

## Families' perceptions of how children with chronic diseases played during the pandemic

*O brincar de crianças com doenças crônicas durante a pandemia na percepção da família*

*El juego de los niños con enfermedades crónicas durante la pandemia en la percepción de la familia*

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### ABSTRACT

**Objective:** to understand the experiences of relatives of children with chronic diseases as regards playing during the pandemic.

**Method:** this qualitative study of 14 family members living with children with chronic diseases, admitted as inpatients to a university hospital in Campinas, São Paulo, drew on the assumptions of Situated Phenomenon Structure Analysis. After approval by the research ethics committee, open interviews were conducted from July to September 2021 and the resulting data were analyzed with Martins and Bicudo as the frame of reference. **Results:** three categories emerged: Playing somewhere else – spatial changes; Playing with (without) other people – interactional changes; and Playing differently – behavioral changes. **Conclusion:** the changes resulted from confinement at home, the closure of public places, and mandatory social distancing. Children's screen use increased massively, with no control of use time.

**Descriptors:** Child; Family; Chronic Disease; Play and Playthings; Pandemics.

### RESUMO

**Objetivo:** compreender as vivências de familiares de crianças com doenças crônicas sobre o brincar durante a pandemia.

**Método:** estudo qualitativo fundamentado nos pressupostos da Análise da Estrutura do Fenômeno Situado, com 14 familiares que convivem com crianças com doenças crônicas, hospitalizadas em um hospital universitário localizado em Campinas, São Paulo. Os discursos foram obtidos, após aprovação do Comitê de Ética, por meio de entrevista aberta, de julho a setembro de 2021 e analisados segundo o referencial de Martins e Bicudo. **Resultados:** emergiram três categorias, brincando em outro lugar - as mudanças espaciais; brincando com (sem) outras pessoas - as mudanças interacionais e brincando diferente - as mudanças comportamentais. **Conclusão:** as mudanças ocorreram por necessidade de confinamento nos domicílios, fechamento dos espaços públicos e obrigatoriedade do distanciamento social. Houve aumento maciço do uso das telas pelas crianças, sem controle do tempo de utilização.

**Descritores:** Criança; Família; Doença Crônica; Jogos e Brinquedos; Pandemias.

### RESUMEN

**Objetivo:** comprender las experiencias de familiares de niños con enfermedades crónicas sobre el juego durante la pandemia.

**Método:** estudio cualitativo basado en los supuestos del Análisis Estructural del Fenómeno Situado, con 14 familiares que viven con niños con enfermedades crónicas, hospitalizados en un hospital universitario ubicado en Campinas, São Paulo. Las declaraciones fueron obtenidas, previa aprobación del Comité de Ética, a través de entrevista abierta, de julio a septiembre de 2021 y analizadas según la referencia de Martins y Bicudo. **Resultados:** surgieron tres categorías: Jugando en otra parte - los cambios espaciales; Jugar con (sin) otras personas - los cambios en la interacción y; Jugar de manera diferente - los cambios en el comportamiento. **Conclusión:** los cambios ocurrieron por la necesidad de confinamiento en los hogares, cierre de los espacios públicos y distanciamiento social obligatorio. Hubo un aumento masivo en el uso de pantallas por parte de los niños, sin control sobre el tiempo de uso.

**Descritores:** Niño; Familia; Enfermedad Crónica; Juego e Implementos de Juego; Pandemias.

## INTRODUCTION

In the context of the pandemic disease caused by the coronavirus 2019 (COVID-19), changes were necessary in several areas, including the area of health. In primary health care, children's care was replaced by telecare and/or teleconsultation, and in-person consultations were held only in selected conditions<sup>1</sup>.

In the care of children with chronic diseases, health follow-up has changed, as individuals with comorbidities are at higher risk for COVID-19. A study conducted in the outpatient clinic of a pediatric hospital revealed that the pandemic interfered with the health of children with chronic diseases, as families missed appointments for fear of getting sick, to avoid overcrowding, by changes in routine and financial problems<sup>2</sup>.

What has not changed were children's needs. According to the Child and Adolescent Statute (ECA), children have the right to play, practice sports and have fun<sup>3</sup>. Playing is important for children's physical and mental health<sup>4</sup>.

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With the closure of schools and leisure spaces, the way of playing also had to change. Playing moved into homes, and family members were held responsible for children's plays. Families sought to adapt by using various materials although sometimes, by the lack of ideas, they adopted electronic equipment as a playful resource<sup>5</sup>.

A study developed with children aged six to 12 years on playing during the pandemic showed that children played traditional games indoors and the backyard, but also played with video games, cell phones, television and the internet. In their plays, children revealed the daily life during the pandemic, such as playing alone for fear of being contaminated and the hope of ending social isolation<sup>6</sup>.

Children with chronic diseases may face obstacles to play, which can affect overall development, and these obstacles can be imposed by the disease and/or by the family that seeks to keep the child's health in balance. Among other causes, the negative consequences of chronic disease may be related to a reduced opportunity to play. In this context, COVID-19 can enhance the already existing obstacles imposed by the chronic condition itself<sup>7</sup>.

By seeking to understand, from the family's perspective, how children with chronic diseases play, it will be possible to apprehend the impact of the COVID-19 pandemic on these children's daily lives. This may bring important elements to broaden discussions about chronic conditions of health in the current context, which are essential in the scope of care, teaching and research in the area of Pediatric Nursing.

Thus, the objective of this study was to understand the experiences of family members of children with chronic diseases regarding playing during the COVID-19 pandemic.

## METHOD

This is a qualitative study based on the assumptions of the analysis of the structure of the situated phenomenon, which seeks to know human phenomena with the aim to understand them<sup>8</sup>. It was conducted with the use of a guiding question and participants spoke freely<sup>9</sup>. From speeches, the researcher had access to the experiences of family members and consequently, to the meanings they attribute to children's plays during the pandemic<sup>8</sup>.

Participants were 14 family members of children with chronic diseases that were hospitalized at a university hospital located in Campinas, São Paulo, during the study period.

Inclusion criteria were being a family member of a child with a chronic disease, over 18 years old, with preserved oral communication and living with the child at home. Exclusion criteria included family members who accompanied the child at home and/or occasionally during hospitalization. Two mothers refused to participate because they did not accept the recording of the interview.

The individual interviews took place from July to September 2021, next to the child's bed (only one interview took place in the courtyard outside the unit), on previously agreed dates and times, based on the following guiding question: "Tell me in detail, how your child (or another degree of kinship) has been playing during the pandemic". The total time of interviews was 75 minutes. They were recorded and transcribed in full for analysis of the structure of the situated phenomenon, and the recommended steps were followed<sup>8</sup>.

The interviews were finished when the speeches proved to be sufficient to help the researcher unveil the phenomenon in question, that is, when reaching theoretical saturation<sup>10</sup>. This moment is the result of the continuous process of analysis of interviews, in addition to the repetition of ideas, as the speeches reveal the uniqueness of experiences of a group of individuals within a certain context and historical time<sup>11</sup>.

The study was approved by the Research Ethics Committee and family members signed the Informed Consent form. The speeches of family members were recorded with their authorization, secrecy regarding identity was guaranteed, as well as the right to refuse or withdraw at any stage of the study without any prejudice to the care provided by the institution. Participants were identified with names of flowers that can survive without full sun, making an analogy to the period of social distancing and the need to stay at home.

After transcription, speeches were analyzed in relation to the structure of the situated phenomenon<sup>8</sup>. The steps followed were: 1) general reading of speeches, seeking to understand what was described; 2) attentive re-reading with the objective of determining the units of meanings representing the parts of speeches that reveal the phenomenon. Note that the units of meaning are not ready in the text, but exist in relation to the researcher's attitude/position. This moment is called ideographic analysis; 3) synthesis of the units of meaning, grouping what converges (common in more than one discourse) and what diverges (peculiar elements to only one discourse or a

few), originating the thematic categories. This step is also called nomothetic analysis; 4) Development of descriptive synthesis by integrating the understandings of the phenomenon in question.

Therefore, it was possible to organize the results into three thematic categories: 1. Playing elsewhere - spatial changes; 2. Playing with (without) other people –interactional changes; and 3. Playing differently - behavioral changes.

## RESULTS

Fourteen family members participated in the study and their characteristics are described in Figure 1.

Family and Degree of Kinship		Age	Child	Age	Chronic Disease
	ANTHURIUM (Father)	40	B.	8	Chronic kidney disease Grade V
	ALSTROEMERIA (Mother)	30	E.	1	Hip dysplasia
	AZALEIA (Mother)	38	V.	14	Myelomeningocele/Kidney transplantation
	BEGONIA (Mother)	41	P.	1	Chronic liver disease/Liver transplantation
	BROMELIAD (Mother)	35	H.	4	Type 1 Diabetes Mellitus
	CAMELIA (Grandmother)	55	L.	15	Nephrotic syndrome/Congenital hypothyroidism
	MAYFLOWER (Mother)	23	D.	2	Congenital esophageal stenosis
	HORTENSIA (Grandmother)	55	A.	8	Chronic kidney disease Grade V
	HYACINTH (Father)	35	A. F.	5	Hydrocephalus
	PEACE LILY (Mother)	30	R.	3	Glottic stenosis
	MAGNOLIA (Mother)	31	L.	14	Niemann-pick disease Type B
	ORCHD (Mother)	39	M.	9	Cystic fibrosis
	TILLANDSIA (Mother)	29	L.	13	Ulcerative colitis
	VIOLET (Mother)	33	M. V.	9	Chronic kidney disease

FIGURE 1: Identification coding of study participants. Campinas, SP, Brazil, 2021.

### Playing elsewhere - spatial changes

The reports of relatives of children with chronic diseases on playing during the pandemic were based on their experiences, pointing out changes. The first change concerns the physical space, that is, playing has changed places.

Before social isolation, playing took place at school, on the street, in the park, in the playground of the compound, at the homes of other family members/friends. The pandemic changed the spatial characteristics of children's play, as it confined them inside their own homes.

*[...] it's always indoors, indoors. Sometimes he complains he has nothing to do. (Violet, 33 years old)*

*Oh, he plays at home, right? (Mayflower, 23 years old)*

Although in general, all rooms in a house can be used by children for playing, some were preferred, such as the living room and the backyard.

*She makes the room a plane, and she is going to travel, so she takes the trolley bag and the room becomes her plane, she is going to Canada. Or she makes her own kitchen and the living room becomes the kitchen, where she cooks things [...] she's already had a clothing thrift shop. (Orchid, 39 years old)*

*Playground is at home, I have a backyard, which has a floor, like, there are pebbles, I let her dig earth, I leave her free at home [...] (Begonia, 41 years old)*

In addition to the living room and the backyard, children played in the kitchen. However, it was not about genuine playing, but an activity that family members understood as playing, although in fact it meant help with household chores.

*Then she will make lunch, make food. (Camellia, 55 years old)*

*Yeah, help with housework, do some dishes for me, tidy up her room. (Tillandsia, 29 years old)*

Some families highlighted occasionally playing outdoors as an alternative to avoid contamination, but not as a routine activity.

*In the afternoon, we go to the playground, he slides, rides his bike, scooter, has fun. (Bromeliad, 35 years old)*

*Hiking. There are some good places to go hiking in Itu and she goes. Hiking, trekking [...] (Anthurium, 40 years old)*

*[...] goes to the playground with her sisters, in the woods and that's it. (Hyacinth, 35 years old)*

Although playing outdoors emerged as an alternative, it was limited to adults' time availability, as it required constant vigilance from those responsible. Therefore, most of the time, the playing of children with chronic diseases took place indoors.

### Playing with (without) other people –interactional changes

In the perception of family members of children with chronic diseases, the COVID-19 pandemic changed friendship relationships since meetings between children, whether at school, outside and/or at the homes of relatives and friends, were interrupted to avoid the spread of the virus. Thus, there was a change in social interactions.

*She had engagements with her school friends, with her friends from ballet class. (Orchid, 39 years old)*

*[...] she used to play with other children at school, but in this pandemic, there was no school. (Hortensia, 55 years old)*

Without interacting with friends, playing became solitary and/or accompanied by new active players or spectators, that is, family members themselves.

*He plays alone at home. Yeah, alone. (Magnolia, 31 years old)*

*Her playing became very lonely, because she is an only child [...] (Orchid, 39 years old)*

*Then, she stays at home, with her sister playing. (Alstroemeria, 30 years old)*

Although children played alone and/or accompanied by relatives, there are toys and the ever-present possibility of pretend play, make-believe plays, where the use of imagination was observed by family members.

*She has good imagination so that helps a lot, because some children are unable to play alone, they always need someone. She is not like that she plays well by herself. (Orchid, 39 years old)*

*[...] and plays with the doll like that, like a mommy. (Camellia, 55 years old)*

In addition to make-believe games, Bromeliad highlighted creative plays.

*[...] his routine has been painting, reading. (Bromeliad, 35 years old)*

In addition to games with symbolic content, the already present technology in children's world gradually gained more space during the COVID-19 pandemic. The television, tablets, cell phones and computers were used in a significant part of the time that children played, either to watch videos, communicate with other children/relatives, play games and/or even to participate in social media.

*Watches TV... (Magnolia, 31 years old)*

*Yeah, she spends all day long on her cell phone and laptop only. (Azalea, 38 years old)*

*Well, at home she stays on her cell phone, plays, is on Facebook. (Camellia, 55 years old)*

However, playing with electronic devices was not always solitary play, as Orchid points out:

*She started making video calls with her school friends, I even have videos of their plays via video calls. [...] By looking at her with the tablet tucked in place, there, with her little dolls and her friend on the other side of the small screen playing, and that way they could play. (Orchid, 39 years old)*

Even though screens are a reality in the world of children nowadays, it is necessary to reflect on the rational use of this technology with the aim to collaborate with children's healthy development, which can be affected when there is no balance between the use of electronic devices and other plays.

### Playing differently - behavioral changes

Relatives of children with chronic diseases pointed out changes in the behavior of children, who were more irritated and bored with the situation of confinement.

*Gets more irritated for not being able to have contact with other people [...] (Violet, 33 years old)*

*She gets very stressed, I guess because of being too stuck, right? We stopped going out. (Peace Lily, 30 years old)*

Children whose routines were permeated by various extracurricular activities were significantly affected by the changes. Orchid highlights children's accumulation of energy and relates it to the performance of activities in the remote modality.

*She misses it a lot. She used to have capoeira, ballet, it was school really, physical education, face-to-face physiotherapy. [...] And now she accumulates a lot of energy. Before, she used to get more tired, she didn't have time to accumulate so much stuff. Now, I'm happy and scared at the same time, because it seems like they'll destroy the house. (Orchid, 39 years old)*

Thus, considering the various changes pointed out by family members of children with chronic diseases, it is necessary to think about strategies that minimize the impact experienced during the period of social isolation by helping children to continue the growth and development process, although permeated by the COVID-19 pandemic.

## DISCUSSION

Although the pandemic has caused transformations in children's spaces, interactions and playful behaviors, playing continues to happen and still does regardless of relationships, whether alone or with spectators, eventually outdoors or in the rooms of houses, through make-believe or still permeated by virtual technologies.

Undeniably, all children on the planet have suffered and/or are still suffering some impact of the COVID-19 pandemic<sup>12</sup>. The United Nations Children's Fund (UNICEF) stated that approximately 2.5 billion children lived in countries that adopted full or partial social distancing, which included the closure of schools and public parks<sup>13</sup>. A literature review suggests that this measure changed children's access and opportunities to play<sup>14</sup>.

In addition to being a child's right, playing promotes their physical and mental health and, in crisis situations, helps the child to deal with stress and anxiety<sup>15</sup>. It also enables their expression of emotions, strengthens family ties, and empowers children to be an active participant and not a passive participant in health care<sup>16</sup>. Thus, considering the COVID-19 pandemic as a crisis situation, playing is certainly essential. However, if playing has changed as a result of the pandemic, children may be suffering doubly – because of the pandemic and the change in the way they play.

Prolonged school closures, home confinement and social restrictions can cause significant harm to children's physical and mental health. A study recommends preventive support and early intervention for children facing social restrictions, and playing is one of the most essential forms of health care<sup>14</sup>.

Although changes have taken place, family members did not emphasize that playing became even more restricted because of chronic diseases, as children continued to play, not outside, but inside their homes. This may indicate that even though the routine of these children has limitations, it is not fixed, allowing healthy growth and development.

Homes are where everything happens. Home is understood as a protective element, at least against the threat of viral contamination<sup>17</sup>. But not every household can be considered protective. There are socioeconomically disadvantaged families crowded into a single room that is the bedroom, living room and kitchen at the same time, unable to go outdoors to play, so the level of stress can be exacerbated, culminating in violence of any kind<sup>18</sup>.

In addition to the possibility of violence, which was not reported by participants in this study, playing indoors kept children away from playing in playgrounds, with the only exception being playing in the backyard for those living in houses.

In order to maintain social isolation, families spend more time at home, and consequently perform household chores. In this context, these tasks were considered as playing by some participants in this study, although children's participation in domestic activities needs to respect their age group in order to keep them safe, given the risks of accidents<sup>19</sup>.

In the pre-pandemic period, homes were places of passage, and with the new epidemiological reality, they became places to stop, stay and work. Given this prolonged time at home, people sought public spaces and green areas as a form of leisure<sup>20</sup>, which was also mentioned as an alternative by family members participating in this study.

Playing outdoors is important for children's physical and mental health and helps to provide emotional balance in times of uncertainty and stress. The COVID-19 pandemic has considerably reduced children's time playing outdoors<sup>21</sup>.

A Canadian study sought policies to balance efforts to contain the transmission of COVID-19, as well as to ensure the health and wellbeing of the population, supporting access to outdoor play. The provinces with the highest number of infected individuals had stricter restrictions, while others created strategies to receive visitors in open spaces. The recommendation was that outdoor games should be a priority when returning to school, keeping public green spaces open<sup>21</sup>.

Playing itself is a moment of interaction with other children and/or adults, but since the beginning of the COVID-19 pandemic, with children away from the school environment, social interactions have changed. Children play in the presence of their parents, grandparents, siblings, cousins or even alone, although they are not always observed.

A study performed with children about playing during the pandemic showed that they play with animals, siblings, family members or alone, with dolls and food, that is, playing for affective development. Children also ride bicycles, which serves for physical development. However, a transition to the use of technologies such as cell phones, televisions, tablets and computers was observed<sup>6</sup>.

According to a neuroscience study, pretend play, especially with dolls, is considered an opportunity to create important social interactions for the development of socio-emotional skills, such as empathy. The same did not happen with children who play games using tablets<sup>22</sup>.

The Brazilian Society of Pediatrics discusses the increased use of screens by children and adolescents, recommending limited time for each age group, one hour a day for children aged two to five years and two to three hours a day for adolescents aged 11 to 18 years. It highlights the importance of supervised use by family members and encourages them to offer alternatives for outdoor activities<sup>23</sup>.

Although technology was already present as a playful resource before the COVID-19 pandemic, the increased use of screens related to the longer time spent at home by children can be a risk to mental health, in addition to the possibility of being exposed to false information, inappropriate content and sexual exploitation<sup>24</sup>.

Another impact related to social isolation was the change in children's behavior. A review study showed that changes in social life, restrictions and changes in routine may be directly related to changes in mood, stress, depression or anxiety<sup>25</sup>.

Considering that children with chronic diseases are at higher risk for mental health problems, such as depression, anxiety and aggressiveness as a result of the chronic stress associated with the disease and its consequences<sup>7</sup>, social isolation resulting from COVID-19 would further increase this risk.

Faced with current challenges and changes, children must be supported by health professionals and families, and other social connections such as school are also necessary, so they can appropriately overcome the anguish condition and stabilize themselves emotionally and physiologically<sup>26</sup>.

Given the above and data presented in the UNICEF Report demonstrating the impact of the COVID-19 pandemic on the mental health of children and adolescents, with a significant increase in mental disorders, including ADHD, anxiety,

autism, bipolar disorder, conduct disorder, depression, eating disorders, intellectual disability and schizophrenia<sup>27</sup>, it is necessary to plan actions to support children whose childhood was interrupted by the COVID-19.

A Chinese study revealed that playing, physical activities and music therapy are potentially beneficial to stimulate resilience in children and adolescents in order to face the psychological consequences of the COVID-19 pandemic<sup>28</sup>.

The National Secretariat for the Rights of Children and Adolescents guides the following as strategies for managing the impact of the pandemic: embracement actions with use of empathy as a tactic to put oneself in the other's shoes without criticism or judgement; safety to maintain awareness for responsible and protective actions regarding COVID-19; artistic and creative activities to express feelings, enabling self-regulation, seeking to see new opportunities at that time. The importance of strengthening ties with the community and family for emotional comfort also stands out<sup>29</sup>.

### Study limitations

This study was limited to the playing of hospitalized children with chronic diseases mainly because this was the option of access to families during the pandemic, as outpatient services served only exceptional cases. Thus, children living in other social and health contexts may present differences in their plays, which highlights the need for further studies, including from the perspective of children themselves, which can broaden the understanding of nurses about children's needs, especially children with chronic diseases.

### CONCLUSION

For the participants of this study, playing changed in three aspects - spatial, interactional and behavioral, but it did not cease to exist. The spatial change was a result of the need for confinement inside home spaces and the closure of public spaces reserved for playing.

The interactional change was motivated by the mandatory social distancing. Finally, behavioral change is a consequence of other changes due to the impact of the COVID-19 pandemic. Note there were no reports relating changes in playing with chronic diseases in children.

The speeches of family members also showed the massive increase in the use of screens by children as part of their daily routine, being an instrument of entertainment, communication and learning, although it is essential to control their use. Some participants had difficulty in describing children's plays by considering domestic chores as playing and not observing their moments of play.

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