

---

## CANCER AMONG INFANTS: ADJUSTMENTS IN FAMILY LIFE

*Daniela Dias Quirino<sup>1</sup>, Neusa Collet<sup>2</sup>*

<sup>1</sup> M.Sc. in Nursing, Graduate Nursing Program at Universidade Federal da Paraíba (UFPB). Nurse, Complexo Pediátrico Arlinda Marques. Paraíba, Brazil. E-mail: danydiasq@hotmail.com

<sup>2</sup> Ph.D. in Nursing, Faculty, Undergraduate Nursing Program and Graduate Nursing Program at UFPB. Paraíba, Brazil. E-mail: neucollet@gmail.com

**ABSTRACT:** The aim of this qualitative case study was to capture the daily life of families of infants with cancer. The empirical data were collected through semi-structured interview with three mothers in the period from May to June 2010. The interpretation of the data followed the basic rules of thematic analysis. The results showed that cancer represents an impact for the family, whose restructuring is promptly necessary in order to meet the needs of the sick child. In this scenario, the mother is seen as the foundation to monitor the child, affecting care for the home and for her other children. The mother experiences a huge burden that involves emotional distress, besides physical exhaustion. The whole family suffers due to the disease of the infant and, in order to alleviate the suffering, the health team needs to use strategies that strengthen the links with the family.

**DESCRIPTORS:** Cancer. Infant. Family. Professional-family relations.

---

## CÂNCER NO LACTENTE: READAPTAÇÕES NA VIDA FAMILIAR

**RESUMO:** Pesquisa qualitativa do tipo estudo de caso que objetivou apreender o cotidiano da família do lactente com câncer. Os dados empíricos foram coletados por meio de entrevista semiestruturada com três mães, no período de maio a junho de 2010. A interpretação dos dados seguiu os fundamentos da análise temática. Os resultados demonstraram que o câncer representa um impacto para a família cuja reestruturação é prontamente necessária para atender às necessidades do filho doente. Nesse cenário, a mãe é compreendida como o alicerce no acompanhamento do filho, comprometendo o cuidado do lar e dos demais filhos. A mãe vivencia uma sobrecarga descomunal que envolve sofrimento emocional, além de desgaste físico. Toda a família sofre com o adoecimento do lactente e para amenizar esse sofrimento a equipe de saúde deve utilizar estratégias que fortaleçam os vínculos com a família.

**DESCRIPTORIOS:** Câncer. Lactente. Família. Relações profissional-família.

---

## CÁNCER EN EL LACTANTE: READAPTACIONES EN LA VIDA FAMILIAR

**RESUMEN:** Investigación cualitativa de tipo estudio de caso que objetivó aprender el cotidiano de la familia del lactante con cáncer. Los datos empíricos fueron recolectados por medio de entrevistas semiestructuradas con tres madres en el período de mayo a junio del 2010. La interpretación de los datos siguió los fundamentos del análisis temático. Los resultados demostraron que el cáncer representa un impacto para la familia cuya reestructuración es imprescindible para atender las necesidades del hijo enfermo. En ese escenario, la madre es comprendida como la base en el acompañamiento del hijo, comprometiendo el cuidado del hogar y de los demás hijos. La madre vivencia una sobrecarga descomunal que envuelve sufrimiento emocional, además de desgaste físico. Toda familia sufre con la enfermedad del lactante, y para amenizar ese sufrimiento, el equipo de salud debe utilizar estrategias que fortalezcan los vínculos con la familia.

**DESCRIPTORIOS:** Cancer. Lactante. Familia. Relaciones profesional-familia.

## INTRODUCTION

The number of cancer cases around the world has considerably increased, representing one of the most important public health problems nowadays.<sup>1</sup> In Brazil, the median percentage of pediatric tumors observed in Population-Based Cancer Records (RCBP) borders on 3% of all malign tumors; this means that they are considered rare in comparison with adult tumors.<sup>2</sup> Despite this characteristic of being rare, in developed as well as developing countries, cancer has represented the second cause of death among children and adolescents.<sup>3</sup>

Today, childhood cancer is characterized as a chronic illness and, despite a good prognosis, the family and child feel threatened by death when diagnostic confirmation comes.<sup>4</sup> This experience entails a range of anguishing and painful feelings, as the disease is loaded with the expectation of death.<sup>5</sup> Therefore, cancer represents a destructuring impact that threatens personal equilibrium and family wellbeing.<sup>6</sup> Living one day at a time means dealing with the disease each day, coping with the new situations it triggers.<sup>7</sup>

In this context, the family accompanies the child to go through difficult and painful situations and, to support and spare him/her from too much suffering, experiences feelings of helplessness that can jeopardize members' wellbeing, making the family vulnerable to psychic suffering.<sup>6</sup> Hence, families of children with cancer demand special attention, due to the chronic nature and severity of the disease, besides the consequences it entails for family structure, imposing the need for reorganization, which is fundamental to cope with the disease.<sup>8</sup>

When seeking explanations for the disease event, the family develops a movement of self-reflection and questioning and starts to reflect on aspects of family dynamics, values and behaviors, which should be preserved or modified in function of the unit's well-being.<sup>9</sup> Adapting to childhood cancer is not easy, as it will always represent a threat to life and wellbeing. This situation entails feelings of sadness, anguish and anxiety that trigger social, emotional, affective, cultural and spiritual transformations.<sup>10</sup>

In view of infant cancer, the family's difficulties are perceived to accept or adapt to this

concerning and unexpected moment. Thus, when facing childhood cancer in that age range, the family seeks answers to its inquiries, and also to the possible causes that made the child present this disease.

A search in databases from nursing and related areas reveals that nursing has greatly contributed to knowledge in that area.<sup>10-14</sup> In view of the problem's dimensions, however, research still has not answered the gaps in knowledge and care practice, mainly concerning infant cancer.

This study aims to unveil the childhood cancer experience in this age range and understand how the family gets restructured to adapt to that situation. We believe that the results can contribute to grant visibility to care delivery that needs to be based on interpersonal relations, constructed based on bonds. In view of the above, in combination with our professional experience, we accomplished this study to apprehend the daily life of families of infants with cancer.

## METHOD

In this study, the qualitative approach was adopted with a case-study design. The qualitative research approach considers the universe of meanings, feelings, motives, aspirations, beliefs, values and attitudes present in processes and phenomena that cannot be measured.<sup>15</sup> The case study<sup>16</sup> permitted an in-depth empirical research about the phenomenon: daily life of families of children with cancer under two years of age in their real-life context, during hospital treatment. The aim of the case study<sup>17</sup> is to investigate, in depth and exhaustively, a situation in the real context, and describe, understand and interpret the complexity of a concrete case. We chose this type of study because we believe that the situation of coping with an infant's cancer is a scenario that unveils the family's difficult daily life. This demands an in-depth study to cover the important events in the family's life.

The place of study was an oncopediatrics unit of a hospital in metropolitan João Pessoa-PB. The institution was chosen because it is a referral hospital for oncological conditions. After the hospital granted authorization to develop the study, the researcher became familiar with the hospital context through weekly visits,

which were important to get to know the professionals who work there and the children and their companions.

During the construction period of the empirical material, there were four infants diagnosed with cancer at the institution. After the research had approached the families and explained about the study and its importance, one family refused to participate and the mothers represented the three families that accepted to participate. The infants were between one and two years old and the inclusion criteria were: having a child between zero and two years of age (infant), in any phase of oncological monitoring (diagnosis or therapeutics) and living in the state of Paraíba.

The empirical material was produced between May and July 2010, using the semistructured interview technique.<sup>15</sup> A recorder was used for registry with the interviewees' authorization. The interviews were fully transcribed to preserve the language and grammatical expressions the participants used. Some grammatical corrections were made that did not change the meaning of the phrases.

For data analysis, the thematic analysis technique was used, which consists in the discovery of meaning cores in communication, whose presence or frequency means something for the analytic objective. In other words, thematic analysis counts the frequency of units of meanings that define the nature of discourse.<sup>15</sup>

After the systematic organization of the transcriptions, the first reading of the data served the purpose of recognition, followed by readings to apprehend the subjects' statements and characterize their similarities and singularities. This process took place through repeated contact with the transcribed material. The final grouping resulted in two cores of meaning: "The family's daily life altered by childhood cancer: intensified daily care and healthy siblings and distancing from the family".

The research was submitted to the Research Ethics Committee for Research involving Human Beings and received a favorable opinion (No. 408/09). The subjects who participated in the study signed the Informed Consent Term. To guarantee anonymity and preserve the interviewees' identity, when identifying the testi-

monies, we used the word "mother", followed by a number to indicate the order in which the interviews took place.

## RESULTS AND DISCUSSION

### The family's daily life altered by childhood cancer: intensified daily care

A disease in a child abruptly destabilizes the family and, in case of a chronic illness like childhood cancer, it needs to return to its life and try to maintain balance. When the child with cancer gets ill, the family's daily life changes extraordinarily; what used to be simple becomes difficult, compromising the development of each member's roles. The impact the disease causes redirects the family's focus to the child with cancer, who becomes the center of attention:

[daily life became] *totally directed at him [child], now the entire time is just for him, to take care of him [...] he [father] thinks everything has to change, the whole routine in the house* (Mother 1).

[...] *everything turned towards her, everything. The world turns around her, imagine, when I found out, I didn't know whether it was day or night, what day of the week it was, I didn't know when it was two o'clock, three o'clock, I didn't know when it was Sunday, when it was Monday* (Mother 3).

The family dynamics is altered to support the new and immediate childcare demands,<sup>18-19</sup> as great transformations are needed to keep up the child's treatment. To cope with this situation, the mother is considered the axis of the family structure, as she controls care for the children, the family and all family members' health. The caregiver role is expected from her and she expects it from herself, but this study demonstrates that the mother is concerned and occupied with care for the child with cancer, to the detriment of care for herself and other family members.<sup>10</sup> "Being a mother", in these cases, involves a posture of altruism, a need for complete and constant dedication around the clock, leaving aside the distress she experiences in function of her relation with the child.<sup>18</sup> Childhood cancer produces affective and instrumental changes within a short time period, demanding faster mobilization from the family in its ability to administer the crisis it experiences, as well as the care burden, which reduces the

family caregiver's free time for herself and other members.

Changes tend to start when the initial symptoms of the disease appear and are intensified with the diagnosis, also changing the mother's social identity. The diagnosis comes with anguish, as well as the period of uncertainty that follows, especially marked by a painful process of assimilating a new life perspective. Treatment entails a range of demands, including emotional interdependence, obligation of proximity with the child and changes in the parental care system.<sup>20</sup>

The child's life is changed irreversibly due to treatment and the consequences of the disease. In this process, the children and their families go through experiences in several dimensions, and adapt to these new situations differently, according to the lifecycle they are in, the repercussions of the disease's impact on each member and they way they get organized in this period.<sup>21</sup>

In addition, daily requirements of dietary care, extended hospitalizations, the need to deal with unpleasant emotions, changes in personal and professional routines and treatment response expectations can potentially arouse conflicts and impair quality of life during treatment:

*[...] when I'm at home, the only thing I do is the food, the rest is my mother and my daughter. Nobody lets me do anything so as not to let the baby along [...] the older sister stays with the baby [sick child] when I need to go out to solve something. The little one [daughter] is four, but she already understands, puts him [sick child] on her lap, she can already change diapers [...]. He [husband] helps with everything, prepares food for the baby, gives him food, changes diapers, takes him for a walk, he takes the baby to get sun in the morning and, the day he's at home, there's more time, because he stays with the child and I go out to do things (Mother 1).*

*[...] at my home, the first thing in the morning is clean everything so that she can sit on the floor. We don't leave any dust, everything's clean, you know [...] when I get home and don't go anywhere [...] I just stay at home with her until the whole chemotherapy is finished (Mother 3).*

The reports are in line with a study about aspects of caregivers' lives the children's disease affect<sup>22</sup>, whose social life is compromised. During the hospitalization, contact with other people decreases and they only interact with the other caregivers (mothers and fathers). When

not in hospital, due to reduced immune defense, visits, excursions and other activities need to be limited, as the family's goal is to keep the child free from infections. Therefore, hygiene care needs to be intensified, for the home as well as the child.

The caregiving mothers experience different feelings. Concern with the care routine was a noteworthy characteristic, mainly when this responsibility is not shared with the other family members.<sup>22</sup> This fact can expose the mother to a greater level of physical fatigue, leading to physical and mental exhaustion. Caregivers find themselves loaded with tasks, their concerns are now constant: when it's not the disease, it's what needs to be done at home:

*[...] the only person who does things at home is me, only me really [...] everything gets messy, when I get home I have to do everything [...] I arrange everything, clothes, food, getting the kids in order, the house, cleaning, just me really [...] when I'm at home, I have too many things to do [...] I don't even have time for myself really (Mother 2).*

As this care demands that much attention from the mother, in most cases, she needs to give up her job to take care of the child.<sup>11</sup> In this study, the mothers worked before their children got ill and, therefore, they had to quit to dedicate themselves to their child with cancer. As childhood cancer demands special care, the mother mentions that she is unable to work and take care of her sick child.

*I had to quit because there was no way I could conciliate things (Mother 3).*

*I had to give up my job to take care of her [...] I stopped working, I worked my entire life [...]. I felt fine because I knew I stopped working to take care of her, so I didn't get that sad, [...] I know I was giving up one thing for the other, but one was for her own good (Mother 2).*

Cancer normally increases family expenses, whose routine<sup>23</sup> now includes constant visits to the health service, which sometimes need to be paid for with family resources. Hence, when a child gets ill and the mother needs to choose between working or giving adequate care, financial difficulties add up to daily difficulties. When she quit, the mother reports how difficult the routine got:

*[...] It got very hard. Because, when I was working, we paid rent. We had to move to his sister's house.*

*At his sister's house it was very hard, very difficult. It seems as if it was more difficult than when we paid rent. So, it was very difficult because we spend almost a year at his sister's house. Then we fought to see if we could arrange something at his mother's house, but it was a very difficult time (Mother 2).*

Care for the child with cancer is yet another responsibility for the mother, as she is the one who usually gives up her job to take care of the child.<sup>22</sup> Although difficulties increase when they leave work, the mothers demonstrate their satisfaction with being able to take care of their children; in this trajectory, they fully surrender to the struggle for the child's life.

Besides the stress, anxiety and depression, the cancer experience arouses mothers' negative feelings regarding their sense of mastering situations, ranging between uncertainty and anxiety. When the mother is in constant control, the correlation between anxiety and uncertainty is reduced.<sup>12</sup> Taking care of the child with cancer entails different implications for the mother's life and quality of life, including the conflict between staying close to the child being treated and mothering the other children.<sup>20</sup>

On the other hand, Mother 1 acknowledges that family life needs to return to daily reality before the disease. The other children need the attention they used to receive. This way of thinking is an important coping strategy, as it makes the mothers feel somewhat at ease in family equilibrium. They acknowledge that this form of thinking least impairs family life:

*[...] if you get like, forget the others, the housework, and just stay with him, it won't do him good. It's not good for the family, and it's not good for him either, impairs him, his treatment, he needs the freedom to do everything he used to do before (Mother 1).*

When experiencing the treatment demands, parents of children with cancer report that it is important to maintain some similarity with the previous situation and to keep the family united.<sup>18</sup> As a way of coping with constant fear in care for their children, mothers mention that care changed, but that they prefer to think that their child has a disease which is popularly known as simple, like a cold. This attitude can demonstrate that the child is receiving adequate care from the mother, as (s) he always has. On the other hand, however, it may demonstrate a defense mechanism, through which the mothers avoid confrontation with the

privations related to their living conditions, like professional and social privations for example, as a result of the need to offer further care to the sick child, especially during hospitalization. The alleged normality would serve as a strategy to cope with the anxiety deriving from these privations.<sup>1</sup> To give an example:

*[...] I've learned something, to treat him [infant], I know that his problem is severe, but I've learned from a physician here, we need to take care of him as if we were taking care of a cold because, if we put into his head that we he has is severe, he may even need a transplant. He may, which has happened a lot here, he may die, you can't do anything anymore [...] I think he needs freedom to live, like he used to live before (Mother 1).*

Another mother indicates that she tries to get accustomed to the new life:

*[...] I got accustomed to the treatment and, so I take care, but I prefer not to get nervous. At home it's extreme. My mother [gets afraid], the girl feel, and I say calm down woman. But not me, I try to be calmer, because if you get nervous it's worse, and I've never cried in front of her [...] I never let myself be brought down (Mother 3).*

As time goes by, the family starts to get restructured to continue with the child's treatment and other themes in its routine. As the child's treatment becomes part of daily life, new strategies need to be adopted to get accustomed to the new way of life. Reorganizing roles and responsibilities is fundamental to adapt to the disease.<sup>14</sup>

The families attempt to maintain a lifestyle that is very close to what they lived before the disease experience, attempting to lead a normal life, with a view to living with the situation.<sup>7</sup> After the initial disease period, adjustment happens over time and distress increases during active treatment phases.

In seeing to the child's needs, it is normally the mother who is always alert and willing to deliver the care needed. This panorama changes in view of a disease that weakens and exposes the child to pain and suffering, making him/her even more dependent on maternal care. In that sense, taking care of an infant with cancer demands dedication and coping with the stress the disease entails, associated with the young age that usually demands further maternal care. This fact exposes the caregiver to an intense daily care burden, as the age range of the person receiving the care should be considered when assessing

the implications this care demand may entail for the mother's life.<sup>22</sup> As observed, the infant demonstrates a growing need to have the mother around at all times, as she represents security and care; at the same time, the mother feels that the burden is unavoidable.

*It doesn't matter whether there are a thousand arms around, she just wants her mother's, and she gets totally clingy, when she gets ill she becomes attached, and there's more mom around the clock. So, no matter whether there's someone to help me, she just wants me, then I get overburdened, a lot really (Mother 3).*

As the infant needs specific care, mainly because of the cancer, the mother demonstrates even more zeal. The fact that this care demands effort from the mother, in turn, evidences the need to focus on the physical and mental fatigue she may experience in this situation. When mother and child are at home, although there is no help from the family to take care of the child full-time, the mother can count on her parents' help to give her daughter attention while she does something, even take care of herself. During hospitalization, the mother complains about this difficulty to leave her alone. As the attachment and bond between mother and child become stronger in case of hospitalization, the mother mentions much more intense fatigue, as she cannot share the care delivered to her daughter with anyone.

The cancer dramatically transforms the family's life, as it is the child's life that is at risk. In response to the new needs, all members redirect their roles to cope with the difficult challenge of seeing to the sick child and other family members' needs. Thus, in most cases, it is the mother who totally surrenders to care for the child, to the detriment of her work, leisure and care for the rest of the family.

In this scenario, the siblings, who often need to stay at home without their mother and sibling under treatment, suffer due to different reasons, including the absence of their loved ones from home. Anxiety or feelings of helplessness can easily appear. In that sense, this problem needs to be reconsidered, demanding actions that can at least minimize this suffering for the siblings who, whether they are young or not, may experience difficulties to adapt to events.

## Healthy siblings and distancing from the family

The mother's role is altered in an extraordinary way, neglecting care for herself, and care for and relations with other children and her husband in view of care for the child with cancer.<sup>10</sup> The healthy siblings perceive that normality and stability represent a challenge and that they are submitted to sudden changes in their lives, representing by the distancing from their parents and the sick sibling, giving rise to a feeling of abandonment and solitude.<sup>24</sup> The child perceives the family distancing that happens during treatment and the need to stay under other people's care as one of the most difficult situations, because (s) he is unable to stay with the other relatives and misses them.<sup>25</sup>

*I practically, kind of, had to abandon [the healthy child]. I spent two months out [of the house] [...] he doesn't see it as abandonment [...] also because I talk to him every day, the mother says that her child complains like: 'mommy, I really miss N' [...] (Mother 3).*

At other times, the healthy siblings are obliged to do housework which, until then, they hadn't done, or to experience unaccustomed situations during their sibling's hospitalization, like temporarily staying with neighbors or other relatives.<sup>21</sup>

*My son, go and take care of N., stay with N. He says: 'mom, I really want you to leave soon, go to João Pessoa soon'. But son, don't say that. 'Yeah, mom, you keep on bothering me, my grandma is really good, she doesn't even fight with me, doesn't keep on annoying me, and there's no boy to take care of, no. I don't know why I was born'. That's how he said it: 'I don't know why mommy had me, to take care of a boy, because I don't like to take care of boys [...] I like watching cartoons'. Unfortunately, he feels and, like, there's no way to avoid this distress, it's very hard (Mother 3).*

The healthy siblings' contact with the childhood cancer imposes the challenge of new discoveries about the child's illness process, of experiencing the changes this process imposes and seeking strategies to adapt to reality.<sup>15</sup> Adapting to this new phase is not an easy task for the healthy siblings. They may present difficulties to adjust to this new routine, as their daily life is changed, together with that of the whole family. Among

other family members, the healthy siblings are being identified as the most emotionally neglected and unhappy ones.<sup>21</sup>

The distress gets more intense as they go through the experiences. The healthy siblings reveal that they suffer when feeling alone, that it is difficult to bear the distancing from the family and the fact of staying at home alone or being taken care of by some relative. Another factor that afflicts them are hospital visits, because they do not get permission to see the child.<sup>25</sup> In our study, we observe that hospital visits are prohibited, only permitting a change of companions. In this respect, the siblings suffer because of their distance from their mother, who normally spends a long time in hospital.

[the six-year old child] *feels that he wants more attention. Which I can't give right now, because I spend more time in hospital than at home. When I'm at home there are too many boys to play with, each of them wants more attention [...] you take more care with one than the other. It's very hard, so I think it's like, that the boys feel more needy, one needier than the others* (Mother 2).

The healthy siblings report the need to receive care and be able to express their feelings and complaints about topics related to the childhood cancer experience.<sup>26</sup> The author mentions that the parents perceive that emotional support and information for healthy siblings can be the best way to see to healthy siblings' lives.

In that context, the risk factors related to the healthy siblings' adjustment to the childhood cancer context are: degree of rupture in family life, available resources and siblings' perceived impact of the diagnosis on themselves. The siblings may interpret their separation from the parents and their absence as rejection and, as a result, express solitude, anxiety, behavioral and educational problems, increased somatic complaints like pain and a range of other social, affective and behavioral symptoms.<sup>27</sup>

The family's daily life is reorganized for the new adaptations needed to keep up treatment of the child with cancer. In view of the new family priorities, the healthy siblings suffer due to this restructuring in their daily life, as the mother and siblings' absence from life at home becomes a constant in their lives.

In this respect, it is important for the health service to adopt strategies to approach

healthy siblings and patients, as they should be involved in the coping process, in the attempt to strengthen the sibling who is suffering and understand the mother and sibling's distancing from home.

## FINAL CONSIDERATIONS

As a disease loaded with stigmas of terminality that are constructed in the social context, childhood cancer stops the family's dream about a child's life. This event implies family destructuring, whether temporary or not, mainly when it is a young child who is affected, in the infant age range and, hence, in the first months of life.

To keep up with the child's treatment, extend his/her days of life and reach a possible cure, the roles family members play need to be reorganized. As the mother is almost always the caregiver, she becomes responsible for this accompaniment. In this process, she is exposed to a range of stressful events that can jeopardize her emotional health and, in turn, care delivery to the child.

The intense involvement in the daily routine of infants with cancer also exposes the mother to physical fatigue, which could be mitigated if the family understood accompaniment at the hospital. Alternating this care could serve as breather for the mother who lives with sad times in different situations, besides the pain of seeing her child, still a baby, exposed to procedures and aggressive therapies. Sharing care with other members can give the mother the time needed to take care of the healthy children who stay at home, or who moved to the home of relatives, like grandmothers and uncles, to avoid the mother's burden and concern.

In health care, it is important to identify the distress of mothers who accompany their infants during treatment. As the burden is very closely related with the accompaniment of such a small child with cancer and all of its emotional involvement, health professionals should provide support to cope with these difficult times, through holistic care, constructed through bonding and accountability that go beyond the biological horizon.

As this theme is not frequently discussed, it is important to highlight the need for further research in this area, in view of the lack of research

on infant cancer and its implications for the family. As these are subjects with specific needs, further research can enhance discussions to improve the quality of health care.

## REFERENCES

1. Beltrão MRLR, Vasconcelos MGL, Pontes CM, Albuquerque MC. Câncer infantil: percepções maternas e estratégias de enfrentamento frente ao diagnóstico. *J Pediatr*. 2007 Nov-Dez; 83(6):562-6.
2. Ministério da Saúde (BR), Instituto Nacional do Câncer, Coordenação de Prevenção e Vigilância do Câncer. Câncer da criança e do adolescente no Brasil: dados dos registros de base populacional e de mortalidade. Rio de Janeiro (RJ): INCA; 2008.
3. Instituto Nacional do Câncer [página na Internet]. Rio de Janeiro (RJ): INCA; 2009 [acesso 2009 Ago 15]. Disponível em: [www.inca.gov.br](http://www.inca.gov.br)
4. Costa JC, Lima RAG. Crianças/adolescentes em quimioterapia ambulatorial: implicações para a enfermagem. *Rev Latino-am Enfermagem*. 2002 Mai-Jun; 10(3):321-33.
5. Souza MGG, Espírito Santo FH. O olhar que olha o outro... um estudo de familiares de pessoas em quimioterapia antineoplásica. *Rev Bras Cancerologia*. 2008 Jan-Mar; 54(1):31-41.
6. Menezes CNB, Passareli PM, Drude FS, Santos MA. Câncer infantil: organização familiar e doença. *Rev Mal-Estar Subjet*. 2007 Mar; 7(1):191-210.
7. Anders JC, Lima RAG, Rocha SMM. Experiência de pais e outros familiares no cuidado à criança e ao adolescente após o transplante de medula óssea. *Rev Bras Enferm*. 2005 Jul-Ago; 58(4):416-21.
8. Silva MRB, Borgognoni K, Rorato C, Morelli S, Silva MRV, Sales CA. O câncer entrou em meu lar: sentimentos expressos por familiares de clientes. *Rev Enferm UERJ*. 2008 Jan-Mar; 16(1):70-5.
9. Silveira AO, Angelo, M, Martins SR. Doença e hospitalização da criança: identificando as habilidades da família. *Rev Enferm UERJ*. 2008 Abr-Jun; 16(2):212-7.
10. Santos LMP, Gonçalves LLC. Crianças com câncer: desvelando o significado do adoecimento atribuído por suas mães. *Rev Enferm UERJ*. 2008 Abr-Jun; 16(2):224-9.
11. Cavicchioli AC. Câncer infantil: as vivências dos irmãos saudáveis [dissertação]. Ribeirão Preto (SP): Universidade de São Paulo, Escola de Enfermagem de Ribeirão Preto; 2005.
12. Mu PF, Ma FC, Ku SM, Shu HQ, Hwang B, Kou BIT. Families of Chinese children with malignancy: the factors impact on mother's anxiety. *J Pediatr Nurs*. 2001 Aug; 16(4):287-95.
13. Moreira PL. Tornar-se mãe de criança com câncer: construindo a parentalidade [dissertação]. São Paulo (SP): Universidade de São Paulo, Escola de Enfermagem; 2007.
14. Nascimento LC, Rocha SMM, Hayes VH, Lima RAG. Crianças com câncer e suas famílias. *Rev Esc Enferm USP*. 2005 Dez; 39(4):469-74.
15. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 10ª ed. São Paulo (SP): Hucitec; 2007.
16. Yin RK. Estudo de caso: planejamento e métodos. 4ª ed. Porto Alegre (RS): Bookman; 2010.
17. Martins GA. Estudo de caso: uma estratégia de pesquisa. 2ª ed. São Paulo (SP): Atlas; 2008.
18. Almeida MI, Molina RCM, Vieira TMM, Higarashi IH, Marcon SS. O ser mãe de criança com doença crônica: realizando cuidados complexos. *Esc Anna Nery Rev Enferm*. 2006 Abr; 10(1):36-46.
19. Comaru NRC, Monteiro ARM. O cuidado domiciliar à criança em quimioterapia na perspectiva do cuidador familiar. *Rev Gaúcha Enferm*. 2008 Set; 29(3):423-30.
20. Young B, Dixon-Wood M, Findlay M, Heney D. Parenting in a crisis: conceptualising mothers of children with cancer. *Social Science Medic*. 2002 Nov; 55(10):1835-4.
21. Faquinello P, Higarashi IH, Marcon SS. O atendimento humanizado em unidade pediátrica: percepção do acompanhante da criança hospitalizada. *Texto Contexto Enferm*. 2007 Out-Dez; 16(4):609-16.
22. Beck ARM, Lopes MHBM. Cuidadores de criança com câncer: aspectos da vida afetados pela atividade de cuidador. *Rev Bras Enferm*. 2007 Nov-Dez; 60(6):670-5.
23. Miedema B, Hamilton R, Fortin P, Easley J, Matthews M. "You can only take so much, and it took everything out of me": coping strategies used by parents of children with cancer. *Palliat Support Care*. 2010 Jun; 8:197-206.
24. Wilkins KL, Woodgate RL. Supporting siblings through the pediatric bone marrow transplant trajectory: perspectives of siblings of BMT recipients. *Cancer Nurs*. 2007 Sep-Oct; 30(5):29-34.
25. Cheron MFL, Pettengill MAM. Experiência do irmão sadio em relação à doença e hospitalização do irmão com câncer. *Acta Paul Enferm*. 2011 Set-Out; 24(5):605-10.
26. Murray JS. Social support for school-aged siblings of children with cancer: a comparison between parent and sibling perceptions. *J Pediatr Oncolgy Nurs*. 2001 Mai-Jun; 18(3):90-104.



- 
27. Sidhu R, Passmore A, Baker D. An investigation into parent perceptions of the needs of siblings of children with cancer. *J Pediatr Oncolgy Nurs.* 2005 Sep-Oct; 22(5):276-87.

Correspondence to: Daniela Dias Quirino  
Rua João Galiza de Andrade, 221, ap. 301, Edf Marília  
58051-180 - Jardim São Paulo, João Pessoa, PB, Brasil  
E-mail: danydiasq@hotmail.com