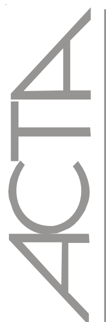

Daily life of children with acute asthma in school settings*

O mundo da criança portadora de asma grave na escola

El mundo del niño portador de asma grave en la escuela

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ABSTRACT

Objectives: To understand the meaning of asthma and its implications in daily life of children with acute asthma and their family in school settings. **Methods:** A qualitative case study with 3 children from a pediatric outpatient clinic of a hospital in the municipal district of São Paulo. Data were collected through participant observation, interviews, and therapeutic play. **Results:** Treatment demands and frequency of asthma crisis affected the daily life of the children in school settings: missing classes, decreased opportunity to learn, restrictions on type of plays, and conflicting interactions with the other children. **Final considerations:** There is need for health care providers and teachers to work together in order to guarantee those children formal education and quality social interactions.
Keywords: Hospitals,teaching; Asthma; Pediatric nursing; Play and playthings

RESUMO

Objetivo: Compreender o significado que a criança asmática grave e sua família atribuem à doença e suas implicações na escola. **Métodos:** Estudo de caso qualitativo, desenvolvido no ambulatório de pediatria de um hospital do Município de São Paulo. Foram estudadas três crianças e seus familiares, utilizando observação participante, entrevista e brinquedo terapêutico dramático. **Resultados:** As demandas do tratamento e as freqüentes crises de asma influenciaram no cotidiano da criança na escola como: falta às aulas; deixar de aprender; restrinção nas brincadeiras e relacionamento conflituoso com colegas. **Considerações finais:** Tendo em vista as dificuldades encontradas pelas crianças em freqüentar a escola e conviver com os colegas, recomenda-se um trabalho conjunto entre os profissionais de saúde e da educação, assegurando a manutenção da educação formal e do convívio social salutar.
Descritores: Hospitais escola; Asma; Enfermagem pediátrica; Jogos e brinquedos

RESUMEN

Objetivo: Comprender el significado que el niño asmático grave y su familia atribuyen a la enfermedad y sus implicancias en la escuela. **Métodos:** Se trata de un estudio de caso cualitativo, desarrollado en el consultorio externo de pediatría de un hospital del Municipio de Sao Paulo. Fueron estudiados tres niños y sus familiares, utilizando la observación participante, entrevista y juego terapéutico dramático. **Resultados:** Las demandas del tratamiento y las frecuentes crisis de asma influenciaron en el cotidiano del niño en la escuela como: falta a las clases; dejar de aprender; restricción en los juegos y relación conflictiva con sus colegas. **Consideraciones finales:** Teniendo en vista las dificultades encontradas por los niños para frecuentar a la escuela y convivir con sus colegas, se recomineda un trabajo conjunto entre los profesionales de salud y de educación, asegurando la manutención de la educación formal y de la convivencia social saludable.
Descritores: Hospitales escuela; Asma; Enfermeria pediátrica; Juego e implementos de juego

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INTRODUCTION

The asthma phenomenon involves not only the biological aspect, but also the interpersonal relationships, in their psychological and social aspects, becoming a difficult experience to the people involved, permeated by suffering, pain, and death threat. The chronic disease experience, such as asthma, involves the entire world around a child, first because it impacts upon their daily routine, and second, because of the fantasies it evokes. Therefore, working with asthma means working with this world, in order to guarantee both the treatment continuity and the child's, and family's quality of life, according to the dynamic conception principles of understanding the disease[1], facing it as part of life.

Within this context, the care provided to an asthmatic child, either in the ambulatory or hospital environment, is more than a set of actions to perform procedures. Because the care is a human condition, it should constitute a moral imperative, for the ethical attitude when providing care is understood as a way of living, where human beings harmonize their well-being feelings based on the other people's well-being, including society, the environment, and nature[2].

Studies show that the disease and hospitalization represent a threatening experience for the child, generating stress which may cause the child to be emotionally traumatized in a higher level than the physical disease. They also emphasize the fact that, when hospitalized, the child is twice as sick: first, because of the physical disease, second, due to the hospitalization itself, which, if not appropriately treated, will leave marks to the child's mental health[3-5]. Additionally, the child's identity and role are, many times, annulled in an admission situation, when they see a reality which is different from their daily lives, suffocated by the hospital routines and practices[6].

Researches have evidenced the low school frequency of children with chronic diseases[7-9]; their desire of going back to school when they are inpatients[3]; the difficulties they have to follow the regular course due to the treatment[7,9], and the conflicts that mark their school life, especially concerning the relationship with classmates[8-9].

With the implementation of the Política Nacional de Humanização (National Humanization Policy)[10] that involves public authorities and civil society entities, the human and subjective dimensions were considered, consolidating care with dignity, solidarity, and warmth to hospitalized people, not only as rights, but as essential steps to the citizenship conquest.

The Estatuto da Criança e do Adolescente (Children and Adolescent's Statute), guarantees to all children and adolescents the right to education[11] through article 4th, and families, the society and the Public Authorities are responsible for its effectiveness. Thus, the family participation becomes essential to the educational attendance development within the hospital environment, acting as mediators between the hospital and the regular school, where the child and/or adolescent is enrolled[12-13]. In order to do so, the healthcare and educational teams should work together to ensure the child's school frequency.

One of the questions that brought up the issue of a child's insertion in the school world and the asthma impact on him/her was: What are the impacts the asthma causes to the child and family's social relationships, before and after the disease was diagnosed?

The issue was to search for the relationship between the disease and the world where the child lives.

Based on such assumptions, the study aimed: understanding the meaning the asthmatic child and his/her family attribute to the disease and the school implications.

METHODS

This research is a qualitative study: such approach works with the meanings, motives, beliefs, values, and attitudes universe, which corresponds to a more deep aspect of relationships[14-15]. The theoretical reference adopted was the disease dynamic conception assumptions, according to which, the disease should not be seen as an organic unbalance or disharmony that threats the desired human values, but as nature's efforts to make man obtain a new balance, as a generalized reaction aiming for the cure[1]. The method utilized was the Case Study, that aims for a broad understanding of an organization or community, emphasizing the interpretation in context, and portraying reality in all its manifestations[14,16-17].

Before being initiated, the research was authorized by the institution where the data collection took place, and approved by the Comitê de Ética em Pesquisa da Universidade Federal de São Paulo (Ethics Committee of Universidade Federal de São Paulo), under n. 680/2000. Each participant signed the Informed Consent Term.

The study was developed in the Allergy, Immunology, and Rheumatology Pediatric Ambulatory of a school hospital in São Paulo. The subjects were three children, a nine-year-old girl, and two boys, one with nine and the other with ten years of age, and their family members. Each child and their surrounding environment were considered a case, that is, their families, and their relationships with the service and the healthcare professionals, when being treated in the ambulatory, and were named: Gabriela Case, Marco Antônio Case, and Milton Case, fictitious names for each child.

Data were collected between the years 2000 and 2002 through: consultations to the children‘s records aiming to extract data regarding identification, anamnesis, diagnosis, treatment and disease evolutio; participant observation, in order to follow up on the *in loco* ambulatory care experiences, registered in a field journal; a semi-structured interview, utilizing a script, aiming to understand the child‘s asthma history and its impact upon his/her social and family life; a non-structured interview performed during observation, through informal conversations with the subjects, aiming to reach deeper aspects of the asthmatic children‘s and their family‘s daily lives, and keeping the focus on the study object and the Dramatic Therapeutic Play (DTP), as a non-structure interview model, for it allows the emotional distress and the children‘s free thoughts and feelings expression, through which it was possible to observe their interaction with their families and the social environment, according to the technique and material recommended by the literature[18-19].

Performing the two first interview modalities, circular questions were utilized to investigate the relationships among individuals, facts, ideas, or beliefs, and reveal the family understanding towards the situation experienced[20], aiming to favor the expression, re-direct the focus and facilitate revelations to come up spontaneously.

With regard to the DTP interviews, four sessions were performed for Gabriela and Marco Antônio’s cases and three for Milton’s case, either together with a family member or with the child alone, according to the technique recommended by the literature[18-19]. Sessions were filmed, photographed, and integrally registered in the field journal in order to be analyzed.

Each case analysis was separately accomplished and allowed the main axes and relationships that comprise the asthmatic child’s social world to be identified: the relationships with the family; the relationships established in their healthcare providing institutions; the school relationships and their expectations and dreams concerning the treatment, the disease cure, and their future accomplishments. In this paper, the asthmatic children’s school relationships related results will be presented, configuring essential aspects to the children’s sociability and citizenship.

RESULTS

The school relationships in the life of a child, and the absences to class were more frequent in the children’s spontaneous conversations and from the DTP dramatizations than in the parents’ speech, besides being part of the thematic related to dreams and hopes expectations.

Milton Case

Milton, in the beginning of the research, was 10 years old, attending the fourth year of elementary school; his diagnosis was: serious asthma, chronic rhinitis, and atopic dermatitis. The child’s mother stated that his asthma came from birth, and his first hospital admission occurred when he was only two months, due to a chest sizzle, a body allergy with little response to medication. When he turned one year and ten months, the boy was helped at an emergency room with a strong bronchospasm crisis, after which he’s been hospitalized several times. In the previous year, he had had countless asthma crises*, having gone through 18 ambulatory appointments along the year. Up until November 2002, when the data collection finished, he had gone through only 8 appointments.

The DTP sessions allowed Milton to demonstrate how much the disease affected him, once, in the first session, when he was proposed to develop a family story, in which one of the characters had asthma, he *immediately refused, saying no and nodding his head*, telling a story about a family scene where family members lived in harmony, in a place surrounded by trees and domestic animals.

The relationship between the asthmatic child and school is marked by conflicts, especially due to the fact that the many crises and treatment demands determine that he/she misses classes and is not always able to perform the physical activities proposed by the school, such as occurred to Milton, who simulated through the DTP, *classroom scenes*.

Missing classes represents something bad to him, for he is not learning. He mentions school as a “cool” place, because he can play and learn. Confirming this declaration, he strongly protests against delays at his medical appointment, while waiting for it, or against the fact his appointment is booked for the time he was supposed to be at school, saying: *She is taking too long! I don’t want to miss my class! I don’t want to!*

When the researcher suggested his appointment returns were booked in the morning, once his classes were in the afternoon, he begged his mom: *Book it in the morning, in the morning, in the morning!*

Such apprehension was due to the fact he was anxious about the school year beginning, for he was going to change schools and reunite with old colleagues from whom he had been separated for having failed and stayed in the same grade one more year.

As to the possibility of a crisis related to Milton’s sport activities return, there is always a question mark, his mom says: *At this school, he will have physical education classes three times a week. At home, he just stays in and plays the*

* Concerns to any asthma characteristic acute symptom that needs medicines and therapeutic intervention, either at the patient’s house or at the healthcare service center.

videogame. I wonder if he can practice sports, though. I wonder if his crisis won't be worse if he does, or if they'll be more frequent, because he constantly complains about a shortage of breath. [...] he is also afraid of having a shortage of breath, followed by a crisis.

Due to the family conflicts, the stress derived from the asthmatic crises, and the difficulties that go along with the treatment, it is possible to verify that Milton and his family have dreams and hopes of a better future, without having to live with the disease.

The mother *dreams* about her son being somebody, meaning, *someone who studied, has a good job, a good wage, is smart, and doesn't do anything wrong*, besides supporting his will of being a lawyer some day.

Marco Antônio case

Nine-year-old Marco Antônio, who is in the third grade of elementary school, has a family life marked by chronic disease experiences, asthma above all, among all family members. Therefore, Marco Antônio's disease, which started with the bronchospasm crises when he was one year old, represents another sick member to the family, for they do not know what it is like to live without a disease situation. Along the four first years he needed the service, the boy needed up to 25 yearly appointments, having had 21 infections, among which, three sinusitis, nine amygdalites and flews, ten pneumonias and bronchopneumonias.

The remarkable emotional weariness is a product of the general life context lived by this family along their family, and social trajectory, besides having to face the disease and medical treatment. Conflicts also mark Marco Antônio's relationship with the school, interfering not only on his frequency and games, but, especially, on his relationship with is classmates, which refused to help him recover the missed classes contents. This evidences how much the asthma crisis occurrence interferes on his school life.

Before I had it all the time, and when I had shortages of breathe because I was tired, my dad would tell me to not go to school. Then I cry because I want to go. I don't like being absent. When I was on the second grade, I only used to go to school on Wednesdays, when they had physical education classes. My classmates used to say I showed up just to play. I answered saying that I missed classes because I had to go to the doctor when I felt bad. [...] I used to ask my classmates to lend me their notebooks, but they wouldn't. [...] And even now, no one lends me their notebooks. They say: "Do it yourself", or "I don't know, do it alone".

Absences also created conflicts with his father, due to the fact he was late to take the boy's medical certificate to school so that his absences could be covered.

[...] my dad kept the medical certificates, for time and time, all of them [...] he said he was going to take them, but he didn't [...] once I got 33 absences!

Many times, Marco Antônio was discriminated by the other school children when playing games, especially during a specific time when he needed several hospitalizations, and they used to say he was "crazy".

I couldn't wait to leave the hospital and go to school. But by the time I got there, my classmates started saying I was crazy. They believe I had been admitted to the hospital because I was crazy. I would say: "No, It happened because I have shortage of breath". But they would say I was hospitalized because I was crazy.

Given the stigma of a "sick" child that is attributed to him by his classmates, Marco Antônio created his own way in this social environment: because he is not able to rely on his classmates when needing help, when they ask him for help, he denies that to them.

Now I deceive them, I say: Well, I don't know, I'm stupid, I forgot. I forgot to do these things. And then I say: I'm not going to help you, because you don't help me. Then, they don't help me. I said, if no one helps me, I won't help anyone either.

Without having anyone to help him study the subjects, he does it by himself at home. He thinks that, if he can guarantee a good school performance only with his own effort and no collaboration from his classmates, he will be able to prove his accomplishment capacity. The need of proving his capacity to the others imposes a constant self-demand, and considering the psycho-emotional aspect is an important element to trigger asthma crises, such factor favors the constant asthma crises this child has.

On the other hand, he used to receive the school teachers' support, for they knew about the asthma situation through the boy's father and complimented his performance and behavior, because he used to *do his homework, be a good student, behave himself, differently from the other students, and do well on the exams.*

The teacher used to even modify the type of game they played so that he could participate without having a crisis interrupting the game.

Sometimes, when my chest started squeaking, due to the cold, shortage of breathe, and cough, my dad would tell me to stay at home and I have to miss my class, but when I go, the teacher organizes a different game. The other day it was dodgeball [...].

As a way to rebel against his classmates attitudes, in no DTP session were his classmates present through the dramatizations, reinforcing the weak social relationships and friendship the boy mentioned when the interview

took place. In the sessions scenario, there was always a girl doll (which in real life was his sister) carrying the school bag, coming to visit the boy doll who was in the hospital, lying in bed, receiving oxygen through a nose catheter and a physiological saline infusion through a peripheral venous puncture.

After two years, in the end of the data collection, Marco Antônio presents now a better health, being able to practice several sport modalities, with no physical limitations, which has been changing his relationship with classmates and facilitating his acceptance in the group.

I played volleyball for a while, then basketball, now I play soccer twice a week.[...] I'm doing good at school, have friends among my classmates, including the rowdy ones, and play with everybody.

Marco Antônio's effort and good performance at school made his dad believe in a different future for his kids, a future related to the possibility of studying and having a better life than his.

He really likes studying. With Antônio and Marco (brother), I have no school troubles. I believe in them and hope they grow up to be something good in life. I have hope. Because my hope comes from Marco Aurélio and Antônio, who like to study. May be they will be able to make the dream I couldn't come true!

Gabriela Case

Gabriela, nine years old, was attending the third grade at elementary school, when she was diagnosed with serious asthma and chronic rhinitis. She presented the first bronchospasm crisis when she was 1 year and six months old, and has a history of many occurrences at the emergency room, admissions, and ambulatory appointments. Besides Gabriela, her mother's mother, her father's sister, and her sister also have asthma.

Gabriela describes the people she likes and does not like according to the way they relate to her mom and herself. When she notices someone is affectively close to her mother, she tries to push that person away.

Having serious asthma, with frequent crisis, and countless restrictions, seems not to have interfered in Gabriela's school and sports' activities.

Her mother says Gabriela is facing the disease well, and has *no problems at school, the disease does not interfere in school, she does not have many absences, and is a straight A student.* Gabriela also tells, happily, how she got "A" for all subjects.

In a DTP, Gabriela and her mother cheerfully represented a school scenario where one of the pre-school teachers *was irritated because only one student came back from vacation, and two on the second week. In the third week, 20 students turned up. The teacher got very happy then, and took the kids to a farm. They were all very happy.*

Concerning the relationship with colleagues, it is possible to verify it has some conflicts. Gabriela says she prefer to keep her distance from them, because *they are annoying*, thus, she goes to a more distant school.

No, it is annoying, I don't want to. The girls are too annoying. [...] They are all stuck up. They keep talking all the time…bla bla bla. If I study at the school close to my house, there will be classmates who will want to come to my place [...] I like to stay alone.

However, the girl shows preference to the Olympic gymnastics school where she is enrolled now and expresses, in several moments, that she likes it a lot and aims to, one day, get a golden medal for it. Such conquest is, for Gabriela, a very important future accomplishment, and the effort she can make in order to reach it is unlimited.

Yes. I like it a loooot! Because she (her mom) told me that if I don't ever get a medal, she would take me out of the gymnastics class.

Just as in the two other cases, the dreams of getting better and having a better life are present in Gabriela's and her family's lives.

Regarding her daughter's future, Mirtes states that she wishes Gabriela *is a good person and gets a job close to home.*

I fight for her, for her future, so that it is not like mine, rushed like this. So many concerns. That's why I say: You two study [...] Because it is not worth it to kill yourself on a sewing machine.

Her mom's expectation is also shared by Gabriela, who says enthusiastically: *When I grow up, I'll be a doctor, a pediatrician! It was very nice building this story today!*

Developing the DTP activity was very pleasant for Gabriela.

It was very cool! The best activity I did in my whole life. I'd never done it before, I got, uhm, I don't know, happy!

DISCUSSION

With regard to the serious asthmatic child's world in school, it was possible to verify in the three cases studied that this is an important institution both for the child and the family.

Although sometimes they have to be absent due to the crises and appointments, which displeases the children very much, they have a satisfactory performance. Only in Milton's case there is a history of failure, on a year the

child presented several crises.

The relationship with school and absences to classes came up more on the children's spontaneous speeches and DTP dramatizations, than on their parents', who, most likely, prioritize the crisis prevention and the child's healthcare. Therefore, any symptom that indicates a possible crisis triggering or appointments at school time are motives to miss classes.

Milton evidences the terror of being absent to class due to medical appointments, which frequently coincide with regular class time and mean to the boy to be legging behind his classmates.

One of the core school age characteristics is the industrious or productive sense, or the accomplishment stage, mainly acquired through the formal education[5,21-22], reason why the data in this research demonstrate how much children value school and make an effort not to be absent. The child obtains great satisfaction being independent, manipulating his/her own environment, and develops the necessary abilities in order to become a useful and contributing member to his/her social community.

However, concerning the relationship with colleagues and classmates, it is possible to observe conflicts and weak friendship bonds. Especially in Marco Antônio's case, the child's discrimination by his classmates is evident, and it is due to his disease, which is stigmatized as "craziness". Knowing that his presence is rejected by his classmates, he demands from himself a good school performance that allows him to prove his capacity and affirm himself.

Society establishes means through which people are categorized, usually through attributes considered common and natural, which become the reference. When a stranger is introduced to a group, the aspects revealed in the first impact allow situating the category to which the subject belong, granting him/her attributes and his/her social identity. In case he/she does not fit in the established models, the stranger is excluded, and is no longer a "common" creature, but a "spoiled" and "diminished" person, that is, a "defective" person, with a weakness or disadvantage. Therefore, they carry a stigma and live with a constant conflict between the virtual social identity and the real social identity[23]. May be this is why children keep away from their classmates, who deny helping them even with school activities.

The school period also brings an important contribution to the cultural practices learning and to the self-esteem competence development, besides being marked by the intellectual growth, work investment, and the first commitment to a social group[5,22].

The motivation and encouraging for such attitudes are mainly derived from the approval and recognition granted by the group one lives with, reason why it is important to facilitate the same age classmates' and friends' interaction maintenance. The lack of these opportunities due to any circumstance, such as the disease and prolonged hospitalization, or when the appropriate pedagogical conditions are not provided, may result in a feeling of inferiority, which may continue in adult life[5,22], affecting self-esteem, and reflecting on a person's professional performance and daily activities.

When Gabriela, rejects the regular school classmates, she values de Olympic gymnastics school, her favorite sport modality, where she aims to reach excellent performance, aiming to gain a medal one day. As Olympic gymnastics represent to the girl the possibility of cure, could not gaining a medal accurately mean getting rid of asthma?

Manifestations such as being distant from her colleagues or isolating herself spontaneously may indicate a possible lack of self-confidence or anxiety felt by the child, generated not only by the uncertainties generated by the disease, but also by the super-protection received from the family, which, trying to protect her from a crisis, also takes away her freedom to grow up and develop normally[23]. Does it not determine her difficulty living with the other children who, obviously, will not provide her with such benevolence?

There are cases reported in the literature where asthmatic children who perceive their parents' weakness trying to satisfy all their wills to make up for their suffering, start using the disease in order to get what they want[24].

Therefore, it is possible to verify that the relationship problems and the risk of thinking they are inferior to their peers, besides not being able to develop their school contents, due to absences the asthmatic crises bring, or the treatment need, is a ghost for the serious asthmatic child.

In this context, it is important that the healthcare professional carefully think about the asthmatic child care in a holistic way, going beyond the biological aspect, and considering the child's development demands. Due to the difficulties faced by children when attending school and living with their colleagues and classmates, as demonstrated by this study, a team work between healthcare and education professionals is recommended, aiming to ensure the formal education maintenance and a healthy social environment.

The work interface between healthcare and education instruments is a target to be recognized by the Ministério da Saúde (Health Department), since 1970, when it defines the hospital as an educational center, considering that: *it is necessary to make it clear that both education is not a school exclusive element and health is not a hospital exclusive element*[25].

FINAL CONSIDERATIONS

According to this research's methodological assumptions, a conclusive-character closure was not intended, but raising relevant questions to better

understand the child serious asthma and the child's school world, contributing with elements to understand how much the occurrences in this universe interfere in the child's health state and think about the healthcare and education services provided, contributing with elements to understand how much the occurrences interfere in their healthcare and educational services to this population.

The data analysis points out to the need of having the serious asthma child healthcare valued in the formal education, which is an essential process to their development and growth as a person. A

It was also verified that the opportunity to speak provided by the method adopted in this research was intensely explored by parents. On the other hand, the therapeutic play enabled the desire expressions, translated into non consolidated "dream", which is constantly attributed to the disease problems.

We believe that the healthcare professional posture (and a holistic perspective), embracing the disease, the patient and his/her family in the socio-cultural they live in, may positively impact on facing the disease as part of life dynamic process and their development.

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