

# Difficulties and facilitating interactions in chronic health conditions: perceptions of children and adolescents

## Dificuldades e interações facilitadoras na condição crônica de saúde: percepções de crianças e adolescentes

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### Abstract

**Objective:** to know the perception of children and adolescents about their chronic health conditions. **Materials and Methods:** This is exploratory descriptive research with a qualitative approach carried out in the southern region of Brazil. Ten children and adolescents with chronic illness participated in the research, and the information was produced through a dynamic of the Sensitive Creative Method. Data analysis took place through thematic analysis. **Results:** children and adolescents perceive the chronic disease associated with positive sensations such as interpersonal relationships, games and activities, but also negative sensations such as pain and sadness. Thus, they live in challenging situations in relation to their health conditions, which impose the need for adjustments in their routines and habits. **Conclusion:** Illness is not a simple process for both the child/adolescent and their families, but as the experience lived, medical procedures become part of the routine and, thus, more easily accepted. In this sense, it is essential that health and education services are equipped to fully assist this population, minimizing suffering and stigma.

**Keywords:** chronic disease; multiple chronic conditions; qualitative research; adolescent.

### Resumo

**Objetivo:** conhecer a percepção de crianças e adolescentes acerca de suas condições crônicas de saúde. **Materiais e Métodos:** Trata-se de uma pesquisa descritiva exploratória com uma abordagem qualitativa realizada na região sul do Brasil. Participaram da pesquisa 10 crianças e adolescentes com doença crônica, para a coleta das informações foi utilizado uma dinâmica do Método Criativo Sensível. A análise dos dados ocorreu por meio da análise temática. **Resultados:** as crianças e os adolescente percebem a doença crônica associada a sensações positivas como relacionamentos interpessoais, brincadeiras e atividades, mas também negativas como dor e tristeza. Assim, vivem situações desafiantes em relação as suas condições de saúde, que impõem necessidade de ajustes em suas rotinas e seus hábitos. **Conclusão:** Considera-se que o adoecimento é um processo complexo tanto para a criança/adolescente quanto para seus familiares, mas como as vivências experienciada dos procedimentos

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terapêuticos tornam-se parte da rotina e, assim, mais facilmente aceita. Nesse sentido, é imprescindível que os serviços de saúde e educação estejam instrumentalizados e constituem-se como redes de apoio para desenvolver um cuidado à saúde integralmente essa população, minimizando sofrimentos e estigmas.

**Palavras-chave:** doença crônica; múltiplas afecções de saúde; pesquisa qualitativa criança; adolescente.

## Introduction

The development of children and adolescents is constituted by fundamental stages in their lives, in which discoveries occur regarding the body, physical and mental abilities, exercising their experiences through play and interaction with peers. However, children and adolescents with chronic conditions face situations of vulnerabilities from an early age that often go beyond their understanding. Thus, as a result, they are impelled to undertake complicated processes of adjustment and reorganization in their daily lives, being able to experience various processes of internalization of problems<sup>1</sup>.

Currently, the epidemiology of diseases that affect the children and adolescents' public has changed, with a progressive increase in children and adolescents suffering from chronic diseases, or with special health needs (CRIANES), mainly due to the improvement in health care, which increase the survival rate<sup>2</sup>. Thus, it is essential that health services and professionals who provide care to this population qualify, seeking to help them develop their maximum potential, within the limitations imposed by their chronic condition.

In Brazil, the chronic conditions of children were classified into five groups, according to the complexity of the needs: children with neuromuscular dysfunction; technology-dependent children for their treatment; drug-dependent children; children who need to modify common actions on a day-to-day life; children who have one or more health requirements<sup>3</sup>.

With the possibility of facing physical complications and psychomotor development, these children and

adolescents face the challenge of learning to adapt to the new reality imposed on them<sup>4</sup>. Understanding the difficulties faced by them enables the development of a support network to meet the needs imposed for care, thus enabling positive coping in the experience of the chronic condition<sup>4</sup>.

Children and adolescents with chronic conditions, as well as their families, need continuous and differentiated care, which requires an articulated care network, between its various levels, as well as professionals prepared to receive and meet their demands<sup>5</sup>.

In this context, it is worth mentioning that children and adolescents with chronic conditions are subject to hospitalizations that, in many cases, end up being prolonged, because they need complex and intermittent care, which ends up considering them as clinically debilitated and socially vulnerable<sup>3</sup>. Thus, care must be performed considering the possibility of minimizing damage and trauma, and it is essential that professionals who provide this care develop bonds, favoring the trust of children and adolescents, as well as their treatment adherence<sup>6</sup>.

Based on the above, the following research question was elaborated: What is the perception of children and adolescents about their chronic health conditions? Objective: To know the perception of children and adolescents about their chronic health conditions.

## Materials and Methods

### Type of study and Sample

This is a descriptive and exploratory research of qualitative nature, part of the multicentric research entitled

“Vulnerabilities of children and adolescents with chronic disease: care in a health care network”, which was carried out concomitantly in other municipalities of Rio Grande do Sul and Santa Catarina, however, the data of this study refer to the collection performed in the city of Pelotas in Rio Grande do Sul.

Because it is a qualitative study, its elaboration sought to meet the checklist of recommendations of the Consolidated Criteria for Qualitative Research Reporting (COREQ)<sup>7</sup>.

The participants were 10 children and adolescents with chronic conditions living in the city of Pelotas.

### **Ethical aspects**

The project was submitted to the Brazil platform and approved by CAEE 54517016.6.1001.5327, under opinion 1.523.198. Moreover, the ethical precepts recommended in Resolution 466/12 of the National Health Council of the Ministry of Health, which addresses aspects of research involving human beings, were respected<sup>8</sup>. The authorization for the research was by signing an Informed Consent Form of the guardians and signing the Consent Form for the Child and/or adolescent. To preserve the identity of the participants, the letters C/Ad (child/adolescent) and a sequential numeral in the order of the interviews were used.

### **Research design**

Data collection was performed between 2018 and 2020, using a dynamic of the Sensitive Creative Method (SCM), followed by a semi-structured interview.

The participants were selected in the first stage of the research, which was quantitative, thus, all children/adolescents with chronic conditions who were hospitalized in the Pediatrics units of the hospitals of the city within one year were recruited. After hospital discharge, the families who lived in the city and who

agreed to participate in the qualitative stage of the research were contacted.

Information collection was through a dynamic of the SCM, followed by interviews with children and adolescents. The interviews were scheduled according to the availability of the families and held in the place that best fit the demands of the participants (domicile and school), recorded on an MP4 audio device, with an average duration of 45 min.

### **Inclusion and Exclusion Criteria**

Children and adolescents with chronic health conditions without understandable verbal communication and who did not live in the municipality were excluded.

### **Procedures**

To conduct the interview, the children answered six questions: Would you like to talk about your daily routine? What facilities and difficulties do you feel about your illness/treatment? How is your routine at school? How is it for you to monitor your health in primary care and/or hospital? Would you like to add anything else? How did you feel participating in the interview or workshop? It is noteworthy that the collections were performed by two researchers, previously trained, and occurred individually with each child and adolescent, in a private place.

Subsequently, the interviews were manually fully transcribed to be analyzed, the transcript had double checking.

To support the collection through the interviews, the Free dynamics were used to create the Sensitive Creative Method (SCM), aiming at the children's expressions before the questions, leading them to explore their creativity in a playful way. The dynamics of the SCM are usually composed of the collective interview, group discussion and participant observation<sup>9</sup>, however, in this research the dynamics were conducted individually, because the participants lived and studied in different

places, and it was not possible to gather them in groups.

In the free dynamics to create<sup>10</sup>, each participant chooses the form of production to answer the questions, being made available paper, crayons, crayons, pens and cloth dolls, so that the participants felt free to use what they thought was most appropriate.

The dynamics was based on the questions of the interview, as the child answered the questions were performed using the playful resources offered. Some participants chose to design, while others preferred to answer the questions directly. In the following moment, the child/adolescent presented his/her production.

The results were analyzed inductively using thematic analysis, which is a method capable of identifying, analyzing and reporting patterns (themes) submerged in the information. For analysis, the six stages were followed: transcription of the data, reading and rereading them and pointing out initial ideas; initial systematic coding of the data; grouping of codes into potential themes; review of the themes, a thematic map of analysis was generated; naming of the themes; and final analysis of the selected points, producing an academic analysis report<sup>11</sup>.

## Results

The participants were 10 children and adolescents with chronic conditions, living in the municipality of Pelotas with mother, father or grandparents. Regarding education, nine study in the public school system and one in the private school system, all were elementary school students. Of these, five were children aged six to ten years, and five adolescents, aged between 12 and 14 years, five female and five male. Among the diagnoses, one with Sickle cell anemia and thalassemia, four with Asthma, one with Williams Syndrome and Autism, one with Phenylketonuria; one with lactose intolerance, one with Type 1

Diabetes Mellitus and one with osteomyelitis.

From the analysis of the information, two themes were designated: Difficulties and limitations perceived by children and adolescents before their chronic condition; Facilitating interactions to cope with situations of vulnerability in the perception of children and adolescents with chronic health conditions.

### Difficulties and limitations perceived by children and adolescents before their chronic condition

This theme addresses the difficulties and limitations perceived and reported by children and adolescents. The reports identified the change in diet, anxiety and fear during hospitalization when submitted to procedures, pain, limitations and sadness as the main difficulties experienced.

Living with dietary restrictions can be difficult, and the change in diet is reported by two children as the greatest difficulty experienced in the face of their disease/treatment. C/Ad7 and C/Ad8 drew (figures 1 and 2) and explained their feeling about the question:

*Not being allowed to drink soft drink. (C/Ad7)*

Figure 1: representation of C/Ad 7.



*Things are not that hard, you just cannot eat so much [...] you cannot eat so much food and unable to eat candy. [...]*

*vegetables, legumes, which have no way of inserting (in the diet) this, ever. (C/Ad 8).*

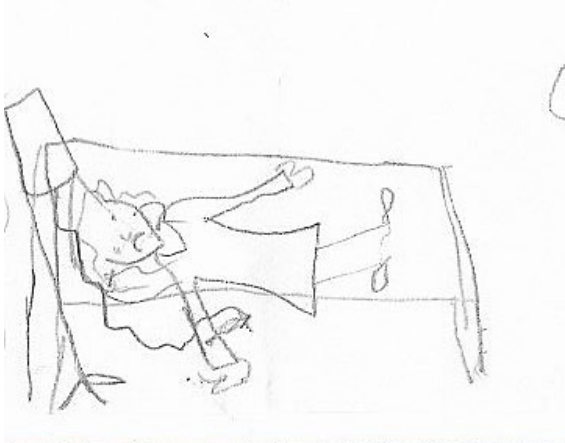
Figure 2: representation of C/Ad8.



Children and adolescents with chronic conditions are often hospitalized, which brings anxiety and fear of being hurt. Pain appears in the speeches and drawings of some participants. C/Ad3 reports in his/her drawing (figure 3) how he/she saw him/herself in this situation during hospitalization.

*Here is when I did not like to use serum and they gave me an injection. And then I would full of punctures. It is just that sometimes they missed the vein and then it hurt. It is because I am afraid of needles. (C/Ad3)*

Figure 3: representation of C/Ad3.



Other participants also reported their experiences of pain, fear and tiredness related to chronic condition and medical procedures resulting from it:

*The worst are the injections. Today I have to take injection, which hurts too. Because the things they did hurt. (C/Ad6)*  
*It is bad, it hurt a lot. I feel very tired. (C/Ad7)*  
*I feel a lot of pain. It starts to hurt and then I get nervous. It gives me a lot of pain, a lot. It gives me fever at night. And then I start to cry chorar. They take me there, to Santa Casa. My mother takes me there and they talk, talk a lot of things. But it does not solve anything. (C/Ad9)*

Children and adolescents with chronic disease experience moments of sadness and demotivation when they know they have some disease and/or when they are submitted to treatments. Sadness was reported by some participants as one of the negative points that their condition imposes during hospitalization.

*[...]sad! (C/Ad2).*  
*Too boring. It is bad, but you have to go. I need it (C/Ad7).*  
*Oh! I feel sad. I feel everything. (C/Ad9).*

In addition to sadness, children/adolescents reported that the limitations imposed by the condition experienced affect their lives, especially during games:

*Then I am that close but cannot run anymore. I am unable to breathe (C/Ad4).*  
*[...] during physical education, I cannot do it; because the*

*doctor does not allow me. I feel pain later. It hurts! (C/Ad9). I cannot play. I like plushy a lot, but I cannot play with plushies (C/Ad10).*

In this theme, the difficulties and limitations imposed by the chronic condition on children and adolescents can be evidenced, such as pain, fear, sadness that interfere in the development, inclusion/exclusion of activities and routine.

### **Facilitating interactions to cope with situations of vulnerability in the perception of children and adolescents with chronic health conditions**

The discovery of the chronic health condition of children and adolescents brings countless uncertainties both for them and for their families, requiring changes in life and relationships. In this sense, some coping strategies may facilitate the adaptation to new routines, according to reports presented.

Sometimes chronic health conditions bring the need for prolonged or lifelong treatments and, in some cases, even hospitalization. Therefore, it is observed that in the hospital environment and in the follow-up with health professionals, there are relationships of friendships that develop, both with health professionals and with other children and adolescents:

*[...] the girls that made the follow-up there with me took me to the play room and helped paint [...] I liked it! It also*

*helped me forget. Sometimes I looked and cried, because I was scared, and sometimes I forgot and kept playing (C/Ad3).*

In this part, it is possible to identify the relationship established with health professionals to provide care to children and adolescents, as well as that the use of simple strategies, which refer to the playful universe, favors treatment. Positive relationships with the school also motivate facilitating interactions, as they allow the insertion of children and adolescents with chronic conditions, as well as the relationship with activities and games, which influence their development and strengthening of the support network already established.

When asked if she likes to go to school and plays, C/Ad1 nods positively and reports some experiences:

*After the drawing, I have to eat and go to school [...]. I do the tests, I make everything [...]. The teacher even stamped it. (C/Ad1)*

C/Ad2 reflects the presence of his/her family in his/her drawings, as shown in figures 4 and 5, also explains his/her drawing referring to family members and the teacher:

*School [...] my mother, my father and I [...] the rainbow and the heart [...] the teacher was holding a rainbow and the heart [...] this is grandpa. (C/Ad2)*

Figures 4 and 5: representation of C/Ad2.



*[...] we play, then we go back to classroom. (C/Ad6)*

*[...] here is during the break, when we play and I play with my friends and then [...]we kept talking, but sometimes we start to play [...]. Here is during the studies and, sometimes, the tests and the works are too many, so I do them with my friends and the teacher. (C/Ad3)*

C/Ad 8 reports his routine and how going to school fits into it:

*First, I wake up in the morning and go to school. Then I come home and I stay alone. Also, Mondays and Wednesdays I go to football school. (C/Ad8)*

The routines implemented at home allow tasks and responsibilities, such as body hygiene and organization in the environment, to be passed on. Participant C/Ad1 refers to her drawing (figure 7), as she sees herself in the day-to-day activities:

*I brush my teeth [...] I make the bed (C/Ad1).*

Figure 6: drawing of C/Ad3.

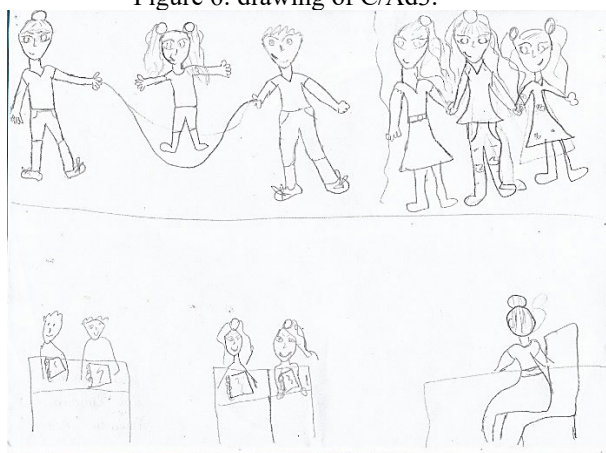
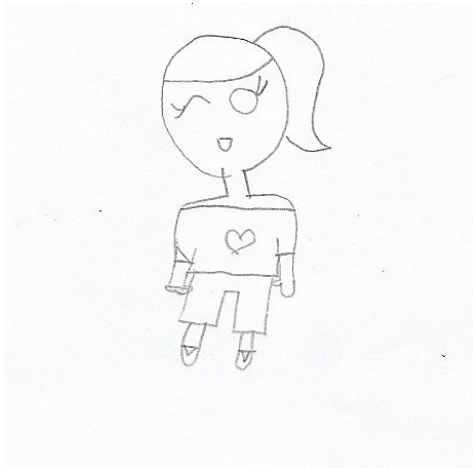
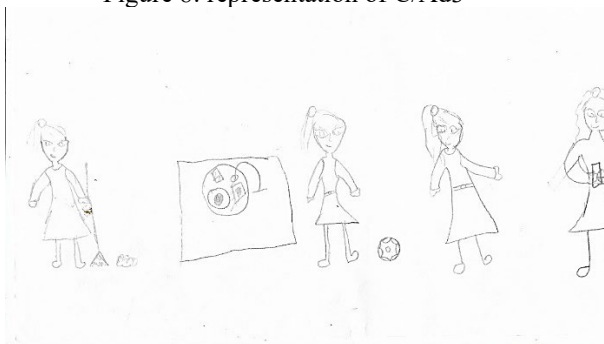


Figure 7: representation of C/Ad1.



*This is when my mom goes to work and she asks me to do the housechores. This is when is my day to do the dish. (C/Ad3)*

Figure 8: representation of C/Ad3



*I take to make a drawing [...] I look at the drawing [...]. I am going to go to the room, if I am going to draw a sand castle, [...]. I play, yesterday I played with Ana. (C/Ad1)*

*I play [...] I play with my cousin [...]. I play tag. (C/Ad2)*

*[...] I play with my sister and then I use the phone [...]. What we play sometimes is tag or football. [...] because before we liked to jump rope (in school), but then [...] they took the rope from us, because it is only for the little ones now (C/Ad3)*

*A cell phone [...] Internet (what he does on mobile) [...] I pick up the phone (right when he wakes up). [...] builder (which game he likes most). [...] sometimes my colleague takes toy, he invites me to play. [...] sometimes he takes a little motorcycle, a little car. (C/Ad4)*

*[...] I play, I eat, I make a mess [...] I eat again, go to play, change clothes and then I draw. (C/Ad6)*

*[...] sometimes I stay in my room (using) the phone. When I have nothing to do, I ask my father to help him (in the workshop). And the easy thing is to be able to have fun [...] I study and play football. (C/Ad7)*

*[...] I keep using my phone, otherwise I play with my brothers [...]. Then I go to school, study a little. When I get home from school, I study, then I keep using it (phone), playing with what I can. (C/Ad9)*

*Oh! I wake up, I go to school, I come back, have lunch [...] eat dessert, Brush my teeth, play a little [...]. Play, play [...] I like to play. (C/Ad10)*



In these reports it is possible to identify the routines of children and adolescents and how play is present in it, the activities that are part of daily life are common to all children and adolescents. The use of electronic devices is also evidenced, and the smartphone is one of the most used for distraction.

## Discussion

Chronic diseases impose several situations of vulnerability for children, adolescents and their families. From an ontological point of view<sup>12</sup>, the human being is vulnerable, is exposed to numerous dangers, since living humanly reveals the vulnerabilities, fragilities, organic and structural. Thus, the human being is exposed to dangerous situations all the time. In this context, being a child and adolescent who needs care adds to the normal situation of vulnerability, the chronic health condition, which can make them extreme population vulnerable, requiring specific care, attention and adaptations in the routine, making the support networks essential for their development.

The statements of children and adolescents express the many changes caused in their lives since the moment of discovery of the chronic condition. The family, their main support network, also undergoes drastic changes in lifestyle<sup>13</sup>. Several chronic diseases impose a new feeding behavior by children and/or adolescents, and the adequacy to a new diet can become one of the greatest difficulties to be faced<sup>13</sup>.

According to the participants, the change in habits, among them, food was highlighted as adaptations difficult to be experienced, and can be observed in Figure 1 and in the speech and drawing (figure 2) of C/Ad7 and C/Ad8, who understand the need to remove the soft drink and sweets from the menu, but feel difficult in this change of their diets, adjustment of the amount of food ingested. Corroborating, the literature exposes research developed with

children with Diabetes Mellitus, which shows that the child needs to learn to deal with a new routine, which is glucose control, insulin administration, insertion of a new diet and complete daily monitoring<sup>14</sup>. Nursing professionals as well as nutritionists are important in the lives of these children and adolescents, in order to provide them with care and guidance on which foods and quantities are most appropriate for their nutrition, thus helping them to face the situations of vulnerabilities experienced.

It is noteworthy that children and adolescents with chronic conditions need continuous guidance carried out by health services, in order to overcome any doubts that may arise with the progress of treatment. The integration of instruments and knowledge directed to the family and the child/adolescent can reduce situations of vulnerability, in order to provide a constant expanded care in the network<sup>15</sup>. Thus, it is appropriate that the political processes, planning, communication and intersectoriality are strengthened, so that professionals have the capacity to act within the health system<sup>15</sup>, consolidating the link between health service and family/child. It is believed that, by having a broad view of the situations of vulnerabilities of these children and adolescents, care can be provided effectively, contributing to their socialization.

Children and adolescents with chronic conditions are often hospitalized. In this scenario, painful and invasive procedures are often necessary for the restoration of health<sup>6</sup>. In the statements, the children/adolescents reported that they do not like the procedures performed, and this brings feelings such as fear, tiredness and nervousness, since figure 3 shows the representation of a child in a hospital bed receiving medication, explaining a face that can be interpreted as sadness or pain. This result corroborates research with pediatric patients with chronic diseases, in which invasive medical procedures can be

traumatizing for them, especially if they are seen as frightening or painful<sup>16</sup>.

Frequent hospitalizations for this public, in many cases, end up being prolonged, because they require complex and intermittent care, which ends up considering them as clinically debilitated and socially vulnerable<sup>3</sup>. Thus, during hospitalization, health professionals, especially nursing, can intervene through therapeutic listening, understanding what makes them vulnerable, such as fear and pain, thus evolving their care in an individualized way, providing them with security and adherence to the necessary treatment to their clinical situation.

The construction of a trust between the patient/health team minimizes damage and trauma, because the professional begins to have a bond with the child/adolescent, favoring the care committed to the patient. Pain causes children and adolescents to create fear and anguish when performing procedures for the treatment of the disease. Thus, the nurse, by providing quality care and establishing a support network with the child/adolescent and his/her family, provides a reliable, healthy and comfortable environment during treatment<sup>6</sup>.

In order to provide quality care, a study identified strategies that can be used by health professionals before, during and after the procedures that help in their development and coping with children and adolescents such as distraction, guided imagination, deep breathing, progressive muscle relaxation. Moreover, a calming activity can be strategically designed to follow up procedures in a hospital environment<sup>16</sup>.

Participant C/Ad7 understands that she needs to perform the treatment to maintain her health, even considering that performing her treatment is 'boring'. When the child perceives and understands about the importance of his/her treatment, it is still effectively monitored by the health team, the viability of acceptance is maximized<sup>17</sup>. In this perspective, if the child and adolescent do not understand the

importance of their treatment, it is up to the professional to explain thoroughly and in a playful way, helping to develop their therapeutic process, which is important in the chronic health condition.

Feelings of concern such as stress, hopelessness and depression may appear in pediatric patients subject to these limitations, at high levels, causing changes in the way the child/adolescent lives<sup>18</sup>. In addition, the limits imposed by the disease interfere even in games, a moment in which the child/adolescent can develop their social function and interaction with others<sup>18</sup>.

In the speech of C/Ad3, having access to play and painting in the hospital context helps to forget and face fears. Playing is fundamental for the child and is part of their development and, within hospitals, it is evident the importance of this for the treatment of children. The therapeutic toy allows greater acceptance of procedures, tranquility and safety, in the most diverse contexts, in the care process, showing the need to articulate care environments to promote these effective practices<sup>19</sup>.

In many cases, chronic conditions bring limitations for children/adolescents. These limitations, imposed by the disease, affect even daily activities, causing losses in the follow-up of growth and development, interfering in the routine of the whole family<sup>3</sup>. For these children/adolescents, it is difficult to understand that certain activities cause them frailties, due to the limits that their condition imposes.

The relationships of friendship and interaction with the school allow the ease of insertion of the child/adolescents in the social environment, enabling coping with situations of vulnerability. The participants refer to their relationships at school, games, as well as the good relationship with the teacher, which can also be seen in Figures 4 and 6. School plays a key role in the lives of children and adolescents. The school is an opportunity to expand the first social experiences, being an important means to expand the skills, independence and

autonomy, essential for cognitive and social development<sup>20</sup>.

For being a place frequented during, on average, five hours a day, the school is responsible for providing intellectual construction, as well as the development of behaviors<sup>21</sup>. Children and adolescents, regardless of physical, intellectual, social, emotional and linguistic conditions, should be received within the school, without any discrimination<sup>21</sup>.

With the possibility of facing physical complications and psychomotor development, these children/adolescents face a challenge of learning to adapt to the new reality imposed on them<sup>4</sup>. Because of the fragile mind, the human being is vulnerable and needs care and attention, the child/adolescent alone, and by his/her innocence, unprotected by nature, is already more vulnerable, and becoming aware of the ways to face this condition, using his/her intellect capacity, is reflected in his/her ontological vulnerability, of being and existing in the world with a chronic condition<sup>2</sup>.

Understanding the greatest difficulties faced by these children/adolescents enables the development of a support network to meet the needs imposed by care, thus enabling positive coping in the experience of chronic conditions<sup>4</sup>.

For children and adolescents, as well as their families, a support network is essential for the experience of the chronic condition. Weaknesses can arise over time, and therefore they can feel undone and undirected from what to do<sup>22</sup>. Therefore, support networks become indispensable in the context of care for the situations of vulnerabilities of this population with chronic disease, because they can contribute to family strengthening and overcoming negative feelings, bringing benefits and more quality of life for them<sup>23</sup>.

Nevertheless, the daily school life of children and adolescents with chronic conditions, in many cases, can be affected due to the number of hospitalizations. The

importance that the school gains in this context is immeasurable, because it will be responsible for keeping this student included, with ethical commitment, quality of life and social insertion may be present in the lives of these children/adolescents with chronic conditions<sup>24</sup>.

In the routine of children and adolescents, play is present, and can be visualized in the representation of Figure 8 as well as in the participants' statements. In this context, it is emphasized that games are indispensable to children, as they contribute to a healthy development, imposing physical, emotional, cognitive and social benefits<sup>25</sup>. In addition, they assist in reasoning, interpersonal relationships and motor coordination. Currently, with the use of technologies and their dissemination in an increasingly rapid and comprehensive way, children and adolescents make frequent use of the cell phone. These devices have facilitating aspects, such as assisting in the development of reasoning and providing interaction with social networks, besides being a form of entertainment. Moreover, it is believed that the involvement of children with other children brings mutual benefits, because there is sharing of thoughts and imaginations, intensifying the discoveries and favoring the relationship with the world.

Finally, it is emphasized the importance of creating a bond between nurses and the population of children and adolescents living in chronic conditions, in order to favor the communication of this public and provide their expression before what they experience, enabling the planning of individualized strategies to mitigate the repercussions of their clinical condition<sup>26</sup>.

## Conclusion

The objective of the research was achieved, allowing knowing the perception of children and adolescents about their chronic health conditions, with their difficulties and limitations, as well as with

the facilitating interactions related to the situations experienced. In this context, the difficulties include a process in the change of diet, anxiety and fear during hospitalization when undergoing procedures, pain, the limitations imposed by chronic disease before activities developed. Situations, which are part of their life, which are added and need coping with situations of vulnerabilities.

The interactions include the relationships of friendship with health professionals in hospital environment, family members, teachers, children and adolescents in the school environment, which are a facilitator for the insertion of the child/adolescent in the social environment, which enables the minimization of situations of imposed vulnerability. Furthermore, the act of playing is an important activity for development. The human being presents his/her existential vulnerability and, added to the chronic health conditions and the perception of a being who still needs care, the multiple situations of vulnerability

experienced by children and adolescents with chronic health conditions are observed.

Limitations of the study include the impossibility of collecting data in groups, as proposed by the SCM, as well as the difficulties related to access to the participants' residence and the scheduling of interviews. It is believed that if data collection had been performed in a community environment such as the school or health service, it would be possible to work as groups and expand the application of the method.

This study shows that children and adolescents with chronic conditions need greater support from caregivers/family members, health team and school, for their psychosocial development, obtaining care in an integral and effective way, enabling the formation of bonds, transmitting an environment with safety and tranquility that allows their adaptation and development. In this sense, it is essential to build support networks and expand the insertion of the school as a care strategy for these children/adolescents and their families.

## Referências Bibliográficas

1. Di RD, Cambrisi E, Bertini S, Miscioscia M Associations between Pretend Play, Psychological Functioning and Coping Strategies in Pediatric Chronic Diseases: A Cross-Illness Study. *Int J Environ Res Public Health*. 2020; 17(12): 06-18.
2. Gallo M, Agostiniani R, Pintus R, Fanos V. The child with medical complexity. *Ital J Pediatr*. 2021; 47(1): 1-7.
3. Barbosa TA, Reis KMN, Lomba GO, Alves GV, Braga PP. Rede de apoio e apoio social às crianças com necessidades especiais de saúde. *Rev Rene*. 2016; 17(1): 60-66.
4. Silva MEA, Moura FM, Albuquerque TM, Reichert APS, Collet N. Rede e apoio social na doença crônica infantil: compreendendo a percepção da criança. *Texto Contexto Enferm*. 2017; 26(1): 2-10.
5. Favaro LC, Marcon SS, Nass EMA, Reis P, Ichisato SMT, Bega AG, Paiano M, Lino IGT. Percepção do enfermeiro sobre assistência às crianças com necessidades especiais de saúde na Atenção Primária. *REME – Rev Min Enferm*. 2020; 24:e-1277.
6. Oliveira OP, Coelho HP, Meneses LC, Lima C. V. M., Sales J. K. D. de, Souza G. dos S. D. de, Oliveira J. D. de, Castro A. P. R. de, Borges A. M. M., & Tavares A. R. B. S. A percepção de crianças escolares acerca da hospitalização: estudo com dados qualitativos. *Revista Eletrônica Acervo Saúde*. 2020; (50): e3409
7. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007; 19(6): 349-57.

8. Ministério da Saúde. Conselho Nacional de Saúde (Brasil). Resolução nº 466/12: sobre pesquisa envolvendo seres humanos. Brasília (DF): Ministério da Saúde, 2012
9. Cabral IE, Neves ET. Pesquisar com o método criativo e sensível na enfermagem: fundamentos teóricos e aplicabilidade. In: Lacerda MR, Costenaro RGS, organizadores. Metodologia da pesquisa para a enfermagem e saúde: da teoria à prática. Porto Alegre, RS(BR): Moriá; 2015.
10. Zanatta EA, Motta MGC, Trindade LL, Vendruscolo C. Vivências de violência no processo de formação em enfermagem: repercussões na corporeidade dos jovens. Texto contexto enferm. 2018; 27(3):e3670016.
11. Braun V, Clarke V, Hayfield N, Terry G. Thematic Analysis. Handbook of Research Methods in Health Social Sciences. 2019; (48): 843-860.
12. Torralba-Roselló, F. Antropologia do cuidar. Petrópolis: Vozes, 2009.
13. Barreto MS, Alencar SF, Marcon SS. Mudanças no cotidiano do adolescente com condição crônica e de seus familiares: uma análise reflexiva. Rev Par Enferm. 2018; 1(1):104-115.
14. Conte AF, Jeneral RBR. Sentimentos vivenciados pelos adolescentes portadores de diabetes mellitus tipo 1. Rev Fac Ciênc Méd. 2018; 20(4): 218-22.
15. Wolkers PCB, Pina JC, Wernet M, Furtado MCC, Mello DF. Crianças com diabetes mellitus tipo 1: vulnerabilidade, cuidado e acesso à saúde. Texto & Contexto Enfermagem. 2019; 28:1-17, 2019.
16. Rohan JM, Verma T. Psychological Considerations in Pediatric Chronic Illness: Case Examples. International Journal of Environmental Research and Public Health. 2020; 17(5):1644.
17. Farias D, Bärtschi Gabatz RI, Milbrath VM, Schwartz E, Freitag VL. Percepção infantil sobre a necessidade de hospitalização para o reestabelecimento da saúde. Revista Enfermagem Atual In Derme. 2019; 87(25): 1-8.
18. Lecce TM, Casarin ST, Santos BP Ações de enfermagem para a qualidade de vida à criança com doença crônica. Rev. Enfermagem Revista. 2017; 20(2) 176-195.
19. Canêz JB, Gabatz RIB, Hense TD, Vaz VG, Marques RS, Milbrath VM. O brinquedo terapêutico no cuidado de enfermagem à criança hospitalizada. Revista Enfermagem Atual In Derme. 2019; 88(26): 1-9.
20. Marques H, Brandão JA, Gonçalves LF, Silva KS, Cardoso VS, Magalhães AT. Percepção de professores e gestores de educação sobre a inclusão de crianças com deficiência visual. Rev. Salusvita (Online). 2017; 36(1):7-21.
21. Brito N, Lima TM, Dias TL, Enumo SRF. A doença crônica no contexto escolar: os saberes de alunos com anemia falciforme. R. Educ. Públ. 2017; 26(62): 675-693.
22. Souza MHN, Nóbrega VM, N Collet. Social network of children with chronic disease: knowledge and practice of nursing. Rev Bras Enferm. 2020; 73(2):e20180371.
23. Araújo MAF, Silva RA, Melo, ES, Silva MAM, Mazza VA, Freitas CASL. Redes sociais de apoio e famílias de crianças com deficiência: uma revisão integrativa. Investigaçao Qualitativa em Saúde. 2018; 2:585-595.
24. Tavares TS, Duarte ED, Sena RR. Direitos sociais das crianças com condições crônicas: análise crítica das políticas públicas brasileiras. Esc. Anna Nery. 2017; 21(4):1-9.
25. Souza AJM. Considerações sobre o brincar: porque os brinquedos auxiliam e podem influenciar nos processos de aprendizado. Revista Acervo Educacional / Journal of Educational Collection. 2020; 2: e2126
26. Silva VE, Nunes MDR, Macedo IF, Possi JCS, Silva-Rodrigues FM, Pacheco STA Crianças e adolescentes com condições crônicas. Rev enferm UERJ, Rio de Janeiro, 2020; 28:e47474.

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