

## Bonds of the child-family binomial before and after the diagnosis of childhood cancer\*

Vínculos do binômio criança-família antes e após o diagnóstico de câncer infantil

Vínculos del binomio niño-familia antes y después del diagnóstico de cáncer infantil

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**Abstract: Objective:** to describe and analyze the bonds of the child-family binomial, before and after the diagnosis of cancer. **Methods:** This is a qualitative and descriptive study conducted with six families of children with cancer. Data collection occurred with guiding questions, construction of Genogram and Ecomap, from July to October 2017 in the participants' homes. Thematic analysis by Braun and Clarke was carried out. **Results:** The results were the broken bonds and those created before and after cancer. The main broken bonds were school activities, walks, living with the pet, and changes in food. The bonds created were new friendships in the hospital and the use of games and electronic games. **Conclusion:** recreational activities proved to be an interesting work tool to be used by health professionals, helping to build bonds, coping, and adapting the child and family.

**Descriptors:** Medical Oncology; Family; Pediatrics; Child; Qualitative Research

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**Resumo: Objetivo:** descrever e analisar os vínculos do binômio criança-família, antes e após o diagnóstico de câncer. **Métodos:** estudo qualitativo e descritivo realizado com seis famílias de crianças com câncer. A coleta de dados ocorreu com questões norteadoras, construção de Genograma e Ecomapa, de julho a outubro de 2017 nos domicílios dos participantes. Realizou-se a análise temática de Braun e Clarke. **Resultados:** os resultados foram os vínculos rompidos e os criados antes e após o câncer. Os principais vínculos rompidos foram as atividades escolares, os passeios, o convívio com o animal de estimação e as mudanças na alimentação. Os vínculos criados foram as novas amizades no hospital e a utilização de brincadeiras e jogos eletrônicos. **Conclusão:** as atividades lúdicas mostraram-se como um interessante instrumento de trabalho a ser utilizado pelos profissionais de saúde, auxiliando na construção de vínculos, no enfrentamento e na adaptação da criança e da família.

**Descritores:** Oncologia; Família; Pediatria; Criança; Pesquisa qualitativa

**Resumen: Objetivo:** describir y analizar los vínculos del binomio niño-familia, antes y después del diagnóstico de cáncer. **Métodos:** estudio cualitativo y descriptivo realizado con seis familias de niños con cáncer. La recolección de datos tuvo preguntas guiadoras, construcción de Genograma y Ecomapa, de julio a octubre de 2017 en los domicilios de los participantes. Se realizó el análisis temático de Braun y Clarke. **Resultados:** los resultados fueron los vínculos rotos y los creados antes y después del cáncer. Los principales vínculos rotos fueron las actividades escolares, los paseos, la convivencia con el animal de estimación y los cambios en la alimentación. Los vínculos creados fueron las nuevas amistades en el hospital y la utilización de juegos y electrónicos. **Conclusión:** las actividades lúdicas se mostraron como un interesante instrumento de trabajo a ser utilizado por los profesionales de salud, auxiliando en la construcción de vínculos, en el enfrentamiento y en la adaptación del niño y l familia.

**Descriptor:** Oncología médica; Familia; Pediatria; Niño; Investigación Cualitativa

## Introduction

Child and adolescent cancer, which occurs between 0 and 19 years old, consists of a set of diseases with their specific characteristics in the histopathology and clinical behavior and can occur anywhere in the body. Unlike adult cancer, this type of cancer is predominantly embryonic and generally affects the blood system cells and supporting tissues, with the predominant types of pediatric cancers being leukemia (28%), cancer in the central nervous system (26%), and lymphomas (8%). Risk factors related to lifestyle do not influence the risk of a child developing cancer and it can rarely present genetic changes that make them prone to develop a certain type of cancer.<sup>1</sup>

The quantity of new cases of childhood and juvenile cancer expected for Brazil, for each year of the 2020-2022 triennium is 4,310 males and 4,150 females. These values correspond to an estimated risk of 137.87 new cases per million in males, and 139.04 per million in females.

Treatment progress has been satisfactory in recent decades, so that today, 80% of children can be cured if diagnosed early, and treated in specialized centers.<sup>1</sup>

Despite the chances of a good prognosis, the diagnosis of cancer is surrounded by stigmas and symbolic meanings related to pain, suffering, and death. When experiencing a chronic disease such as cancer, with one of the family members, they go through a series of changes, such as increased spending due to hospitalization, transportation, and accommodation. Sometimes the family provider is the same that will take care of the child, and there is a disorganization of the family routine due to increased responsibilities. As a consequence of this, there is the emergence of feelings, such as fear, anxiety, and insecurity that the family and the child experience during the whole process, from diagnosis, the treatment process to recovery.<sup>2</sup> In this sense, reflections and adaptations are important for the new reality of the family, requiring several adjustments, organizations, and redefinitions of roles to preserve family balance.

Cancer in children is a disease that requires several moments of hospitalization as they leave their homes and live with their families to adapt to the hospital environment and everything that involves it. In this sense, the illness and hospitalization of a child mean the disruptions in his daily life and of his family, since he starts to be in a limited place, in which hospital routines and the environment reduce the amount and variety of activities, which can disrupt his natural development.<sup>3</sup>

Thus, the bonds built before and after hospitalization can result in changes that alter the dynamics in the child's daily life and development. A supportive bond is understood to mean people who may participate in two or more systems, forming a link, facilitating the process of resolving crises generated by the family and in the family.<sup>4</sup>

Therefore, the bond is an important strategy for adherence and the quality of care provided to the child and the family since from this network of relationships, the bonds with neighbors, community, school, and the hospital can whether or not, enhance the development process of the child with cancer and the family in carrying out and seeking care practices.<sup>4</sup>

Thus, the Genogram and the Ecomap are instruments to describe and analyze changes in the dynamics of the child and family, used as strategies to visualize the family conformation and the bonds that this family and the child establish in their life, between them and outside it. The Genogram is a graphic representation of family composition and basic relationships in at least three generations, elaborated by symbols.<sup>5</sup> The Ecomap is a diagram of the relationships between the family and the community and aims to assist in the evaluation of the support available and its use by the family. It can represent the presence or absence of social, cultural, and economic resources, being the portrait of a particular moment in the life of family members.<sup>6</sup> These instruments are used in the health area, including nursing, as a way of representing structural, emotional, and affective family processes.

From the above, the study research proposal becomes relevant as it addresses the difficulties arising from the diagnosis, treatment, and impact of cancer in childhood for the child and his family, and to the hospital context. Therefore, the study focuses on describing and analyzing the bonds of the child-family binomial, before and after the diagnosis of cancer.

## **Method**

This study has a qualitative and descriptive approach, focusing on the playful interaction between the family and the child with cancer-based on the construction of a Genogram and an Ecomap. For this purpose, we carried out the study in a municipality in the south of Rio Grande do Sul (RS), from July to October 2017. The city in which the study took place is not considered a reference for cancer treatment in children, and, for this reason, the research participants traveled to the state capital, Porto Alegre, to undergo chemotherapy and medical follow-ups, remaining in their homes in the city where this study was applied during the other periods of treatment.

We adopted the following factors for the research as inclusion criteria for children: a) being between 04 and 12 years old; b) not being in a hospital in the city where they performed the treatment during data collection; c) having been diagnosed with any type of cancer; d) being in

physical and psychological conditions to participate in the study, and e) live in the city in which the study was developed, or in cities distant up to 50 kilometers. The inclusion criteria for family members were: a) being a family member of a child aged between 4 and 12 years old who has a diagnosis of cancer; and, b) accept their participation in the proposed activities and have full and complete agreement on the child's participation in the study. We excluded only children in palliative care from the research.

Following these criteria, the first family contacted was sent by the reference Oncology Service. The others were identified using the snowball technique,<sup>7</sup> which consists of a non-probabilistic sample and not made for convenience, in which the initial participants indicate new cases, and they will also indicate other participants, successively, until there are no more new indications.

Thus, Family 01 indicated new participants, and the following families indicated other families to participate in the study. The saturation point was when the last family indicated only families that had already been contacted to be part of the study. Finally, a total of 08 families were indicated, and 06 of them accepted to participate in the study. One family denied participating because the child is recovering from a bone marrow transplant and one family did not answer the invitation. Of the 06 families, a total of 18 members participated in this research.

Thus, the researcher made the previous contact with the families by phone, explained the research objectives, and, after acceptance, scheduled the collection at the participants' own homes. The data collection instruments used were as already mentioned, the Genogram and the Ecomap applied by the main researcher of the study. The researcher received training for data collection during workshops offered throughout her Master's course.

Therefore, the Genogram was built together with the family using drawings that represented the members and the bonds playfully established between them. On the other hand, the Ecomap was produced on cardboard with the family in the center and, around it, the family members drew, wrote, or represented with toys their main support networks and the playful

activities (PA), the lost bonds, the bonds created and/or strengthened during this process. The construction of the Genogram and the Ecomap was carried out by the family members jointly. The drawings and symbols of the Genograms and Ecomaps were photographed and attached to the study through images.

For the drawings, we presented a legend to the families represented by a) a straight line as a weak bond; b) two straight lines as a moderate bond; c) three straight lines as a strong bond; d) a winding line representing the conflicting bond; e) a transverse red line characterizing the bond that was not interrupted; f) two red lines as a partially broken bond; and, finally, g) three red lines as a broken bond. During the construction of the Genogram and the Ecomap, the following guiding questions were proposed to the families: a) represent what was your and your child daily life like before the diagnosis?; b) how were the child's games before the diagnosis?; c) what did the family used to do to have fun before the diagnosis?; c) what is the routine of games and leisure now?; d) how do you feel playing with your child in this post-diagnosis period?; e) draw the activities that are no longer carried out; and, f) what games and leisure activities would you like to do again? The proposition of both activities had, on average of two hours. We recorded the speeches of the participants during the construction of the Genogram and Ecomap with an audio device.

The ethical principles considered for carrying out this work were ensured by Resolution 466/2012 of the National Health Council of the Ministry of Health,<sup>8</sup> and the Resolution of the Federal Nursing Council (COFEN) 311/2007.<sup>9</sup> The Committee of Research Ethics approved this study under opinion number 2,130,783, on June 21, 2017. The children participating in the research signed the Informed Assent Form and the family members signed the Informed Consent Term, prepared in two copies, leaving a copy with the participants and another with the researcher. Also, the participating families were identified by numerals, and the individuals

of each family were identified by fictitious names. Example: João, father of Family 01, Maria, daughter of family 02.

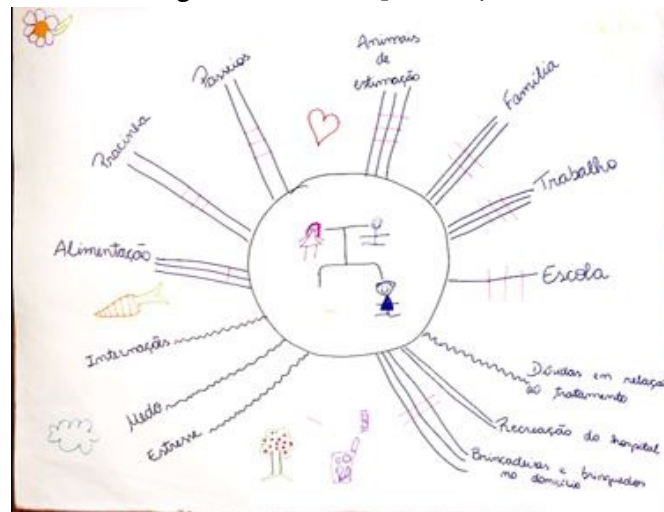
The analysis of the data obtained in the research was based on the Thematic Analysis proposal, covering its six phases.<sup>10</sup> The data recorded in audio were transcribed in full, read, and reread, aiming at familiarization with them according to phase 1 of the analysis. The following phases were carried out using the Ethnograph software to assist in the process of code generation (phase 2), search and review of themes (phases 3 and 4), and definition of the themes (phase 5). After these steps, the final report (phase 6) was prepared according to the themes built from the grouping of the codes with the main research results.

## **Results**

### **Family 01**

This family is composed of Bianca, five years old, her sister Bárbara, 10 years old, her mother Beatriz, 41 years old, and Beto, the father, 40 years old. Bianca was diagnosed with Acute Lymphoid Leukemia in 2016, at the age of four. Both parents were teachers, but the mother had to leave work to be able to accompany her daughter during treatment. Bianca spent days in Porto Alegre (RS) and other days at her residence. After Bianca's diagnosis, the PAs of Family 01 changed, bonds were broken and others strengthened, as expressed in the Ecomap (Figure 1) developed by the family, with Bianca and Bárbara drawing and their parents helping to write.

**Figure 1-** Ecomap family 01.



In the Ecomap of the Family 01, we verified the PA that changed the diagnosis, in which walks and meetings with other relatives gave rise to the conflictive/stressful bond with hospitalizations, fear, stress, and all doubts related to treatment. The parents also experienced changes in their activities and expressed the link with the work that needed to be stopped. Bianca had to stop attending a school that was only two months old, a weak bond that was still strengthening but interrupted after the diagnosis.

Family 01 also designed a strong bond with pets interrupted due to Bianca's treatment. For fear that the animals would cause harm to the girl, the parents decided to donate them to another family. Feeding was another point brought up by the family when talking about the broken bonds after the diagnosis. Drawing a carrot, Bianca and Bárbara said that they had to remove raw vegetables and fruits from the family's diet.

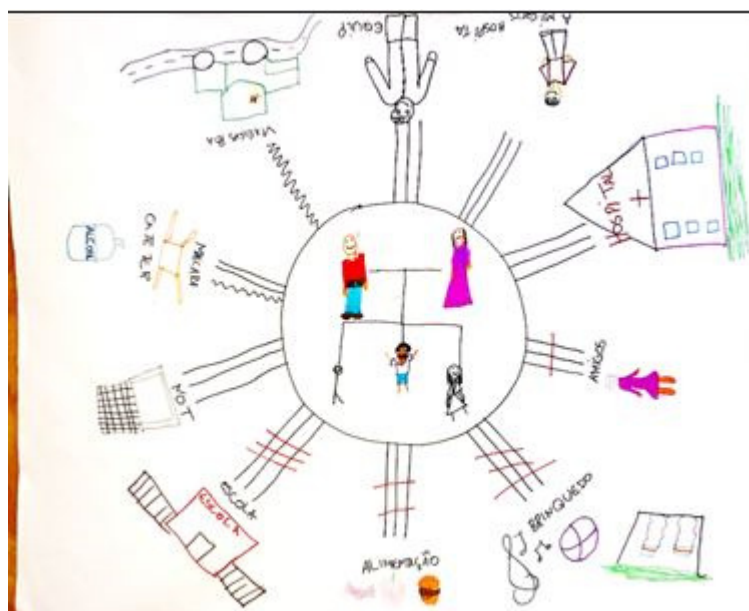
Regarding PA that involves playing, Family 01 reported a moderate bond with recreation in the hospital, as Bianca did not always feel like playing. When returning home, Family 01 considered that the bond with playing was interrupted in parts, as Bianca has physical limitations related to treatment. Among all the broken bonds in Family 01, playing in the square was the activity that Bianca reported missing most.



## Family 02

Family 02 consists of João, 10 years old, son of José, 64 years old, and Joana, 55 years old. João has two older brothers, Joice, 27, and Jonathan, 32, who do not live in the family home. The parents have a mini-market next to their residence. João was diagnosed with rhabdomyosarcoma at the age of six, with lung, liver, intestinal, and bone metastasis. He has already undergone surgical treatment, injectable, and oral chemotherapy. The ecomap (Figure 2) shows the relationships and bonds of Family 02, designed by João, with the help of the other participants.

**Figure 2** – Ecomap of family 02.



Family 02 represented in the Ecomap the stressful bond with trips to Porto Alegre (RS) to carry out the treatment. Besides this travel issue, João showed how stressful the bond he created with the mask and alcohol gel due to low immunity and care with the catheter. Also, the bond to the school had to be interrupted and some friends visited him infrequently. Now, at a time when he has the highest immunity, the games with friends are gradually resuming.

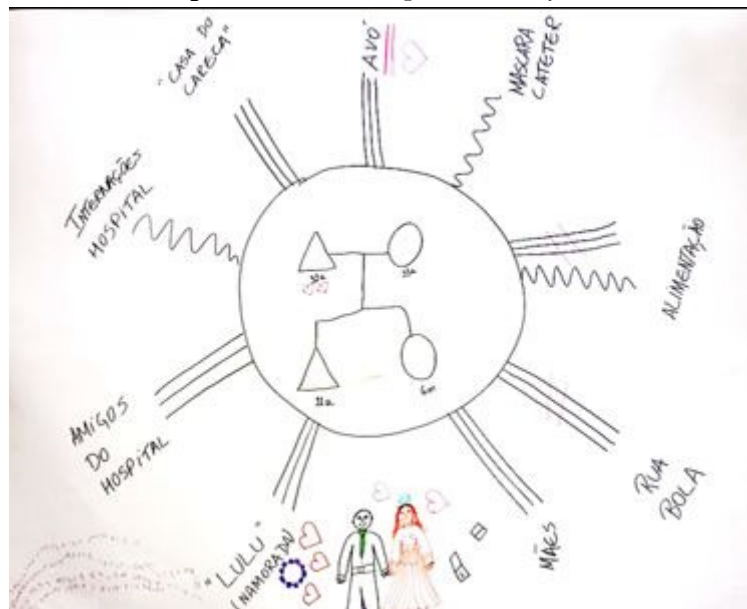
The PA related to games and playing were restricted in the routine of Family 02. José said that he very much liked to take João in the square to play and play football, but after the

diagnosis, this was a bond that had to be completely interrupted. This bond with outdoor activities was replaced by electronic games on the computer and cell phones.

### Family 03

Family 03 is composed of Mateus, 11 years old, his mother, Marta, 33 years old, housewife, his father, Marco, 32 years old, security, and his six-month sister, Mariana. Mateus was diagnosed with Acute Lymphoid Leukemia (ALL) in 2016 and has been under treatment ever since. Besides the diagnosis of ALL, Mateus has Down Syndrome and his mother says that since he was a little boy, he attends a special school but that he did not develop drawing skills. For this reason, in the construction of the Genogram and Ecomap, Mateus made some symbols and asked his mother to draw what he wanted. In the Family 03 drawing, Marta represented men with triangles and women with circles. The bonds of Family 03 are represented in the Ecomap (Figure 3):

**Figure 3 – Ecomap of Family 03.**



Mateus and Marta put the stress bond with the hospitalizations and long periods away from home on the Ecomap. Marta said that she was away from her husband for a long time because Marco works, not being able to accompany them, and Mateus reported that he misses

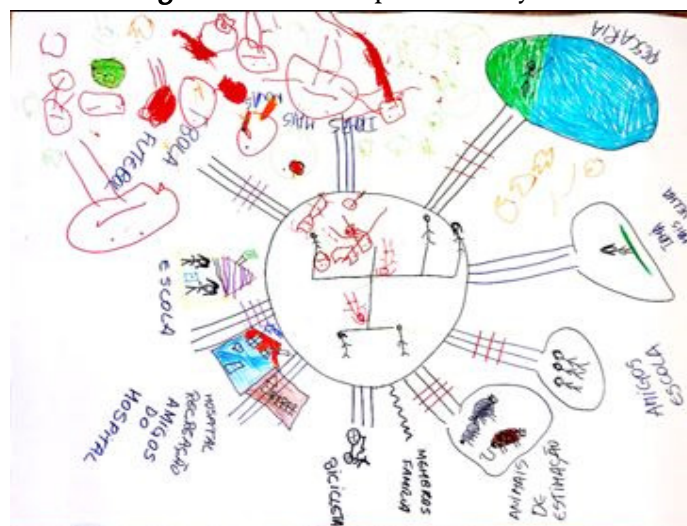
his father a lot. Another stressful bond for the family is to have Mateus wear a face mask when his immunity is low after chemotherapy sessions. The mother also said how much she cares about her son's catheter, as she is afraid that he will displace it and needs to undergo a new procedure. For this reason, some games that Mateus used to play were partially interrupted, such as playing in the street and playing ball.

Family 03 brought the strong bond created with “Casa do Careca” which is how Mateus calls the Hospital and the Support House that were in Porto Alegre (RS). Playfully, we observed that Mateus created new meanings for the disease and hospitalization. Mateus very lovingly spoke of his friend "Lulu". They met at the special education school he attended and have become close friends since then. Marta said that Lulu is the only friend that Mateus kept even after the diagnosis, that he always visits him and that they play a lot.

#### Family 04

Family 04 has Rafael, eight years old, diagnosed with Acute Myeloid Leukemia (AML) in January 2017, his mother Raquel, 53 years old, housewife, his father Roberto, 67 years old, retired, and his sisters, Renata, 27 years old, Raissa, seven years old and Rita, four years old. Rafael, Raquel, Raissa, and Rita participated in the data collection, and Rafael designed the Ecomap (Figure 4).

**Figure 4** – Ecomap of Family 04.



Due to treatment restrictions and low immunity, Rafael plays only with his sisters to adapt the games, and Raissa and Ruth take care that he is not hurt. The bond with other children was completely interrupted since he stopped attending school after the diagnosis.

Thus, due to Rafael's low immunity, Family 04 needed to get rid of pets. The children had a very strong bond with the two cats and the family dog, with whom they played daily. The bond had to be broken, but the children keep photographs with the animals, showing them affectionately during the construction of the Ecomap.

In addition to this broken bond, Rafael represented on the Ecomap the restrictions related to the two activities he likes a lot: football and fishing. Raquel said that Rafael always liked fishing very much and that his uncle always took him on weekends, which was the bond that Rafael misses most.

### **Family 05**

Family 05 consists of Artur, nine years old, his mother Ana, 39 years old, and his stepfather Alberto, 38 years old. Artur's parents split up when he was still small and Artur has a very strong bond with Alberto. The boy was diagnosed with Chronic Myeloid Leukemia (CML) in 2014, starting treatment with chemotherapy, and, in July 2016, he underwent a bone marrow transplant. Artur drew the Ecomap (Figure 5), placing his family in the center, made up of him, his mother, and his stepfather.

**Figure 5** – Ecomap of family 05.

Artur represented the hospital and medicines as strong bonds created after his diagnosis. Artur counted the medications he takes, knowing everyone's name and how each one helps in his illness. The boy demonstrated knowledge about the restrictions related to his treatment and presented on the Ecomap the interrupted bond with certain foods, such as nuts, peanuts, and mate.

Another strong bond brought by Family 05 are trips to Porto Alegre (RS). Artur said that he became very friendly with a city hall driver who always took him. Regarding the issues involving hospitalizations and travel, Ana worked in a candy factory and had to stop after her son's diagnosis since she had to accompany him.

Artur said that he likes to draw a lot, reproducing on his Ecomap the drawings he made when he was in the hospital. He drew things that he missed and wanted to do, for example, jumping on a trampoline, riding a horse, and playing football on a field in front of his house. He also drew police cars because he dreams of being a policeman. During the hospitalization period, the boy said that he made friends in the hospital, but he did not play much while he was hospitalized, having a strong bond with electronic games on the computer.

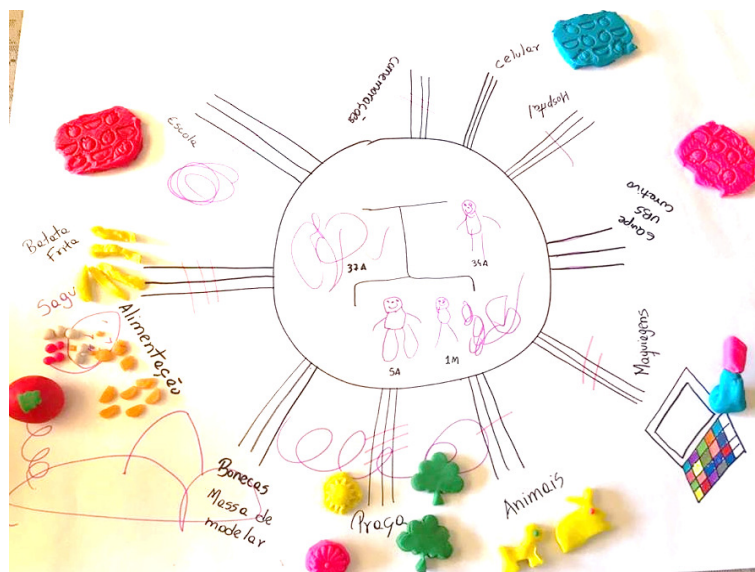
Since he was diagnosed, Artur had to break the bond with the school and friends on the street. After the diagnosis, the boy said that he felt very sad, as he kept looking out the window

while friends on the street played and played ball. Among the PAs of Family 05, fishing, horseback riding, and bathing in the river were the activities interrupted since the beginning of Artur's symptoms. Ana said that they liked to go to the countryside very much and that her son liked to fish and bathe in the river, besides riding a horse.

### Family 06

Family 06 is composed of Sofia, five years old, her mother Sara, 34 years old, a housewife, her father Sergio, 38 years old, truck driver, and brother Samuel, one month old. Sofia was diagnosed with Osteosarcoma about two years ago.

**Figure 6** – Ecomap of family 06.



The Ecomap was designed by Sofia, representing the bonds of Family 06 with symbols she made with modeling clay and drawing. The mother wrote and assisted her daughter in carrying out the activity. Family 06 had PA to go to the square together, they liked to take Sofia to play and walk. This was a very present activity in their lives, being reported as a strong bond that was completely interrupted after the daughter's treatment began.

The Family has a dog and a rabbit as pets. Although it was indicated that it would be better for Sofia to get rid of the animals, the parents opted to just take their daughter away from society a little while she was in a weaker phase of treatment. They believe that the bond with the animals helps Sofia to face the moment she is experiencing.

After the diagnosis, they moved away from family and friends, and created new bonds with other families of children with cancer, with the team of the Hospital, and with the team of a Basic Health Unit (UBS) that goes to the family residence to perform dressings on the catheter used by Sofia. Family 06 reported Sofia's bonds interrupted with the school that she stopped attending and the dietary restrictions imposed by the treatment. As a strong bond of the girl, she indicated the modeling dough, playing with dolls and games on her cell phone.

## Discussion

Cancer is a disease permeated with negative feelings. Therefore, receiving such a diagnosis is difficult for anyone, especially for a child and his family.<sup>11-12</sup> Knowing that the child is a member of the family, when he is sick, most other members are affected, especially their caregivers.<sup>13-14</sup>

Considering the conversations with the families, we found that the diagnosis of cancer in the child brought feelings of fear, burden, and stress. Parents had to change their routines, be distanced from other family members, and changed family dynamics. For them, cancer overlaps other activities, leading to prioritizing care and care for the sick child. Thus, the family goes through an adaptation period, starting to have special needs related to the disease and treatment.<sup>12,14</sup>

Thus, after the diagnosis of cancer in childhood, the child had a disruption of his school activities, and, consequently, of the playful activities carried out at school and living with colleagues. Children from Families 01, 03, 04, and 06 had their school activities interrupted. Families 02 and 05 point out that, although the child is not attending classes, school activities have been adapted so that he does not miss school.

Besides the school, children with cancer found restrictions in their social life since childhood cancer interferes in the practice of group play, in social and interpersonal relationships in the community in which they live.<sup>13-14</sup>

For the families in this study, the children's social interaction was partially interrupted since with treatment and low immunity, they are susceptible to infections. We also observed that the restrictions also occurred with pets, even though it is known that the sick child can have moments of joy when playing beside their animal. Although families and some professionals are afraid of the interaction between the child and the animals, studies point out the advantages of allowing such a practice as long as the necessary care is taken to avoid infection.<sup>12-15</sup>

Playful activities, previously exercised intrinsically in the children's routine, become difficult for the children studied because when facing and experiencing cancer, they need to adapt to a new reality. Cancer treatment provides side effects that make the child unwilling to play, reducing free time for leisure activities.<sup>16</sup> In contrast, playfulness in the hospital environment was preserved, remaining as a stimulating tool for child development. PA during hospitalizations is understood as fundamental by the importance of preserving such actions so that the child does not completely lose the tools that provide him with cognitive and emotional growth.<sup>17</sup>

Another aspect to be highlighted was the possibility for the child to perform playful activities being released by the medical team. However, the family members still found resistance and fear that they would get hurt during the activity. Thus, it is evident how much it is necessary to clarify the doubts of these families so that they are empowered and provide a caring environment that aims at healthy child development and that the child's happiness is superior to this fear. Thus, it is relevant how much a family well assisted by health professionals can provide healthy play for children with cancer and a more peaceful family in the face of this PA.

For the selection of participants in this study, one of the children has Down syndrome, which requires specific analysis of the issues related to child development. Also, the study



analyzed the impact that childhood cancer has on playful activities and child development in a qualitative and short-term way. The relevance of studies that also analyze this long-term impact is emphasized, seeking to establish a comparison with children who have not had childhood cancer.

The limitations of the study include the difficulty in finding participants who obeyed the proposed criteria. This is mainly because the research is carried out in a city in which there is no child cancer care as a reference health service.

## **Conclusion**

This study enabled us to describe and analyze the bonds between the child and the family before and after the diagnosis of cancer, carried out using the Genogram and Ecomap. Through the data, we identified that cancer modifies, in several aspects, the lives of children and their families, breaking several bonds. Among the main ones, school activities, leisure time, and socializing with other children stand out, besides outdoor walks, changes in food, and distance from pets. However, given these changes and the adaptation to the new context of life, new bonds were created and new friendships emerged within the hospital environment, especially in the recreation space, a place that promotes unrestricted entertainment, under medical guidance.

The main contribution of this study to the practice with children with cancer and their families is the importance of stimulating the performance of PA since it is essential for the child's cognitive and social development, making the environment lighter and nice. The PA favor the construction of safe bonds, and promote health and well-being, collaborating in coping and adapting life due to the changes that the disease establishes. However, we also perceived how little it is used as a work tool by health professionals, who suggest the need for training and instrumentalization with this work methodology to highlight its importance and the positive effects in the lives of children and families experiencing the diagnosis of childhood cancer.

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She was responsible for all aspects of the study, ensuring the accuracy or integrity of any part of the study.

#### **2 – Rosani Manfrin Muniz**

Approval of the final version of the study to be published.

#### **3 – Michele Cristiene Nachtigall Barboza**

Substantial contributions to the conception or design of the study; construction and analysis of the study

**4 – Aline Blaas Schiavon**

Acquisition, analysis or interpretation of study data.

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