

## Living with multiple symptoms: the experience of children and adolescents with chronic condition

*Convivendo com múltiplos sintomas: a experiência de crianças e adolescentes com condição crônica*

*Vivir con múltiples síntomas: la experiencia de niños y adolescentes con condición crónica*

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### ABSTRACT

**Objective:** to comprehend children's or adolescents' experiences of living with symptoms of a chronic condition. **Method:** on a qualitative approach, taking Grounded Theory as a frame of reference and 11 children and adolescents aged 6 to 18 years hospitalized in a state university hospital as participants, data were collected by semi-structured interview using the "draw, write, and tell" technique. The interviews were recorded and transcribed, and then analyzed following the steps of Grounded Theory. **Results:** analysis identified the category "Having to live with symptoms", which comprised 5 subcategories featuring physical, emotional and general symptoms, the experience of living with multiple simultaneous symptoms, and the consequences of living with them. **Conclusion:** living with several symptoms entails limitations. Nursing needs to favor children's and adolescents' expressions of their experiences in order to minimize stressful situations and improve symptom management by planning individualized strategies.

**Descriptors:** Child; Adolescent; Chronic Disease; Sign and Symptoms; Pediatric Nursing.

### RESUMO

**Objetivo:** compreender como é a experiência das crianças/adolescentes de conviver com sintomas de uma condição crônica. **Método:** abordagem qualitativa, utilizando como referencial a Teoria Fundamentada nos Dados. Os participantes foram 11 crianças e adolescentes de seis a 18 anos incompletos hospitalizados em um hospital estadual universitário. Como instrumentos de coleta de dados, utilizou-se a entrevista semiestruturada e a técnica "draw, write and tell". As entrevistas foram audiogravadas e transcritas, e a análise seguiu os passos do referencial. **Resultados:** apreendeu-se a categoria "Tendo que conviver com os sintomas", que engloba cinco subcategorias que apresentam sintomas físicos, emocionais e gerais, a convivência com a multiplicidade de sintomas simultâneos e as consequências de se conviver com eles. **Conclusão:** a convivência com diversos sintomas leva a limitações. A enfermagem precisa favorecer a expressão das vivências das crianças/adolescentes, minimizando situações de estresse e melhorar o gerenciamento dos sintomas, através do planejamento de estratégias individualizadas.

**Descritores:** Criança; Adolescente; Doença Crônica; Sinais e Sintomas; Enfermagem Pediátrica.

### RESUMEN

**Objetivo:** comprender las experiencias de niños o adolescentes de vivir con síntomas de una enfermedad crónica. **Método:** con un enfoque cualitativo, tomando como marco de referencia la Teoría Fundamentada y como participantes a 11 niños y adolescentes de 6 a 18 años hospitalizados en un hospital universitario estatal, los datos se recolectaron mediante entrevista semiestructurada utilizando el método "dibujar, escribir y decir" técnica. Las entrevistas fueron grabadas y transcritas, y luego analizadas siguiendo los pasos de Grounded Theory. **Resultados:** el análisis identificó la categoría "Tener que vivir con síntomas", que comprendía 5 subcategorías que presentaban síntomas físicos, emocionales y generales, la experiencia de vivir con múltiples síntomas simultáneos y las consecuencias de vivir con ellos. **Conclusión:** vivir con varios síntomas conlleva limitaciones. La enfermería debe favorecer la expresión de las experiencias de los niños y adolescentes para minimizar las situaciones estresantes y mejorar el manejo de los síntomas mediante la planificación de estrategias individualizadas.

**Descritores:** Niño; Adolescente; Enfermedad Crónica; Signos y Síntomas; Enfermería Pediátrica.

## INTRODUCTION

With the investment in technologies for hospital care, the number of children and adolescents with chronic conditions grows worldwide<sup>1</sup>. In Brazil, 9.1% of the children from zero to five years of age; 9.7% from six to thirteen years of age and 11% of the adolescents from fourteen to nineteen years of age of the total population in this age group have chronic diseases<sup>2</sup>. When we think about chronic conditions, these data are even higher, estimated to represent nearly 85% of the health problems in Brazil<sup>3</sup>.

This study uses the term chronic condition because it is comprehensive and encompasses not only chronic diseases, disorders and disabilities. It includes a variety of health conditions such as asthma, sickle cell anemia, diabetes, long-term communicable diseases like HIV/AIDS, maternal and perinatal conditions, long-term mental disorders, and

ongoing physical and structural disabilities, such as amputations and persistent motor disabilities. It also includes many other disorders that may not necessarily imply long hospitalizations or being significantly disabled<sup>3,4</sup>.

The main characteristics of chronic conditions are the following: permanent nature, residual disability, long-term, recurrent drug dependence, almost always incurable, irreversible and degenerative. They are complex, continuous and permanent, and require strategies for necessary lifestyle changes<sup>5</sup>.

When a chronic condition emerges, it imposes several changes in people's lives, requiring re-adaptations in face of the new situation in the family, professional and social fields. Strategies are necessary for coping, in order to satisfy their needs and regain balance. Children and adolescents particularly experience changes in their daily lives, often with limitations, mainly physical, due to the signs and symptoms of their health condition, and are often hospitalized for exams and treatment as the condition progresses<sup>6</sup>.

Among the signs and symptoms experienced, the most common in children and adolescents are the following: fatigue, pain, nausea, changes in sleep patterns, worry and sadness<sup>7-11</sup>, negatively interfering with their quality of life<sup>12</sup>.

Thus, it is particularly important to learn the symptoms in children/adolescents with chronic health conditions through their own report, so that appropriate Nursing interventions are planned for this population, thus improving quality of life for them and their families. In this sense, the objective of this study was to: Understand the characteristics of the experience of the child/adolescent living with the symptoms of a chronic condition.

## METHOD

A qualitative research study, with deepening in the world of meanings, actions and human relationships<sup>13</sup>.

Children and adolescents with chronic conditions between six and eighteen incomplete years old hospitalized in a University Hospital in Rio de Janeiro participated in the study. Those in end-of-life care or in critical situations were excluded due to the fragility of the moment they were living and to the possibility of predominance and severity of symptoms characteristic of advanced disease progression, common at this stage.

The data collection sites were the pediatric ward, which has 16 beds for children from 29 days to 12 years old; and the adolescent ward (13 to 18 years old), which has eight beds. The units were visited daily, between December 2018 and July 2019, in the search and identification of participants. The guardians were approached first and, if they agreed with the participation of the child/adolescent, these were consulted regarding their desire to participate. No child/adolescent or guardian refused to participate.

The study was approved by the Committee of Ethics and Research with Human beings of the institution proposing the research (Opinion No. 3,138,245). It followed the guidelines of Resolution 466/2012 of the National Health Council. Each participant voluntarily expressed their desire to participate in the study, providing their assent and, in the case of children'/adolescents' and the guardians' consent, signed through the Free and Informed Assent Form (FI AF) and the Free and Informed Consent Form (FICF), respectively.

Semi-structured interviews were used for data collection, conducted at the patients' own beds. The health team was informed about the beginning of the interview in order to avoid interruptions as much as possible and maintain the participants' privacy. Along with the interviews, the *draw-write-tell interview*, developed by POPE and associates (2019)<sup>14</sup>, was used. The authors propose interviews using drawing, writing and telling with their own words what was portrayed on paper. In this way, children/adolescents communicate their experiences by drawing, writing and telling the story of their drawings in response to the interview questions<sup>14</sup>.

The participants were invited to draw and/or write about the following topic: "Draw a child/teenager with (the participant's chronic condition) in the hospital." The patients received a clipboard, colored sheets, coloring pencils, crayons, and pens. From the drawing, the participants were invited to talk about what they wrote and/or drew and their meanings; they were then asked to answer the open research questions: "What do you feel in your body related to your disease?", "How is it for you to feel this way?"

The Grounded Theory (GT) was used as Methodological Framework. It extracts the experiences lived by the social actors, enhancing the expansion of knowledge in Nursing and other fields<sup>15</sup>. The analysis was carried out according to Strauss & Corbin (2008), concomitantly with collection, proceeding to a constant comparative analysis, following the steps recommended by the framework, namely: (1) open coding – thorough analysis of the statements, transforming them into codes and grouping them according to their similarities in initial categories; (2) axial coding: the categories are consolidated, compared, grouped and reorganized, resulting in more extensive and broader categories. The paradigm model was used to determine the structure and process of the investigated phenomenon,

which includes the following aspects: causal, intervening, contextual, action/interaction strategies and consequences; (3) selective coding: integration and refinement of the categories, determination of the central category<sup>16</sup>. During the analysis process, memos and diagrams were used to facilitate the identification of the central category and integration of concepts.

Data collection ended upon theoretical saturation, in which no new or relevant data is obtained to answer the research question; the developed category is extensive and includes all elements of the paradigm<sup>16</sup>.

## RESULTS AND DISCUSSION

Eleven children/adolescents participated in the study, six between 7 and 11 years old, most of them female (7) and with hematological diseases (8).

Through the analysis of the data, the “Having to live with the symptoms” central category was apprehended.

### Having to live with the symptoms

The “Having to live with the symptoms” category is composed of the central idea of coexistence of the child/adolescent with the symptoms triggered by the chronic condition with which they live (according to the paradigm model: consequence). Among them are the physical, emotional and general symptoms and living with the multiplicity of simultaneous symptoms, triggered by the health condition itself (causal condition) or by the treatment (causal and intervening condition). The consequences of living with the symptoms can be exemplified by the various hospitalizations and distancing from school and from the social environment (contextual condition). These symptoms are dynamic and change during the health condition and treatment, worsening or decreasing in intensity, for example, with rest and medication (action-interaction), knowing that some are more present in the diagnosis and that others arise at specific times of the treatment.

The central category comprises five subcategories: Suffering with the physical symptoms; Experiencing the emotional symptoms; Living with general symptoms; Having several symptoms at the same time; and Suffering the consequences; all presented below.

### Suffering with the physical symptoms

A variety of physical symptoms were reported, including pain, nausea, vomiting, loss of appetite, mucositis, bleeding, and shortness of breath. Pain is among the most mentioned symptoms and is present in almost all the chronic conditions.

*No, this time I checked in because I had a tooth bleeding [...]. Then the bleeding increased and it was hurting a lot, then there were some small wounds [...]. I started to feel pain in the joints; I felt a lot of pain in the bones of my hand, I couldn't bend. (E5, lupus, 17 years old).*

*Shortness of breath, miss. I was feeling short of breath, then I just sat for a while; when I got up to pee I got very tired. [...] Then I just had a headache, and my foot and calf hurt too. (E6, hemolytic anemia, 13 years old).*

For some, the worst symptoms experienced were nausea and vomiting, which imposed direct limitations on food acceptance by the child/adolescent, as the following excerpt illustrates:

*Really bad [...] I feel a horrible nausea [...]. Wow, I don't even like to remember it. I felt sick every day, my vomit bag was always under my bed, every day, every day, every single day. (E1, 11 years old, ALL).*

Figure 1 shows the drawing of one of the study participants.

*I drew a patient on the bed, and he's undergoing chemotherapy, and after he finished chemotherapy he vomited. (E1, 11 years old, ALL).*

The literature<sup>17-19</sup> corroborates with the results found. Pain is one of the most studied symptoms and a major problem for children/adolescents with cancer. The presence and intensity vary during treatment<sup>17,18</sup>, as well as nausea and vomiting<sup>19</sup>. Changes in appetite were also identified, both in terms of inhibition and exacerbation of the desire to eat.

*I can't eat anymore at all, gosh. I don't even like to remember. (E10, 11 years old, ALL).*

As shown in this study, in which children/adolescents were able to identify most of the symptoms and relate them to a plausible etiology, other research studies<sup>7,20</sup> also indicate that older children are able to establish a cause and consequence of the symptoms, as noted in the following excerpts.

*If I miss the hemodialysis session, I get very swollen. (E9, 8 years old, chronic kidney disease).*

*When my platelet is very low, then it makes me very sleepy. (E7, 15 years old, marrow aplasia).*



**FIGURE 1:** Drawing made by participant E1, 11 years old, during the data collection stage. Rio de Janeiro, Brazil, 2019.

For younger children, on the other hand, it is still difficult to describe the symptoms and the relationship with the disease itself, whereas adolescents are able to even discern if a symptom refers to the disease or to the treatment, providing information about the concomitance of symptoms and the dependence on some specific events during the illness experience<sup>20</sup>.

### Experiencing the emotional symptoms

Among the most mentioned symptoms, sadness stands out, followed by concern and changes in self-esteem.

*There was a time when I was very sad, really very sad and I didn't know why [...] I didn't like to talk. I wasn't even tired anymore, but I just lay there. (E8, 7 years old, ALL).*

The perception of one of the participants is shown in Figure 2.



**FIGURE 2:** Drawing made by participant E9, 8 years old, during the data collection stage. Rio de Janeiro, Brazil, 2019.

The potential causes of emotional changes were the following: not being able to eat, hospitalization, isolation and distancing from friends.

*Yes, I couldn't eat anything and I was super moody. (E05, 17 years old, Lupus).*

*I don't like it when I have to be hospitalized. (E03, 13 years old, Myelomeningocele).*

*I don't go to school anymore because I feel tired. My school is far from home so I can't go, I get very tired... I miss some of my friends. (E07, 15 years old, marrow aplasia).*

With regard to depressive symptoms, a recent literature review with children and adolescents indicates that the depressive condition is severe and common to many children and adolescents and that studies that focus on interventions to minimize this symptom are still scarce<sup>21</sup>. Emotional changes appear not only in the literature, but also stand out as those that cause the most discomfort to the patients and, in many cases, lead to deep suffering and social isolation<sup>22</sup>.

Another symptom present was concern, both with the emotional state of the family members who are also immersed in the daily activities of the child/adolescent with a chronic condition and with the fear of being a burden or bothering them.

*Then I spent many days at the PICU, I even had a PICC on me [...] My mother cried a lot there... (E8, 7 years old, ALL).*

*Oh, miss, I have it cut for my father, you know? He gets very sad to see me like this. It's even hard to speak. He never says anything. He always does everything for me, takes good care, comes to all of my appointments, but I know it's bad. (E01, 11 years old, ALL).*

Despite the causes of concern of children with chronic conditions and their families in many cultures being linked to fear of recurrence, adverse effects and ineffective treatment<sup>23,24</sup>, one of the highlights of this study was the participants' concern with their caregivers and the burden that this care represents. Many studies have reported the burden of caregivers of children/adolescents with chronic conditions, since they demand a series of daily care actions that requires time, energy and dedication from the caregivers<sup>25-27</sup>. However, the recognition and concern of the child/adolescent with their caregivers stood out as a differential of this research, as children and adolescents were concerned about the well-being of their main caregivers, suggesting a feeling of guilt for overloading their parents in the care process.

Situations that can trigger changes in self-esteem were also mentioned by the participants:

*Because everyone kept asking how it was [the hair], if it had already fallen. In the street people kept looking, I didn't like it. (E01, 12 years old, ALL).*

*Now just the swelling. My face gets huge, I feel weird and people ask what's going on, but the doctor said it gets better with time. (E5, 17 years old, Lupus).*

The literature supports the findings regarding changes in the self-esteem of children and adolescents with chronic conditions due to the changes in their body as a result of the side effects of the treatment (edema and hair loss, for example) or because they suffer from the stigma of the disease<sup>24,28</sup>.

### Living with general symptoms

General symptoms are those that are beyond the specifics of the disease or treatment and that can be common to several pathologies. Tiredness, sleep disorders, fever, constipation, lack of appetite and dizziness are among them, with fatigue being the most reported by the participants.

*Oh, when I walk a lot I get tired. When I go up or down the stairs [...] I get tired, like, at many moments. Walking very fast, walking slowly. It makes you want to sleep all day, it's really bad. (E7, 15 years old, Marrow aplasia).*

*This (tiredness) chases me, I already wake up tired, then I sleep again, then I get tired again. (E10, 11 years old, ALL).*

It is common for children/adolescents to mention tiredness as a symptom. Tiredness or fatigue can be physical, emotional or cognitive and is not proportional to the activities performed by these patients<sup>20,22</sup>. Fatigue is a symptom widely explored in the international literature<sup>4,29</sup>, but is still little studied in Brazil<sup>30</sup>, despite being considered debilitating, distressing and persistent, in addition to accompanying the child in all stages of the disease and treatment, deserving evaluation and management by the health professionals<sup>26</sup>.

Another symptom that was related to tiredness was altered sleep, which can be both understood as a disorder that interferes with the night sleep of children/adolescents, as well as the daytime sleepiness reported by some participants.

*There are some nights that I don't know what happens but I can't sleep either... (E10, 11 years old, Leukemia). I also get very sleepy sometimes when my platelet is very low, then it makes me very sleepy. (E7, 15 years old, Marrow aplasia).*

Sleep can be altered not only by the symptoms of the disease but, above all, by the treatment. The use of certain medications, including corticosteroids, can be associated with sleep disorders in the pediatric population in different chronic diseases. In addition, therapeutic and surgical procedures and clinical complications are also associated with

impaired sleep in these individuals<sup>22,30</sup>. They can interfere with other symptoms, such as fatigue and mood swings, and are still considered a challenge for practice and research<sup>23</sup>.

Other general symptoms such as fever, constipation, lack of appetite and dizziness are also among the symptoms experienced and which significantly interfere with the life of the child/adolescent.

*I had a fever a few days ago too, I took dipyrene. [...] I can't go to the bathroom. (E5, 17 years old, Lupus).  
[...] I got really dizzy [...] (E02, 6 years old, Chronic kidney disease).*

Fever is a common manifestation of almost all the chronic diseases and can be indicative of several changes, especially infections. Symptoms such as diarrhea, constipation, lack of appetite and dizziness are described in the literature in association with adverse effects caused by the treatment<sup>20,22</sup>. Constipation can be linked to the decreased mobility of the child/adolescent and to the use of a specific class of drugs, opioids<sup>22,29</sup>.

### Having several symptoms at the same time

Something that is evident to all the participants is the coexistence with several simultaneous symptoms. They usually do not have an isolated symptom, but a set of them, combined or triggered by others, which further compromises their quality of life and experience with the disease.

*Because it's very bad to have this. I felt a lot of things, I had to stop going to school, to undergo chemotherapy, I was always sick, my hair fell out. [...] At first I had a fever, I felt pain, a lot of things. (E1, 11 years old, ALL).  
I didn't feel like eating, almost every day I needed a transfusion and I was still tired. (E08, 7 years old, ALL).  
I didn't eat! I wasn't eating anything. It hurt very, very much! Now [...] I can't go the bathroom. (E5, 17 years old, Lupus).*

To alleviate the difficulties in living with several symptoms at the same time and their inter-subjective repercussions on the trajectory of the children with a chronic condition and their families, it is necessary to plan Nursing care and action strategies. It is understood that playfulness, dialog, empathy, affective relationship and teamwork are potential strategies for action and relational interaction that nurses can develop with the child, family members and as a team<sup>18</sup>. To corroborate this idea, a study on the management of care for hospitalized children with chronic conditions revealed that, to meet the child's multiple needs, it is necessary to implement action and interaction strategies anchored in the perspective of complementarity, reciprocity, recursion, and non-linearity. Only from a dynamic, interdisciplinary and multi-directional approach will it be possible to take care of the children and their families in their complexities<sup>26,30,31</sup>.

### Suffering the consequences

Physical, emotional and general symptoms influence the daily life of children/adolescents, changing their daily activities, mood, relationships and social interaction. Habits like going to school, eating habits and relationships with friends are compromised by the symptoms and the long stay in the hospital.

*"Because it's very bad to have this. I felt a lot of things, I had to stop going to school." (E1, 11 years old, ALL).  
"[...] it's bad because I can't do almost anything. I can't eat a lot of things, I can't go to crowded places, and I can't get sick." (E10, 11 years old, ALL).  
"I stopped peeing, nothing comes out and I don't even feel the need to... it was just bad when they inserted the catheter, now I don't need it anymore. [...] I can't eat anything with a lot of salt." (E09, 8 years old, Chronic kidney disease).*

The perception of one of the participating children can be seen in Figure 3.

It can be identified that living with the symptoms generates suffering and several limitations to the life of the child/adolescent, who stops doing things and going to places due to the indisposition caused by the symptoms, frequent hospitalizations and the change in daily activities. According to the literature, living with dietary restrictions, medication, changes in playing games, interruptions in daily and school activities and fear of infection, disease progression and death causes the child/adolescent to feel sad, angry, anxious and insecure<sup>26</sup>.

In addition, among the daily activities, the school stands out in this age group, causing patients to feel the changes more strongly. Social relationships take place in this space, and children and adolescents miss them. As a result of this isolation and limitations, other symptoms are triggered and perceived in the statements, such as depressive symptoms, sadness, insomnia or drowsiness, with the disease being a major source of stress for children/adolescents and their families<sup>25,30,31</sup>.

Social isolation and psychological distress stand out as consequences of symptoms in life and in the daily activities<sup>21,23,24,29</sup>. Regardless of the diagnosis, the concomitance of symptoms will imply the need for adaptation. Therefore, early identification, evaluation and treatment are the primary responsibilities of the professionals in charge of the treatment of this population, in order to make adaptation as less traumatic as possible.



**FIGURE 3:** Drawing made by participant E8, 7 years old, during the data collection stage. Rio de Janeiro, Brazil, 2019.

### Study limitations

Possible limitations of the study are related to the fact that the participants belong only to a single research scenario and to the absence of a theoretical framework to assist in data analysis.

### CONCLUSION

Children and adolescents with chronic health conditions experience several symptoms, with pain, sadness, concern, fatigue, nausea and fever among the main ones. The experience in the face of the symptoms is wide, complex and poorly understood. They have to live with the multiplicity and simultaneity of symptoms, a reality that requires them to live with different feelings.

The importance of the collaboration between nurses and children and adolescents who experience symptoms resulting from chronic conditions and their treatment is emphasized, in order to favor the communication of these patients and the expression of what they experience, enabling for the planning of individualized strategies to mitigate the repercussions of these symptoms for this population. In view of the scarcity of publications on the symptoms resulting from chronic conditions and their treatment, there is an urgent need for future research studies on the subject, focusing on self-reporting.

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