they assume and when one is absent, the other will assume that same place right? There is no difference, one assumes the role of the other.*

Family 2 - *"[...] When I'm here my husband takes care of the house, he makes the expenses, lunch, these things. When I'm here I cannot handle everything. But when I'm there we'll take care of it. "*

Family 3 - *At home, we share the tasks, when she is well I stay at home because I gave up work so I can take care of her, right?*

Wright and Leahey (2012), point out in their study that gender plays a key role in family health care, especially with children. The family being a system is also formed by subsystems whose goal is to perform tasks through family functions. In the study by Charepe *et al.* (2011), the family assessment of the parents of children with chronic disease is fundamental and extremely important, especially when analyzed in a structured way through the genogram and ecomap, which make possible the understanding of family processes and the recognition of level of relationship established through care for the sick child and the resources available in the community.

Feelings of family members about how they were informed about the diagnosis

Understanding patients 'and their families' feelings about the diagnosis and treatment situation is essential so that the health team can plan their actions, specific and systematized care to their needs, as the changes of feelings, doubts, and fears are not so easy to identify and interpret. Silva and Cruz (2011) emphasize that cancer represents more than physical pain and discomfort, having several individuals and collective meanings with direct and indirect influences related to the life goals of the patients and their family, changing the family dynamics. As we noted in the report below:

Family 2 - *The worst advice was when I found out she had this disease and the community health agent said she was going to die, that she did not need to run after us, that we were going back in vain. And I told her that she was an old person and that she was throwing a plague on her and I asked: Are you a doctor? Are you God?*

Family 3 - *Because I did not know how to tell her because she's a very worried child, right? Then a doctor we did not know arrived there and said: look she has it, she has a TU so*

"made a gesture with her hand" and we will open and will have surgery, and she was desperate.

Family 5 - *Everything is different now since the diagnosis of it there have been many changes, and we have already adapted to these new changes and will continue. In fact, it's not even in the final stage, just chemotherapy, because she uses a colostomy "pocket" from here a few more years we'll have to go back and look for a way to get it, because here in Pará, they still do not have this reconstruction, because hers was closed and it is a very rare case, and we will not give up, so this is another phase that we are ending.*

The caregiver and the overload assumed

The caregiver who can be anyone, in the vast majority is always a family member who in all circumstances takes responsibility for the sick member, forgetting their care. The other relatives even seeing this person run over by the daily routine are not sensitized, to reduce in the caregiver the stress experienced in these situations. It is understood that in these cases all the relatives are in full suffering before an often somber diagnosis. We can verify the accuracy of this information in the reports below.

Family 1 - *Oh my sister when she was diagnosed as a major disturbance for everyone in the family, unstructured everything. It's time I ask myself: God gave me so healthy, she did not walk or in the hospital and suddenly things collapsed. Do you know when you see that things are falling apart and you can not handle it? Yes, it's so heavy that sometimes you can not stand it, you can not stand it, I even say God in my life.*

Family 2 - *I stay here and go there, and every once in a while I try to quit the service, then we lose everything, right up to the signed right that gives us everything right, right? We lose all that, then we get the medical report, delivery to the caretaker, there the caretaker releases, releases three days, a maximum of 4 to 5 days. There you have to return. But sometimes we get this certificate and give it to them and sometimes it's 10 days too, but it's even worse for people in relation to work and our income for the month.*

Family 4 - *Everyone is suffering, but the one who is suffering is her mother. She is a warm sister and welcomes everyone well into her home and now she is sad.*

Through the reports, we observe how each family member responds to the stress caused by hospitalization. In this context, it is essential to emphasize the importance of the other family members favoring a network of support and care to the needs of this caregiver who is most often the mother. To Cecilio, Santos, and Marcon (2014), family care in the health-disease process is often related to chronic diseases, which require continued care and attention. Moreover, in most cases directly affects a family member in the sense of becoming a motive of overload, triggered by daily care, recurrent and prolonged hospitalizations, also causing stresses to the patient himself, also affecting the social relationship of the family system. It is also emphasized that, usually, the overload is directly linked to the caregiver "mother" who leaves her home, her routine, her children, her husband, her work, everything related to her daily personal and professional life to take care of her child (a) ill and from then on live the uncertainties, fears, anguish and recurrent hospitalizations, which children

with cancer are affected, but above all believe that everything will end well, through faith and their beliefs according to the following:

Family 1 - *Every day they have an expectation of us to return, only there, I know that it is not time yet before the treatment that is still lacking. It is that I have not even told them, our back will be that neither is coming, a great surprise, hence I say to them: it is only you have patience and believe in the will of God.*

Family 3 - *When I see that she is well I try to thank God very soon because without him nothing is done and when I am sad, I also turn to Him because if we did not trust God, it would be more difficult.*

Family 4 - *The diagnosis changed the family routine, her mother had to leave the house, she and the children had never separated from them, the family members are helping in the best way possible. Princess Sofia misses her brothers. Everyone has been unstructured without knowing what to do, but we believe in a powerful God who will guide us in the best way possible, and he will be healed.*

The modified life routine before the diagnosis

Family support is imperative, since becoming sick involves the entire family context in the face of the various changes triggered by the established diagnosis, and specific changes in the way of living are necessary (SANTOS, CECILIO & TESTON, 2012). A diagnosis of cancer, whatever it is and in which person in the family group, manifests itself will always be a traumatic moment for the family unit. The types present in the children of these family groups have brought numerous transformations in the lives of these people. From a father who can not keep up with work, from the mother who abandons work and study, from the family that regularly sells their property to pay the daily expenses to the family that distributes the children to relatives' homes so that they can move forward with the treatment of the sick daughter. Highlighted in the following reports:

Family 3 - *The diagnosis influenced a lot in the family routine, the food was one of them, we adopted a healthier and therefore, more expensive food. Certain things like food supplement to keep her weight are more expensive, there are things that in my city does not sell, they prescribe, there we have no money comes to Bethlehem to buy. We have to go back and pay for the transportation, so it's an extra expense and we do not have government help.*

Family 2 - *When I am not here I am working. My wife takes care of her and my other daughter. There is a net kit rented in Augusto Montenegro to be able to stay here because we do not have any of the family here in Belém.*

Family 5 - *The change was in question the food that before we did not give much value and ate anything and today Princess Sofia has an entirely restricted food, and with that, I changed the whole food of our house and ours and the other children. We started to worry more, so that was the change.*

In this sense, we understand that the family system is characterized by points that interconnect giving support to life and health linked to its members, constituting units with

energies with the capacity to self-organize in the face of emerging needs. To Souza *et al.*, (2012), children in cancer treatment, as well as their families, have different reactions. Among them, the main ones are directly related to emotional and behavioral factors. Also important to highlight the anxiety and anticipatory anxiety responses because of the diagnosis and especially of the treatment, which is unknown and is repeated periodically, since they cannot be programmed in the event of emergencies related to adverse effects that the child may present during the established protocol. As noted below in household reports.

Family 1 - *When she did the myelogram, I told her the news, the one who answered was Antoniel, and he said: oh mother I wanted so badly that it was not true because it is my son I wanted too, but God willing. Everyone was desperate at home.*

Family 2 - *We sometimes have the will to give up as a result of the illness itself, the treatment and now with the relapse, everyone is shaken. It is also because we want to work, can not, we have to stay here straight. So, I work for a contract signed for six months, because we work there with earthworks, there in the winter, so when it comes back to summer we go back there again.*

Family 3 - *We do not know when it will end, or how long it will be here. Then she moves and moves. From December to here she has had 5 hospitalizations, she comes and goes, and most of the time we stayed in the hospital and the maximum time we stayed at home after the diagnosis was 20 days, because from then on people stay a maximum of 5 days at home and from here to there you will find it.*

A child who is ill, especially those who have undergone prolonged treatments, such as those diagnosed with cancer, who need to stay hospitalized during treatment for a long time, and who have an adverse event related to the adverse effects of antineoplastic chemotherapy, have difficulty understanding what is happening. Especially concerning the disease itself and the invasive procedures diagnoses and therapeutic procedures to which they are submitted (SOUZA *et al.*, 2012). It is also necessary to emphasize the need for hospitalizations that occur most of the time unexpectedly, resulting in a high family impact related to the routine of daily life linked to the interruption of the planned and planned and above all to the fear of the unknown. The dynamics of caring and emotions in this context undergo significant modifications, especially those that permeate family relationships, the arrangement of this family needs to be most often remade and adapted to needs often accompanied by feelings of insecurity and suffering (AZEVEDO, 2016).

In the face of such situations, they present significant difficulties in interacting with the sick body, as well as the relationships that sometimes get damaged in support groups, in the games, talk wheels, music therapy and playfulness as activities performed in the hospital. According to reports below:

Family 1 - *My day-to-day is just Stefany, running after her, you saw how she left here now. She does not settle down. When I am in church it is all the time behind her, just because she can not catch the sun, take a shower right? There is the whole time behind her when she is not lying down. I can not leave her*

with anyone and also have the difficulty to participate in the support groups and also the church.

Family 3 - *When she has the activity of the clowns and she is down I force her a little to go because it is difficult, there are times when she gets angry and does not want to interact with anyone even with me, and when I get her to go to the therapy room, it comes even better from there.*

The wider systems on the day of a family with a sick member

The broader systems that make up an institution, any groups of people who come together to promote help, someone, from friends, who together with the network of health services assist in providing care to needy family groups, such as those we observe in the reports below:

Family 1 - *Church Christian Congregation gave me much support when I arrived here in Bethlehem, I was lost without knowing what to do and in the middle of nowhere in Hemopa the people from where I live that is all of the church too, got in touch with the group here and asked them to help me, they gave me the address and they sent me there and to this day they are our support.*

Family 4 - *The church Assembly of God, help in prayer and at times a little financial help.*

Family 5 - *There is a group of volunteers that most of the time helps us with diapers, hygiene materials and at other times it is with AVAO.*

According to Menezes *et al.*, (2016), social networks are significant to health care needs, being characterized as a set of complex relationships between members of a family, school, health, social assistance, among others resources. According to Lavall *et al.* (2009), the quality of the links in the internal and external structure of the family allows the professional and the health team to know the set of those who interact directly or indirectly with the suffering individual in the face of the illness process. Making it possible to identify the relations of their daily life and social space and to evaluate their social support network.

Final Considerations

The family assessment allowed to identify that the majority of the families participating in the study were nuclear families. One being characterized as an extended family and the overload as regards the care that falls on the central caretaker mother, who assumes a diversification of roles, as it needs to move away from the other children, husband, of their daily activities and even distance themselves from their professional life. Care with the cancer child and each independent family member specifically of the complexity of care that each family in particular needs, should be well planned and structured knowing that the families have their structure and functioning, whose interpretation based on a greater understanding of family dynamics, through this extended and systematized look. The adjustments and emphasis of the nursing practice were centered in the family as the center, the focus of attention in order to provide essential points that favor the evaluation and performance of the nursing staff and especially of the nurse in

the process of evaluation and family intervention, through the facilitating instruments that subsidize quality care. Thus, the results of this study show that families, even in the face of their particularities, go through the same process in the face of the diagnosis, being observed in some moments the overload of tasks and are attributed to the majority of the times to the mother, assuming ways to overcome the difficulties of a general way. The child and his / her family need to be qualified and systematized assistance in order to enable paths that foster feelings of hope, confidence, and confidence regarding the treatment and consequently with a satisfactory prognosis.

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