

# Experiences of siblings of children with chronic diseases revealed by the dramatic therapeutic play

*Vivências de irmãos de crianças com doenças crônicas reveladas pelo brinqueado terapêutico dramático*

*Experiencias de hermanos de niños con enfermedades crónicas reveladas por el juego terapéutico dramático*

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## ABSTRACT

**Objective:** To understand, through dramatic therapeutic play, the experiences of siblings of children with chronic diseases.

**Method:** Phenomenological study, in the light of Heideggerian philosophical framework, conducted with 12 siblings of children with chronic diseases, aged between three and 11 years, accompanied in a public teaching hospital in the countryside of the state of São Paulo. The phenomenological interviews were audio-recorded and mediated by sessions of dramatic therapeutic play; later, interpreted from the Heideggerian philosophical framework and thematic literature.

**Results:** The siblings demonstrated that they are affectively touched in the mode of sadness, longing and affection towards the sick child and, by the daily occupations imposed by the disease.

**Conclusion:** The dramatic therapeutic play enabled the siblings of children with chronic diseases to expose their experiences permeated by the limitations of the child's chronic disease. Instituting actions for the inclusion of the sibling during the nursing care of the child with chronic disease is urgent to improve its quality.

**Keywords:** Siblings. Chronic disease. Qualitative research. Play and playthings. Pediatric nursing.

## RESUMO

**Objetivo:** Compreender por meio do brinqueado terapêutico dramático, vivências de irmãos de crianças com doenças crônicas.

**Método:** Estudo fenomenológico heideggeriano, realizado com 12 irmãos de crianças com doenças crônicas, com idades entre três e 11 anos, acompanhadas em hospital público de ensino, no interior do estado de São Paulo. As entrevistas fenomenológicas foram audiogravadas e mediadas por sessões de brinqueado terapêutico dramático; posteriormente, interpretadas a partir do referencial filosófico heideggeriano e literatura temática.

**Resultados:** Os irmãos demonstraram que são tocados afetivamente no modo da tristeza, saudade e carinho em relação à criança doente e, pelas ocupações diárias impostas pela doença.

**Conclusão:** O brinqueado terapêutico dramático possibilitou que os irmãos de crianças com doenças crônicas expusessem suas vivências permeadas pelas limitações da doença crônica da criança. Instituir ações para a inclusão do irmão durante a assistência de enfermagem à criança com doença crônica faz-se urgente para melhoria da sua qualidade.

**Palavras-chave:** Irmãos. Doença crônica. Pesquisa qualitativa. Jogos e brinquedos. Enfermagem pediátrica.

## RESUMEN

**Objetivo:** Comprender, a través del juego dramático terapéutico, las experiencias de los hermanos de niños con enfermedades crónicas.

**Método:** Estudio fenomenológico, a la luz del referente filosófico heideggeriano, realizado con 12 hijos de niños con enfermedades crónicas, de edades comprendidas entre los tres y los 11 años, acompañados en el hospital público de enseñanza, en el interior del estado de São Paulo. Las entrevistas fenomenológicas fueron grabadas en audio y mediadas por sesiones de juego terapéutico dramático; luego, interpretada desde el marco filosófico heideggeriano y la literatura temática.

**Resultados:** Los hermanos demostraron que están tocados afectivamente en el modo de la tristeza, la añoranza y el afecto en relación con el niño enfermo y, por las ocupaciones diarias impuestas por la enfermedad. El brinco terapéutico dramático permitió que los hijos de los niños con enfermedades crónicas expusieran su vida a las limitaciones de la enfermedad crónica del niño.

**Conclusión:** Es urgente instituir medidas para la inclusión del hermano durante la asistencia de enfermera al niño con enfermedades crónicas urgente para mejorar su calidad.

**Palabras clave:** Hermanos. Enfermedad crónica. Investigación cualitativa. Juego e implementos de juego. Enfermería pediátrica.

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## ■ INTRODUCTION

To be a sibling is to share close or distant relationships, conflicting or not, along with feelings such as rivalry, competition, jealousy, affection, companionship, which influence and shape the future social relationships that those involved will play beyond the family setting<sup>(1)</sup>. However, when there is a child with a chronic disease, these relationships can be harmed and this diagnosis may impact the siblings' lives in different ways, according to their stage of development<sup>(2,3)</sup>.

The siblings report the difficulty of the parents to make clear the health condition of the ill child and demonstrate the need to understand what is happening, as this brings the siblings closer to the context of the chronic disease. Consequently, the lack of information regarding the diagnosis and the fear of the unknown trigger negative impacts, such as anxiety and wrong thoughts about the health status of the child with chronic disease<sup>(2-4)</sup>.

Studies that aim to understand how siblings experience the situation of chronic disease, address specific topics such as anxiety, coping skills and psychological adjustments, especially in the face of diseases such as cancer and diabetes<sup>(2,4)</sup>. In addition, the siblings' view of the chronic disease come from the parents' perspective and not from the discourse of the siblings themselves<sup>(5)</sup>.

Thus, in view of the above and considering that siblings throughout their lives are faced with different feelings that affect them positively or negatively, depending on their experiences<sup>(5)</sup>, this study was conducted based on the following research question: how is the experience of being a sibling of a child with chronic disease?

For this, we sought to give voice to siblings for their experiences to be understood, respected and recognized through them, using dramatic therapeutic play (DTP) as a technology and strategy that enables children to express how they feel and what they think about the situation experienced<sup>(6,7)</sup>.

The DTP is a structured play, considered a technology of care used by nurses and has long been highlighted as a resource for data collection in qualitative research with children, as it allows the child, while playing, to relieve anxiety, relieve tensions, express feelings and, favors researcher-child interaction, motivating the participants<sup>(6-8)</sup>.

This study corroborates the literature by considering essential that health professionals recognize siblings as family members who need attention, considering their needs and identifying strategies to be implemented in the planning and

execution of nursing care that includes all those involved<sup>(2,5,9)</sup>, for example, permission for siblings to visit hospital pediatric units, if that is the wish of the child and the family.

Therefore, it is important to understand the experiences of siblings of children with chronic diseases, so that the results allow proposals to improve the quality of nursing care provided to these children and, at the same time, boost new studies that give voice to children who experience situations of diseases in the family.

It is believed that the benefits arising from this research will provide support to contribute to reducing the knowledge gap between the experiences of siblings and the way they are seen in the context of pediatric nursing.

Thus, the objective of this study was to understand, through dramatic therapeutic play, the experiences of siblings of children with chronic diseases.

## Theoretical-philosophical framework

Phenomenology, based on the assumptions of Martin Heidegger, seeks the meaning of the phenomenon, that is, the meaning of what can be put clear, i.e., the entity. Thus, the entity is something that is always shown to someone; it is understood as everything that the human can talk about and the way he himself is, and relates to others around<sup>(10,11)</sup>.

Thus, Phenomenology is able to understand human existence, which consists of man's way-of-being in the world and is always located in time and space, launched into facticity, that is, exposed to a certain situation, from a historical world, having to deal with the way their life and situations are given<sup>(10)</sup>.

The *being-there*, or Dasein, is the concept used to assign the specific character of the human being, understood as the place where the being reveals itself. *Being-there* is being-in-the-world and corresponds to the various possibilities that humans have to live in constant relationship with the beings that present themselves to them. In this way, each person is his own situation and being-in-a-world makes their existence<sup>(10,11)</sup>.

From the beginning, the child is considered a being-there, an entity that is launched and constituted by the mode of indetermination, which affirms the character of being-able. At birth, they are immersed in a relation with the world<sup>(12)</sup>, understanding it through the openness of being and being-with-others. For the child, things are not yet and are not conceptually closed, and the opening, as constitutive of the being-there, allows them to discover the world<sup>(13)</sup>.

In this way, Phenomenology comes as a theoretical framework, as it comprises the descriptions of unique phenomena and how they are experienced and felt by individuals<sup>(10,11,14,15)</sup>. In this study, it will help in the understanding of what the experience of being a sibling of a child with chronic disease means in their life world, revealed from the siblings' discourses during the DTP sessions.

## ■ METHOD

The phenomenological qualitative research was chosen because it enables the understanding of how human experiences are lived and the apprehension of meanings not unveiled from internal experiences<sup>(15)</sup>.

The participants were 12 siblings of a child with chronic disease, who met the inclusion criteria: children aged between three and 11 years, living with a brother or sister with a chronic disease hospitalized in the Pediatric Nursing Service (PNS). It was considered as exclusion criterion, siblings who presented cognitive alterations that hindered the expression of experiences.

To access the participants of the study, the first author and doctoral student of the Postgraduate Nursing course attended the PNS four days a week, during the activities of the Teaching Internship Program (*Programa Estágio Docente* - PED) and approached the nurse responsible for the shift, asking about children with chronic disease, whose siblings were between three and 11 years old.

Families that met the inclusion criteria were informed about the research objectives through an individual visit to the bed of the child with chronic disease, so that the responsible could assess the possibility of participation of the other child/children, through the Free and Informed Consent Form (FICF). Being present, usually at the service, favored the formation of bonds with the nursing team professionals and with the families of children with chronic disease.

After the consent of the guardians, and according to their indications, the siblings were invited to play and received guidance about the study through the Child Assent Form (CAF), prepared and illustrated especially for this purpose.

There were three scenarios<sup>(14)</sup>, where the DTP sessions took place:

1. Pediatric Nursing Service (PNS): public hospital and teaching institution, in the countryside of the state of São Paulo. In this service, the DTP sessions were performed at a table in the external area. Of the five DTP sessions held at the PNS, four were individual and one group with two siblings, corresponding to six siblings. The siblings opted for the group DTP session.

2. Households: two of the residences were in municipalities that make up the Metropolitan Region of Campinas and two are part of the Urban Region of Jundiaí. In this context, there were five individual DTP session, totaling five siblings;

3. Public square: exceptionally, one DTP session with a single sibling took place in a public square, located in the center of the city where the child's family lived. It occurred because the family lived in an area of drug trafficking and because they considered it the best option for them.

The environment was not determinant for the sibling to participate or not in the session. However, at the hospital, the presence of other toys in the external area of service aroused the curiosity of two siblings, encouraging them to explore the surrounding environment, ending their participation in the DTP session ahead of time.

The sibling was invited to participate in the phenomenological interview<sup>(15)</sup>, mediated by the DTP, guided by the following question: *Let's play like a child who has a sibling who always needs to stay in the hospital?* After acceptance, the material was presented and the session met what was exposed in the literature<sup>(9,15)</sup>, giving the sibling the freedom to choose the toys and how they wanted to play.

During the phenomenological interviews, the researcher followed the assumptions of the literature, which consider the researcher's openness to understand the perspective of the other, empathy, removing prejudices, attentive and understanding listening to unveil the phenomenon, respecting the time and space of the other<sup>(15)</sup>.

The material used for the DTP sessions was selected based on the literature recommendation<sup>(7,8)</sup>: plastic dolls of superheroes, cloth dolls representing the family, household items, food, baby bottle, animals, carts, motorcycles, tools, artistic materials (colored pencils, crayons, brushes, blank paper, paint, modeling clay and magic board) and a playful set of hospital materials<sup>(7,8)</sup>. The whole set of toys was in a plastic box.

Access to the siblings and the phenomenological interviews mediated by the DTP took place from April 2017 to April 2019. Fourteen guardians were invited and four refused the invitation for personal reasons.

Participants were identified by nicknames of children's story characters: Secret, Dream, Heart, Beloved, Loving, Tenderness, Sleepy, Sincere, Champion, Cheerful, Fun and Friend, with the aim of ensuring confidentiality regarding the identity of the participating siblings. When the siblings mentioned the children with chronic diseases, the real names were replaced by the names with the same initial letter.

The siblings' statements during the phenomenological interviews were audio-recorded, with an average duration of

50 minutes, totaling 552 minutes. The interviews were fully transcribed by the first author, who has extensive experience in phenomenological qualitative research since the undergraduate level in 2009. The behavior and reactions of the siblings were recorded in a field diary right after the end of each interview, aiming to preserve the most original form of the phenomenon<sup>(15)</sup>. The transcriptions and field diary notes constituted the textual *corpus*. All siblings participated in a single interview.

The phenomenological interviews mediated by the DTP ended when, during data collection, playing allowed understanding the facticity of these siblings. As the emerging statements, during the sessions, were transcribed, they were also being explored individually. This continuous task makes the researcher assess the theoretical saturation, i.e., the moment when there is no new information and/or these are no longer necessary, as they no longer change the understanding of the studied phenomenon<sup>(14,15)</sup>.

After a constant interpretative process of reading and rereading of the total content of the textual *corpus*, according to what is recommended by the phenomenological method<sup>(11,15)</sup>, convergences and divergences were sought in the statements, identifying the meanings units, which gave rise to the thematic axes, enabling to apprehend the meaning of the phenomenon, according to Martin Heidegger's philosophical theoretical framework and the thematic literature<sup>(10,15)</sup>.

This study was approved by the Research Ethics Committee of the *Universidade Estadual de Campinas* under opinion no.1,950,007 – CAAE 64261816,6,0000,5404.

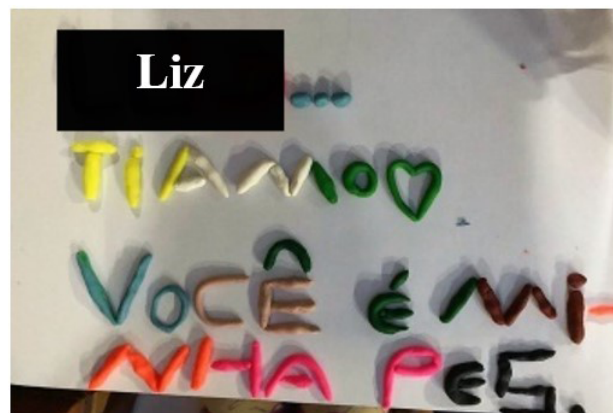
## ■ RESULTS

The phenomenological analysis of the interviews mediated by the DTP allowed the emergence of two thematic axes: 1) The moment of art: the sibling of the child with chronic disease being-in freedom and, 2) The daily life of being launched: the sibling of a child with chronic disease being oneself.

### The moment of art: the sibling of the child with chronic disease being-in freedom

After the siblings accepted the invitation to play, immediately, when they realized they had the possibility of choosing the way of playing to become when they found themselves launched, the first manifestation was to explore the toys in the DTP box. The siblings, in a singular and spontaneous way,

considered the magic board, modeling clay, gouache paints and painting materials as means of expression. Cheerful, she began playing with modeling clay of different colors, rolling the clay and, in small pieces, forming letters until she completed a sentence, clearly verbalizing what she was composing: a declaration of love for a child with chronic disease, highlighted in Figure 1.



**Figure 1** - Modeling clays molded by Cheerful, 8 years old. Campinas, São Paulo, Brazil, 2020

*Liz [child with chronic disease, 11 years old] I love you, you are my teacher. (Cheerful, 8 years old)*

Cheerful, 8 years old, in silence, modeling clays in the different colors, one by one; she takes small pieces, rolls them up, forms letters, and verbalizes:

During the play, some of the siblings showed to be comfortable to verbalize about what they were producing. However, others handled the modeling clay in silence and without announcing what they were creating. Thus, their plays were marked by the modeling of the masses in repetitive movements of rolling and unrolling, kneading, and opening, followed or not by emotions.

*Secret takes the orange modeling clay and rolls it. While modeling it, smile. Rolls, breaks, rolls again, shapes the end, for approximately 15 minutes. At one moment, sighs loudly and his eyes fill with tears, sighs and seems to get emotional. He turns his body more, distancing himself from the researcher, while remains modeling the orange mass. He keeps manipulating and shaping the orange mass between his hands, rolling it cylindrically in silence, until the end of the session. (Secret, 9 years old)*

This movement of (un)making and (trans)forming, which the modeling clay makes possible, also emerged in Loving's play. However, the way in which she used artistic materials was peculiar. When modeling, she also appropriated gouache paints and colored them, therefore modifying the original colors of the toys.

*Modeling clay. I want to play with play modeling clay. I'm going to paint this one yellow. Then, she opens the pots of gouache paint and paints, one by one, with her fingers, all the modeling clay. She notices that her hands are colored and when she shows joy with the new situation, she starts playing with her hands and forearms with different colors. A very blue glove. More to go. [Spreads more blue paint on hands] A little more to go [...]. I'm going to paint this one green. The glove. Look, it will turn green. It turned. She picks up the Barbie doll and asks if she can paint the Barbie® doll's legs blue and black.*  
(Loving, 5 years old)

While playing with the paints, in Loving's DTP session, it was noticed that this material gave her pleasure to continue and reinvent it, giving her new experiences. At birth after the child with chronic disease, Loving, was already exposed to the situation of chronic disease in her daily life, when coloring the Barbie® doll's legs, she revealed the way she understands the disease that is related to physical changes in the lower limbs due to the edema caused by the Nephrotic Syndrome, diagnosis of the child's chronic disease.

Expressing, by drawing of lines and colors, did not emerge sole, but also came, interspersed with the magic board. In the case of Tenderness, during the dramatization with the family's cloth dolls, she alternated playing with the use of drawing on the magic board. Playing with Tenderness revealed the understanding of a world-life marked by interruptions, that is, it dramatized in playing that its possibilities of being-in-the-world are interrupted at all times due to the discontinuation of its daily life, which is imposed by hospitalization of the child with chronic disease.

*Tenderness rests the magic board on her lap, makes a drawing and erases it. She performs another one and quickly erases it. She starts to draw the third one, putting a lot of strength on the pen and then erases it again. Afterwards, she plays with the family dolls, new family arrangements. Tenderness takes the magic board on her lap and makes a drawing. When finished, she erases in a discreet and delicate way. She draws another one, putting*

*more intensity into the lines and erases it. She takes a deep breath and lets it out quickly [...]. Then, she goes back to playing with the family dolls. Afterwards, she takes the magic board and again draws a picture. She sighs. She erases the drawing with force.* (Tenderness, 5 years old)

The possibility of revealing their being-in-the-world through design, that is, through drawing, on white paper, with colored pencils and/or gouache paint or on a magic board, allowed the siblings to express, during the DTP session, what they were feeling at that moment and the world they live in. Secret started playing with drawing on the magic board and immediately got emotional, crying as he drew with his head down and, when finished, he watched it.

The sibling illustrated, as shown in Figure 2, the moment when the mother leaves the family house to go to the hospital with the child with the chronic disease. She asks about her doubt about when the mother will come back home, and the mother replies that she has no prediction. He revealed that living with a child with chronic disease changes his life, as there are ruptures in family relationships, and the most evident change is when there is, in fact, the need for hospitalization. Therefore, the trip of the family member with the child to the hospital generates fear, suffering, pain and concerns, about himself, the child with chronic disease and the mother.



**Figure 2** - Drawing made by Secret, 9 years old. Campinas, São Paulo, Brazil, 2020

R (researcher): *Do you want to tell me about your drawing?*

Secret: *Yes. [Speaks in a choked voice and keeps head down] It's my house. [Points to the drawing of the house]. My mother and I. [Pointing to the drawings on the sides]*

R: *And what did you write?*

Secret: *When are you coming back? I don't know.* (Secret, 9 years old)



Secret: *I keep thinking about Livia and my mother, when will she come back. I'm worried if I get sick if she's going to worry about me [...]. [Speaks with a choked voice, tears in his eyes] If when I feel ill, she'll be worried.*

R: *What do you think??*

Secret: *I think so. [Speaks crying] From Livia. If she is ok there. [Referring to the hospital]. (Secret, 9 years old)*

Through the drawing, regardless of the tools used, Secret revealed that the situation of hospitalization of the child with chronic disease is permeated by difficult moments and different feelings, such as doubts and worries. However, other children used colored paints and did not seem to be uncomfortable when playing with these tools, as they showed a feeling of affection towards the child with the chronic disease.

Although not all siblings showed closeness and chose to use artistic resources during the DTP session, when chosen, these enabled the understanding of the siblings' experience. Although they used artistic materials, they also played with other toys and the revelation of their playing will be exposed in the next category.

### **The daily life of being launched: the sibling of a child with a chronic disease being oneself**

Immersed in the DTP session, the siblings revealed their daily life and historicity, removed, and handled the toys, exploring the contents of the DTP box, without showing preference for a specific toy.

*Corn. The knife! Look, of ironing clothes. The little plates. (Heart, 5 years old)*

*Look! Mr. Dinosaur. A lion. Wow that's great. Wow, Mr. Rhino, great! [...] A little pan. Let me see here. Corn, the egg. (Friend, 8 years old)*

When approaching the toys and considering possibilities for playing, the siblings revealed daily situations in their life-worlds and the relationship between family members. In Champion's playing, his food preferences, situations of his daily life and interactions between his parents and brother emerged.

Champion: *I'm going to have dinner now.*

Champion (answers as mother): *Meat? Corn. Egg and beef for you. [...] Mom is cooking dinner [Plays frying food] Do you want eggs for dinner?*

Champion: *Yes. I don't like corn, ew. I want! Egg.*

Champion (answers as mother): *Beef?*

Champion: *I don't like beef!*

Champion (answers as mother): *It's ok, but tomorrow you'll have to eat, okay? Look, Daddy has arrived. Dad doesn't like that you don't eat beef, huh.*

(Champion, 8 years old)

The relationships of the being-there contemplate relationships with oneself, with the others and with the things and are always based on a world that is being constructed through daily life. In this study, playing cooking was expressed in almost all the siblings' play.

*Knife, eggs and corn. Yes. The cookie. Cookie. Put it there. Put it here for us to play. Separate two pink pots, the stove, the chicken, the eggs and the corn. Let's make food. (Sleepy, 8 years old)*

*I already know what I'm going to do. A sausage will fry. Pretending. But then the sausage. [...] A shrimp. Tomato Sauce. [...] I put the... sausage. Who wants sausage coming out of the oven? Delivery to the researcher. Did it smell good? It's for you to eat. (Funny, 8 years old)*

During the playing cooking, it was revealed that for the family of Heart, Beloved and Giovana, the concern regarding the foods that can be consumed is part of daily life and the use of sodium to cook is something present daily.

Giovana: *Oh Beloved, your food. The Heart is making your juice.*

Heart: *I added salt. (Beloved, 3 years old; Heart, 5 years old; Giovana, 9 years old)*

Thus, diet restriction, regarding the use of sodium and linked to chronic disease, stand out and Heart highlighted the use of salt in preparing food during play.

Directly or indirectly, the disease permeates the existence of these siblings. The reference to the world of the disease was revealed in situations like the one portrayed above, through dramatizations related to the contexts of disease. Although the siblings do not use hospital materials or need routine health care, when they visualize these objects in the DTP box, they somehow use them and/or relate them to certain situations.

When relating to these materials, the siblings did not hesitate to recall situations involving the medical context.

Friend [Speaks as doctor]: *Hi, Mr. Lion.*

Friend [Speaks like lion]: *Ouch I have a stomachache.*

Friend [Speaks as doctor]: *You have to take some medicine and we'll measure your pressure, okay?*

Friend [Speaks like lion]: *It's good.*

Friend [Speaks as doctor]: *You have a fever, that's all. Then you will take the medicine. It's a quick saline, it won't hurt at all, okay?* (Friend, 8 years old)

Tacitly, the brother revealed while playing the impact that the disease generates, the abrupt changes and worries linked to this context. In Sincere's DTP session, this situation is clearly reported:

*Now everything happened suddenly. It was... it was suddenly. Then, yeah... then my mother can't stay at home anymore, she only comes for the weekend. My dad is working there. Then there is no way to be always with my mother. She was here yesterday and she's already gone. [...] It's horrible.* (Sincere, 11 years old)

The changes triggered by the situation of a child with a chronic disease make the siblings to express other feelings. After living with this fact, they reveal longing and the desire to see the ill child again, in addition to send messages and express their affection.

*I really missed Lavinia. I'm her sister. Tell my sister you played with me.* (Loving, 5 years old)

At the same time that they find themselves going through winding paths, with worries and questions, the siblings resumed their being-onese and were able to project themselves by verbalizing projects.

*Look! The ballet dancer. I always wanted to be a ballerina (ballet dancer).* (Heart, 5 years old)

*When I grow up I want to be a veterinarian. But one day I'm going to leave the vet and do the same as your job. It's just like you, making the children draw a picture of their sibling and make the children happy.* (Funny, 8 years old)

Existence is to (re)construct itself at every moment, in the same way that chronic diseases impose this condition on the lives of those involved. Through the opening of each *being-there*, its possibilities of being and not being-itself, the existence of the being-in-the-world reconstitutes itself with

each lack and each need, because being-in-the-world the existence is at every situation.

## ■ DISCUSSION

The revealing of the world to the child can happen through playing because the child discovers the world, others and themselves, what they can and cannot do. When they play, experiment, modifying, inventing, and updating, what they want and what they do not want in the face of what is imposed on them and, thus, in a creative way, they grow. Constant mobility in the construction of meanings encompasses previous memories and expectations that are gathered in the present, that is, in the moment of playing<sup>(13)</sup>.

This mobility, this grouping of the child's experiences is what makes up the plot of each play<sup>(12,13)</sup>, because in the constant articulation of ways-of-being in face of its facticity, the child idealizes the possible world through the diverse discoveries that playing gives them.

By surrendering to their own existence and considering their ability to relate to the other beings around them, the child glimpses the possibility of the new, being possible to assign meanings and re-signify things and relationships in the world, through their actions<sup>(12,13)</sup>. This means that a child launched into the world of a family member's chronic disease has in his/her play, ways of being that update this condition.

Heidegger states that playing is essential for understanding ways of being-in-the-world, considering the act as something that is part of human identity. When portraying about playing (*spielen*), he points out to the original playing of transcendence, that is, what boosts the being-in-the-world to *become* together with its life world and go beyond its own existence<sup>(10,16)</sup>. This playing, as an affective tone, drives the *being-there* to build their world. Therefore, the *being-there* is always situated in a game of life<sup>(10,17)</sup>.

The work of art, for this reference, is linked to the truth, described in the work *Being and Time*<sup>(11)</sup>, produced by the being-there and, therefore, refers to unveiling, not in the sense of uncovering something that is veiled and revealing it to someone, but rather in the sense of perceiving before oneself how something is, being-in-the-world with others and entities<sup>(17,18)</sup>.

When we refer to the work of art, the literature states that drawing and painting are revealing records of the child's perception of a certain theme. The use of such resources allows the child the freedom to express what they want, therefore, it is also a work of art. Therefore, artistic making is a way of relating the man/child with the world, which allows

the event of being in which the existential factual horizon becomes possible and themable<sup>(18,19)</sup>. In this context, the siblings revealed the relationship with their surrounding world, which is also involved by the chronic disease of the child.

In this way, the truth expressed, in the DTP session, is the showing of the sibling her/himself in contact with the toys and their expressions, revealed in the form of a piece of art and their narrations. Thus, it was possible to understand that the siblings handled the modeling clay, giving them concrete meanings, as in the situation of Funny, the importance of Liz (a child with chronic disease) in her life. On the other hand, some siblings veiled the meaning of what they were doing, like Secret.

The silence and the not revealing something is also a *way-of-being*, like the brother's 'unavailability' to open up at that moment. In addition, it shows that the facticity of having a sibling with chronic disease is not always amenable to concrete explanations, and the silence reveals the way in which Secret and Tenderness, mainly, filled their existential void<sup>(10)</sup>.

In this perspective, understanding a work phenomenologically means asking about the fundamental affective tonality that occurs when the *being-there* feels touched by something, e.g., when feeling afraid of something, the fear is prior, because the *being-there* already has a meaning for what is appearing at that moment and is something threatening for the *being-there*<sup>(17)</sup>.

Previous knowledge of something threatening, generating fear, changes the way the *being-there* lives his life, as it is necessary to recognize what is harmful to himself in order to avoid it<sup>(11)</sup>. This something that emerges, triggering insecurities, is only threatening if it is somehow already present in the sibling's life or may become. This defines fear as a way of being occupied with entities that the *being-there* lets come to meet him.

By expressing himself through art, Secret revealed his anxiety regarding the uncertainty of his mother returning home from the hospital, his concern about getting ill and who would take care of him, as illustrated in Figure 2. During the Funny session, it was revealed that the sister's chronic disease and hospitalization affect her in the way of love, when remembering the feeling of consideration through the modeling clay, according to Figure 1.

Seeing oneself before a threatening situation, as in the case of Secret, through drawing, and Sincere, through speech, reveals not only things, but also the others, with whom the *being-there* relates being in the world. When the *being-there* fears for someone who is not him, it is for himself that he fears. He fears the possibility of losing his own existence; he fears that the evil that hurts the other will also hurt his surrounding world<sup>(10,17)</sup>.

The hospitalization of children with a chronic disease emerges abruptly in the daily lives of those involved, directly affecting and changing the world-life of both the sibling and other family members. When realizing the new situation, there is often no time to organize and the need to go to the hospital setting, as in Secret's situation, leaves him without concrete information about the new horizon of possibilities that has been established.

The results of this study corroborate with other research conducted with siblings of children with chronic diseases in the national and international contexts, by revealing that the fear of the unknown and the lack of concrete information about the child with chronic disease are the main factors that interfere in the psychosocial health of siblings and, in addition, show that they fear for their future and are concerned about the well-being of the child with chronic disease<sup>(2,5,20)</sup>.

For Heidegger, it is only possible to uncover the *being-there* through the hermeneutics of facticity, since it fundamentally deals with what the 'concrete' human being is and its existence as a being-in-the-world, and is characterized by three concomitant moments: the having a previous of the purpose, a previous view of caution and a previous concept<sup>(11)</sup>.

The previous having is the indication of a way of seeing a certain situation/thing, that is, the siblings already look at their existence, based on what their life already is and is being, according to their relationships in the world. The previous view of caution is looking at a given situation already being, i.e., the sibling, when looking at the needs imposed by the child's chronic disease, as an example, hospitalization, he already has a guiding look for what will happen when, in fact, the family finds themselves living the hospitalization. The previous capture is the 'fixed' mode/the thought that the sibling has about a situation and what it changes in its historicity<sup>(14)</sup>.

The siblings, together with their experiences, when looking at the toys and naming them, show the relationships maintained with this entity that comes to meet them in a subsistent, usable way and, at each moment, according to the previous-having. Thus, the siblings already understand their situation of living with a child with a chronic disease, before any event that the treatment of the disease imposes on their daily lives, as this facticity is already implanted in the historicity of the siblings.

In the session of Heart and Beloved, the diet restriction of sodium, specific for kidney disease in children with chronic disease, was highlighted, in the form of a warning, by sister Heart. There was a relationship between playing and the situation experienced, being noticeable their concern and the care already inserted in their routine, which is caution in relation to the use of salt. The child's chronic disease and the



limitations they impose on the sibling's life can also be noticed when Friend, while playing, remembers and links food with the need for health care, such as serum therapy. Henrique, Friend's brother, has severe diet restriction due to the pathology, requiring the use of enteral and parenteral nutrition.

The issue of the *being-there* involved in different types of relationships means that the (pre)occupation of these siblings extends beyond the child with chronic disease, and the suffering that affects them can occur in different ways<sup>(14)</sup>. In this context, although the brother's concern is not the need for routine medical interventions, he makes choices for toys that refer to the hospital world. For others, his concerns are on longing and the desire to visit the child with chronic disease and about changes in the family core.

Up to the present moment, we have talked about the understanding of the brother fixed in a 'previous having' that aims his gaze to the child's chronic disease, which implies the need for health care. However, for Heidegger's framework, the exercise that man must do, on the hermeneutics of facticity, is to get out of himself, put himself in another position/place and see the different possibilities of being-able, envision different ways of look at your life-world<sup>(14)</sup>.

The sessions of Funny and Heart, taken for their historicity, showed this movement of bringing to light new perspectives that move them away from the "lens" of seeing life only with the chronic disease of the child. They seek meaning for their existences, aiming for future projects, such as the desire to be a ballet dancer and veterinarian.

By uniting the vision of Phenomenology and the purposes of the DTP it was observed that it is possible, through this technology, to help the siblings discover other ways of being-in-the-world. Positioning themselves in their own way, the way they want to play, they make everything plausible. The DTP contributed to the siblings recognizing themselves within their factual situation and being able to 'jump'/move into another way of understanding their existence<sup>(11,14)</sup>.

Siblings of children with chronic disease revealed in their playing that the onset of a chronic disease, for the child and his/her family, causes changes in the family dynamics and interferes in the relationship between its members and, when faced with this facticity, they experience transformations, because the need for frequent hospitalizations due to the disease triggers ruptures in their life-world. Therefore, these changes can be considered a unique moment for the siblings.

In this way, allowing the sibling to play and verbalize 'difficult' moments of their existence helps them to understand their original and unique existential condition of being

launched into the world of the child's chronic disease. When launching into this universe, it is necessarily faced with the treatment of the ill child. Thus, the hermeneutic situation of these siblings regarding the organization and understanding of their life-worlds are around the existence of a child with chronic disease and that, deep down, they are always occupied dealing with this disease. Therefore, the disease marks the existence of the siblings day by day.

Given the above, providing hermeneutical elements for the sibling, as in this case, a session of DTP, is to favor so that he does not stiffen within their situation and may develop other ways of being-there-sibling and deal with their situation, elaborating their condition authentically. The siblings could understand their historicity by themselves and, by participating in a DTP session, it was possible to realize how much their historicity and their way-of-being-in-the-world can be expanded and seen in another way.

## ■ FINAL CONSIDERATIONS

The experiences of siblings of children with chronic diseases, through phenomenological interviews mediated by the DTP, enabled the understanding that being-in-the-world for the siblings is being-in-the-world-with-the-others, with their families and at the side of the child with a chronic disease.

The perception that the child with a chronic disease needs health resources and frequent hospitalizations, linked to limited information, trigger feelings such as fear, sadness, longing and curiosity in the siblings. Therefore, it is important for the nursing team to talk to the families about the importance of providing clear and appropriate information about the child's health status to the siblings, so that they can understand its facticity and avoid wrong thoughts about the situation they experience.

In addition, it is important to discuss about the need for nurses to approach families and to learn about how the siblings of children with chronic diseases live with this facticity, aiming at contributing to the inclusion of siblings in the nursing care provided to the child, if so desired by the family.

The DTP proved to be an indispensable technology to access the siblings' experiences, allowing them to express feelings and anxieties regarding the ill child, understand their life-world and release tensions. In addition, it allowed the sibling to glimpse their existence beyond the child's chronic disease.

Thus, it is urgent the need to institute actions for the inclusion of the sibling in nursing care for children with a

chronic disease, in order to promote the well-being of the sibling and the family. In addition, the results of this study have the potential to support public policy propositions, not only for children with a chronic disease, but also for their siblings and their families, along with other studies on this theme.

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