

## Being-child with asthma: assuming its particularities and dealing with restrictions

Karina Machado Siqueira<sup>1</sup>, Isabela Cristine Ferreira Fernandes<sup>2</sup>, Juliana Chaves Araújo<sup>3</sup>,  
Ana Karina Marques Salge<sup>4</sup>, Thaíla Corrêa Castral<sup>5</sup>, Maria Alves Barbosa<sup>6</sup>

<sup>1</sup> Nurse, Ph.D. in Nursing. Adjunct Professor of the Nursing Faculty at Universidade Federal de Goiás. Goiânia, GO, Brazil. E-mail: [karinams.fen@gmail.com](mailto:karinams.fen@gmail.com).

<sup>2</sup> Nurse, Master in Nursing. Student of the Nursing Graduate Program of the Nursing Faculty at Universidade Federal de Goiás. Goiânia, GO, Brazil. E-mail: [isabela\\_cristine@hotmail.com](mailto:isabela_cristine@hotmail.com).

<sup>3</sup> Nursing Academic of the Nursing Faculty at Universidade Federal de Goiás. Goiânia, GO, Brazil. E-mail: [juliana.chaves09@gmail.com](mailto:juliana.chaves09@gmail.com).

<sup>4</sup> Nurse, Ph.D. in Pathology. Associate Professor of the Nursing Faculty at Universidade Federal de Goiás. Goiânia, GO, Brazil. E-mail: [anasalge@gmail.com](mailto:anasalge@gmail.com).

<sup>5</sup> Nurse, Ph.D. in Public Health Nursing. Adjunct Professor of the Nursing Faculty at Universidade Federal de Goiás. Goiânia, GO, Brazil. E-mail: [thaccastral@gmail.com](mailto:thaccastral@gmail.com).

<sup>6</sup> Nurse, Ph.D. in Nursing. Retired Professor of the Nursing Faculty of the Universidade Federal de Goiás. Goiânia, GO, Brazil. E-mail: [maria.malves@gmail.com](mailto:maria.malves@gmail.com).

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### ABSTRACT

The study aimed to comprehend how children with asthma and their families perceive themselves in their experience with the chronic disease and, how they develop their coping ways and care. We conducted a phenomenological study, with five families of children with moderate or severe asthma. Data collection occurred through interviews with the children and their families, during home visits, between September of 2013 and January of 2014. From the child's perspective, the difficulty of dealing with fears, frustrations, and constraints related to the disease and treatment was apparent, especially at school. Family members emphasized the restrictions imposed in the child's life and family environment, besides mentioning care attitudes demonstrating overprotection. Professionals involved in attention to childhood asthma need to value the child's potentialities and the family autonomy in care actions, favoring the experience with the chronic disease and the empowerment for care.

**Descriptors:** Pediatric Nursing; Child; Asthma; Family; School Health.

### INTRODUCTION

Asthma is a common condition within the chronic respiratory diseases, which provokes inflammation of the airways and limitation of the air flow, leading to the occurrence of wheezing episodes, dyspnoea, chest tightness and coughing<sup>(1-2)</sup>.

In Brazil, there was a significant increase in the prevalence of diagnosed asthma, varying from 14.3% to 17.6%<sup>(3)</sup>. Besides, it is one of the leading causes for admission in the Unified Health System – SUS and, a motive to search for urgency and emergency services<sup>(2)</sup>.

The low treatment adherence can be responsible for the higher negative impact of the disease in the

patient's life, especially among the younger ones<sup>(4)</sup>. The disease control is obtained with well-succeeded management actions, highlighting the acquired knowledge about the disease, the triggering factors, the use of inhalers, the control signals and the symptoms that characterize exacerbations<sup>(1,5-6)</sup>.

Due to the chronicity, the asthma treatment is prolonged and requires an efficient interaction between the patient, caregivers and multi-professional team who assists. In the child context, the interdisciplinary attention has been shown as effective to the clinical asthma improvement and should be valued in the process<sup>(7)</sup>. Besides, interventions centered in the patient and family care improve satisfaction and communication during clinical interactions<sup>(8)</sup>.

It is important that the child with asthma, depending on the cognitive development, should be included in decisive processes and involved in discussions about the proposed therapeutic plan and, care actions to be undertaken. The child's opinion deserves to be valued, mainly because the child will assume responsibilities that will favor the effective disease self-management.

Few studies address the child conviviality with chronic diseases and their implications to the family<sup>(9-11)</sup>, including severe allergies and asthma<sup>(12)</sup>. However, from the children's perceptions, the ways that the family cope and, the integral care with the child were still little explored. Thus, in our study, we tried to comprehend some aspects of the phenomenon essence. Being-child with asthma, based on the perceptions of who live with the disease and also of those who share their world-life and its care.

This study aimed to comprehend how children with asthma and their families perceive themselves in the conviviality with the chronic disease and how they undertake their coping ways and care actions.

## METHODS

A descriptive study, grounded in the phenomenological method, developed with families of children with asthma, accompanied by a specialized ambulatory in Goiânia – Goiás/Brazil.

The option for phenomenology as theoretical-methodological referential is based on the understanding that it concerns the essence of the experience and at the same time, it is presented as a descriptive and rigorous science that shows and explicit phenomenon as they appear to the perceptive conscience<sup>(13)</sup>.

Following the comprehension that the child with asthma is not ill, but experiences a disease situation, without exercising the being-child, we took the care comprehensions from the referential of Martin Heidegger as a reference<sup>(14)</sup>. According to this thinker, the ways of care can have different meanings. They can reveal the indifference with the other, configuring a neglective caring way, or achieving two extreme possibilities, understood as positive ways<sup>(15)</sup>.

Regarding the positive ways, care can be given with a substitutive or anticipatory solicitude. In the first, it takes the place of the other in their concerns, making it for the other, substituting the other, not allowing the other to care for himself. In the second possibility, the care does not replace the other, but it anticipates for the other, forwarding it to his responsibility<sup>(14)</sup>.

We conducted the data collection from September of 2013 to January of 2014; five families of children with moderate or severe asthma participated in the study. The children were seven to ten years old. We conducted interviews for data collection, being attentive to the assumptions of the phenomenological research and, using the following guiding questions: To you, how is to care for a child with asthma? How do you perceive this child? How does asthma care impact your family?

In total, five children and 13 family members participated in the study: five mothers, one father, two step-fathers, two grandmothers, two aunts and, one sister. We considered family as the people indicated by their members<sup>(16)</sup>.

We initially contacted the family members in the ambulatory on the same day of the children's consultations. At this moment, the responsible researcher explained the objectives and how we would conduct the study and, we scheduled the first home visit. For each family, we had two visits, respecting the agreed times.

We conducted the interviews with all family members present during the home visits, and they were indicated as participants in the care for the child. The children also participated in the interviews with the freedom to intervene and express their opinions. From the verbalizations initiated by the family members, the child was included in the interviews, and, the child's participation was incentivized by the researcher. All children had the opportunity to take part in the interviews with their families and to express their experiences.

We recorded all interviews, and we transcribed them after. They lasted an average of 40 minutes for each home visit. As all present members had the opportunity to speak at the same time and in the same environment, the researcher proceeded with the interview transcription paying attention to the distinction and identifying the different participants.

We defined the number of participating families during the data collection according to the data saturation criteria, where the convergences of the collected information indicated to the end of data collection<sup>(17)</sup>.

Regarding the ethical matters, before the collection, all participants signed the "Free and Informed Consent Term". Also, the participating child signed the "Approval Term", according to the current recommendation in the country.

The study is part of the research project "Impact of the chronic health condition in the life of asthmatic children and adolescents and their family members", approved by the Ethics in Medical Human and Animal Research Committee of the Clinic Hospital at Universidade Federal de Goiás, protocol CAAE 15563113.2.0000.5078.

We based the analysis of the descriptions on the "Quantitative Analysis Method of the Situated Phenomenon"<sup>(17)</sup>. In the first analysis step, we read the descriptions, trying to understand the full meaning. After, we opted for a more attentive reading, trying to identify the meaning units. During the organization of these units, we apprehended the meanings of the contents and the convergencies for the categorizing or

construction of themes. In this last step, we synthesized the meaning units with the intention to reach the phenomenon structure, that is, its essence<sup>(17)</sup>.

During the analysis of the meaning units, we organized them in two categories that synthesized the meanings containing in them and, converged to the theme that entitles this article – Being-child with asthma: assuming its particularities and dealing with restrictions.

To keep the identity secrecy, we used codes. The first letter referred to the child or the representation of the person related to the child ( C: child, M: mother, F: father, SF: step-father, S: sister, G: grandmother, A: aunt). The second letter, followed by a number, referred to the participant's family. The numbers attributed to families followed its order of inclusion in the study.

## RESULTS

### Particularities of the child with asthma: own perceptions and of the family members

The discomfort caused by the disease, as well as, fears and anguish in coping with asthmatic crises were noted in the reports of few children:

*Asthma? It is like this, it is too bad, I have shortness of breath, it disturbs me at school, and here at home, when I go to sleep at night, I fear feeling sick, not to breathe anymore. (Cf1)*

*There are times that I keep thinking that I'll have a crisis, then I stay quieter, the shortness of breath really disturbs. What if I stop breathing, I get scared... (Cf2)*

The fear of death appeared in some parts of the children's testimonials, in a veiled way, especially when they refer to fear of not being able to breathe or to feel bad, as well as, in an explicit way, according to the following testimonials:

*It is, it is very bad. I feel headache, shortness of breath and pain here in my belly. I feel fear, lots of fear, fear that..that I'm going to die. (Cf4)*

*When there is a strong crisis, I think it even has the danger of dying. What if I stop breathing and die? (Cf5)*

For the asthma drug treatment, there is the need to use medications that have specific forms of presentation and few particularities to administer. Some children affirmed to feel ashamed and to avoid using the medication at school, notably the pressurized metered dosed inhalers, attached to the spacers. The children, as well as, family members, reported this difficulty:

*When needed, I think it is better to leave than to use the medication there at school. The little inhaler I use, but the small bottle [craft spacer] I don't use, everyone thinks its awkward. (Cf3)*

*If it is to use it at school, I feel embarrassed. My schoolmates keep laughing at me. But when I feel tired, I stay quiet. I don't use the medicine there. (Cf2)*

*She always said that she would not take medication to school, she was embarrassed by the disease, of her medication. (Gf2)*

Also emerged descriptions of family member's narratives about the children. They reported how they

perceive the conviviality with the disease and their differences in comparison to other children. These differences were related, especially to the possibility of, at any moment, triggering asthmatic crises:

*I am so careful with him; it is different because of asthma. I have another child; he doesn't have asthma. With G. is different because of the breathing, the shortness of breath. (Mf1)*

*She complains, gets angry, but she is different in these things, it doesn't work if she wants to do all that other children do because she can feel sick. (Gf3).*

The protection attitudes generate conflicts between family members and disagreements in how to perceive and deal with the child. Following, we will present a dialogue between a grandmother and mother of the same family, given as an example to make evident the divergent aspects between family members in what refers to the care for the child with asthma:

*I always felt pity of her because she is skinnier, she was always in the hospital, all the time she stayed in the hospital, she suffered so much with that. Her mother is more angry with her; I cannot be, I feel pity, She already had so much suffering, poor her. (Gf2)*

*She is harder, more stubborn; she is too spoiled by my mother, she has always been. There are days that she doesn't want to use the medicine, the asthma one, and she stays without it (...) My mom defends her; she says I need to be patient because she is a little sick one, I think she spoils her too much. (Mf2)*

Few family members highlighted the importance to consider the child's particularities related to the disease, but treating the child as any other person:

*I always try to look at him as a normal person. I always show him that he is not different. He has a disease that allows him to live as the other children (Mf4)*

*G. is smart; he doesn't let himself down with the disease. (STf1)*

This possibility to treat the child as others of the same age group seems to be related to asthma control. In many cases, the family members who actively participated in the care of the child reported improvement with the treatment and, they highlighted the possibilities of being a child in the conviviality with the disease:

*I leave him freer. Now it's me a bit more like that. Because when I arrived at the hospital, I protected him too much. I used to try to isolate him more. (Mf4)*

*His mother is the one who always reminds me of what he can and cannot do. But he hasn't felt sick, he plays, run with my boys, and he is not feeling sick. (Ff5)*

### **The conviviality with the restrictions imposed by the disease and treatment**

Usually, children with asthma have restrictions in activities typical to the age, as to run, to swim, and to ride a bicycle. The justification of caregivers to these limitations are related to the worsening of the symptoms, especially coughing and dyspnoea. Some speeches express this attitude:

*I traveled these days, but she didn't go, my sister didn't let her, we are afraid of her feeling sick, coughing, having shortness of breath. (Af3)*

*We play everything; he gets tired more easily, then I feel scared of him feeling ill, and I don't keep running, riding the bicycle. Urgh, if he feels sick, causes shortness of breath. (Sf5)*

*I stay with an eye on him too; I play with him on the weekends. In the way that is possible, not running too much, not playing in the dust. (Sf1)*

The caregivers also reported the difficulty of children in adhering to some guidance from health professionals, especially the ones aimed at controlling allergens and environmental irritants, triggering factors to asthmatic crises. They cited the contact with dust, stuffed animals, and cloth couches.

*Few things I removed a lot from the house, it improved a lot, but he likes to play in the backyard, in the dirt. He plays with kites, with the ball, there in the dust. How can we not allowing him also, right? (Mf6)*

*L. liked to play with old dolls, this I have to take away. Still, there is the stuffed animal, just one, but there is. You can see there in the room. This one she didn't allow to give it to no one. (Mf2)*

*Her mother always tells her to not stay too much on the couch. But she likes there. The couch is old. (Ff3)*

Interviewers gave special focus to the limitation in contact with pets with hair or feathers. Also, there were complaints from the children who referred to not follow orientations with rigor, as in the following example:

*I like to play with my dog, but my mom says that I can't, there at the hospital too, but I play. (Cf2)*

*My mom is funny, she doesn't want me to play with P., he likes to run after me, I let him. My aunt also keeps saying: leave this dog alone! What is the matter with us running? I'm not touching him, right? (Cf3)*

The children frequently recorded the restrictions related to playing and practice of physical activities in the school environment. Although these events are not prohibited by health professionals, in some cases, the symptoms can be exacerbated by physical effort. The children reported their dissatisfactions in their testimonials:

*What I think is the worst is when I cannot play with my friends. When I get tired, then I really have to stop. I fear to get worse and stop breathing. (Cf3)*

*I almost don't feel sick at school, only when I run too much, play ball with the girls, play basketball. (Cf2)*

*There are times that I want to play with the boys, but if I'm tired, I can't handle playing ball, then I stop all the time. (Cf4)*

## DISCUSSION

Besides the physical restrictions imposed with the intention to prevent asthmatic crises, the descriptions made in this study revealed concerns and anguish in dealing with the symptoms. Inclusively highlighting the fear of dying by the family members, as well as, by the children themselves.

Few children affirmed to fear death during asthmatic crises when they can feel intense respiratory distress. Despite the human factuality and the existential condition of being-to-death, inherent to the human existence<sup>(14)</sup>, the death possibility of a child always tends to be denied. In this study, it appeared in a veiled way in the testimonials of family members and, only in few speeches of the children, we can observe the fear of dying explicitly.

Besides their fears, children spoke about their frustrations and embarrassment situations in the conviviality with their peers. In many moments, they cited discomfort in using the medication at school,

which can be needed, especially in symptoms exacerbations.

Timidity seems to be related to the type of medication presentation that, in many cases, are pressurized metered dose inhalers, which required the use of a spacer attached for better efficacy and reduction of side effects<sup>(2,18)</sup>. The use of these inhalers, also known as sprays or little pumps (“*bombinhas*”), appears as denouncing the disease situation. There is a strong relationship between this type of medication and asthma.

When feeling embarrassed of using the medication, the treatment can be impaired and affect the disease control. Education actions aimed at the child should be conducted so that the adherence to the therapeutic plan is achieved, as the ineffective control of asthma is directly related to the low use of the maintenance medication and higher need to use relief medications<sup>(19-20)</sup>.

In our study, children also highlighted the feeling of exclusion and frustration as they were not integrated into games and practice of physical activities developed in the school environment. The conviviality with the disease can influence the school routine and interfere with learning and school frequency. Besides, children also cope with conflicts with their mates and restrictions during games or physical activities conducted in this environment<sup>(21)</sup>.

Comprehending that the school represents an essential place in the world-life of the child, it should be the target of actions mediated by health professionals working on attention to childhood asthma. A systematic review showed that the direct access of nursing in schools and other health services, as well as, the specific disease education, resulted in improvement of the health state and of the academic performance of students with chronic diseases<sup>(22)</sup>.

In what refers to perceptions of family members about the child with asthma, they noted the differences in comparison to other children, highlighting the disease particularities and the needed restrictions for effective management. The family and children recognize few protection attitudes as excessive.

These attitudes seem to be related to the constant state of alert of family members for the health condition of the child with a chronic disease, especially in cases when severe exacerbations can occur, like asthma. In a study with parents of children with severe allergies, they referred to live on guard constantly, and they highlighted the different types of limitations experienced by the family<sup>(12)</sup>.

The conviviality with the chronic disease, especially those with severe exacerbations, as asthma, can lead the child to live with different ways of limitations, besides making the family members always feel alert for any change in the child’s health state.

Families and health professionals can be attentive to overprotection attitudes, as they can configure as a way of caring denominated substitutive solicitude, according to the Heideggerian care referential<sup>(9)</sup>, where the child stops having autonomy and responsibility of her health state. It is interesting for care to happen as anticipatory solicitude, where is allowing the other to assume their paths<sup>(9)</sup> and one tries to care in an attentive mode, concerning with the other and aiming for its freedom<sup>(23)</sup>.



Despite being a complicated process, children who experience chronic diseases are capable of adapting themselves to a sickness situation and to change their coping strategies, at the measure that they overcome adversities. Also, they can recognize restrictions imposed in their lives and feel responsible for their treatment<sup>(10)</sup>.

## CONCLUSION

The unveilings of this study collaborate to a better comprehension of how the child perceives herself in the conviviality with the disease and, how family members perceive the child. We highlighted the difficulty of the child in dealing with some fears, frustrations and embarrassing situations related to the disease and the treatment.

The school emerged as an essential space of conviviality for the child, where the child meets colleagues and conduct ordinary activities of the childhood routine. However, it also appeared to be an environment where the child feels discriminated and excluded. Thus, we recommend actions involving the partnership between the formal education and health services to be conducted, intended to better inform teachers and students about asthma and their repercussions in the child's life. Thus, the school can become a supportive environment for the child to develop effective ways to cope with the chronic sickness situation.

The family members of the child with asthma perceived particularities as Being-child and highlighted the restrictions imposed by the disease. They recognized that some protection attitudes are excessive and they are part of their care actions. These overprotective attitudes are prevalent among caregivers of children with some chronic disease, and they give a clear meaning of collaboration with the child. However, despite the positive intention, this behavior of family members can be harming to the child's development.

In their care actions, the family can collaborate, so the child recognizes restrictions, fears, and frustrations and, at the same time, develops effective coping mechanisms. Thus, besides living with a chronic disease, the child can transcend this condition and rescue her Being-child, and assume authentically her existential possibilities.

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