https://doi.org/10.23925/2176-2724.2024v36i2e66826

Childhood chronic illness: from body marks to symbolic marks

Adoecimento crônico Infantil: das marcas do corpo às marcas simbólicas

Enfermedad crónica Infantil: de las marcas corporales a las marcas simbólicas

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Abstract

Introduction: Chronic illness and hospitalization bring experiences to children that are threatening from both a physical and psychological point of view. Falling ill is a complex, disruptive and traumatic experience, which causes emotional overload for children and their families. **Objective**: to understand the scenario of childhood illness and hospitalization, linking body marks to symbolic marks.**Method:**This is qualitative, exploratory theoretical-clinical research in the field of psychoanalysis. **Result:** The process of chronic illness places the subject in a subjective drama with the need to mourn and deal with the narcissistic wound and even think about death in the face . The hospital gains symbolic contours beyond the space for treating the disease and its symptoms: a place where the disease insists on showing itself and remaining. **Conclusion:** Illness involves components beyond the biological, cognitive and emotional dimensions, being crossed by subjective and symbolic issues that guide the way the subject will deal with their ill body, therefore implying reflections on the child as the protagonist of their process and listening of the subject in its symbolic dimension.

Keywords: Illness; Hospitalization; Disease; Psychoanalysis;Children's health

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Authors' contributions:
SAA: study conception; methodology; data collection; study outline and critical review;
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Received: 05/24/2024
Accepted: 07/08/2024

Resumo

Introdução: O adoecimento crônico e a hospitalização trazem para o universo infantil vivências que são ameaçadoras tanto do ponto de vista físico quanto psíquico. Adoecer é uma experiência complexa, disruptiva e traumática, que acarreta sobrecarga emocional para as crianças e seus familiares. **Objetivo:** compreender o cenário do adoecimento infantil e a hospitalização, articulando as marcas do corpo às marcas simbólicas. **Método:** Trata-se de uma pesquisa qualitativa, exploratória de ordem teórico-clínica no campo da psicanálise. **Resultado:** O processo de adoecimento crônico coloca o sujeito em um drama subjetivo com necessidade de elaborar lutos e lidar com a ferida narcísica e, até mesmo pensar a morte de frente. O hospital ganha contornos simbólicos para além do espaço de tratamento da doença e seus sintomas: lugar em que a doença insiste em se dar a ver e permanecer. **Conclusão:** O adoecimento envolve componentes para além das dimensões biológica, cognitiva e emocional, sendo atravessado por questões subjetivas e simbólicas que norteiam a forma como o sujeito lidará com seu corpo adoecido, portanto implica reflexões acerca da criança como protagonista de seu processo e a escuta do sujeito em sua dimensão simbólica.

Palavras-chave: Enfermidade; Hospitalização; Doença; Psicanálise; Saúde infantil.

Resumen

Introducción: Las enfermedades crónicas y la hospitalización traen a los niños experiencias amenazantes tanto desde el punto de vista físico como psicológico. Enfermar es una experiencia compleja, perturbadora y traumática, que provoca una sobrecarga emocional en los niños y sus familias. **Objetivo:** comprender el escenario de la enfermedad y la hospitalización infantil, vinculando las marcas corporales con las marcas simbólicas**. Método:** Se trata de una investigación teórico-clínica exploratoria, cualitativa, en el campo del psicoanálisis. **Resultado:** El proceso de enfermedad crónica sitúa al sujeto en un drama subjetivo con la necesidad de llorar y lidiar con la herida narcisista e incluso pensar en la muerte en el rostro. El hospital gana contornos simbólicos más allá del espacio de tratamiento de la enfermedad y sus síntomas: un lugar donde la enfermedad insiste en mostrarse y permanecer. **Conclusión:** La enfermedad involucra componentes más allá de las dimensiones biológica, cognitiva y emocional, siendo atravesada por cuestiones subjetivas y simbólicas que orientan la forma en que el sujeto afrontará su cuerpo enfermo, implicando por tanto reflexiones sobre el niño como protagonista de su proceso y escucha del sujeto en su dimensión simbólica.

Palabras clave: Enfermedad; Hospitalización; Enfermedad; Psicoanálisis; salud infantil.

Introduction

With advances in technology and medicine, diseases once destined to be fatal can now be treated, enabling individuals to face a different reality: that of being a chronic patient. Chronic illness and hospitalization bring to the child's universe experiences that are threatening both physically and psychologically.

When working in hospital institutions providing clinical care to hospitalized children and their families, one of the authors clearly noticed the difference between the demands of children admitted with acute illness and those with chronic illness. In the first case, although hospitalization has intense repercussions on family dynamics and emotional effects on the child, the process has a beginning, middle, and end; in the second case, however, there is no end because the disease persists.

Childhood is filled with numerous transitions – physical, cognitive, emotional development, and psychological constitution – and some children must also deal with stressful and demanding factors, such as chronic illnesses. Castro & Piccinini[1] report that chronic diseases are characterized by a gradual onset, prolonged course, and uncertain prognosis, requiring long-term treatments, and having a significant impact on functional capacity.

In view of the daily complexity that these children live with - symptoms, physical discomforts, hospitalizations, and consultations at reference outpatient clinics – studies indicate impacts on quality of life[2,3].

Without the prospect of a cure, children with chronic illnesses require complex and long-term care, with follow-up by a multidisciplinary team, including all fields of knowledge, such as: Medicine, Physiotherapy, Social Services, Nursing, Speech-Language Pathology, and Nutrition, which uniquely build comprehensive care for the child in their social, family, economic, emotional, and cognitive aspects.

In turn, Andrade[4] believes that the persistence of the disease is shown in surgeries, the auxiliary use of devices, bodies marked by edemas, drain scars, tubes, and catheters, and in subjective fragility and helplessness. Psychoanalysis in a hospital context involves intervening with individuals whose bodies are afflicted by a severe illness, resulting in cuts, holes, and pains that remind each person of their own finitude.

According to Gomes & Próchno[5], the sick body reveals helplessness in the face of the disease and the rapid changes demanded in this specific situation; there is a sensation of subjective emptiness. These experiences highlight the importance of reflecting on the individual confronted with human fragility exposed by illness. Caring for human fragility requires all professionals in the multidisciplinary team to have a keen and careful perspective. It should be noted that doctors need to see the body beyond the biological aspect; Physiotherapy should focus on the recovery of movements and respiratory issues involved in the individual's desire; Nursing should understand care as encompassing the body and family aspects; Nutrition should expand the concept of feeding and nourishment; Social Services need to consider what the person wants to say and not just what is being said; and speech-language pathologists who work with the rehabilitation of dysphagia and speech should consider communication beyond what is spoken.

Walking through a Pediatric Inpatient Unit, one can encounter children in bodily suffering, treated as objects of medical interventions by the health team that generally deals with sick organisms. The hospitalized child is the target of medical interventions authorized by their caregivers but does not participate in or assess the necessity of such invasions[6].

Carvalho[6] highlights that the child's subjective dependence – along with their inability to demand or authorize procedures – amid the medical intervention needs of chronic illness, creates difficulties in interpreting signs and symptoms and distinguishing the objectification of the organism. This experience can cause anxiety that produces more traumatic subjective effects than the disease itself.

Andrade[4] emphasizes that subjection affects the child, making it important for the child to emerge amid so many institutional crossings, and for the analyst to be someone with whom the child can speak.

The hospital becomes a space for disease care. But what about the children? Who takes care of them? Who takes care of childhood? Although the patients in pediatric inpatient units are children, there is a tendency not to value their uniqueness and their forms of expression.

Cohen and Melo[7] consider the need to understand the specificities of practices with children in

a hospital environment, in contrast with medical specializations. This perspective highlights the need to embrace differences, fostering a clinical practice centered on the individual rather than on patients and diseases.

Bulik[8] draws attention to the technicism and specializations focused on biological devices that fail, while neglecting the symbolic dimension of the illness, thus ignoring the individual's history, the particularities of their life, and their desires.

Psychoanalytic practice sustains a theoretical-clinical construction that returns this knowledge to the complaining subject, denying the possibility of universalization and technicism in its practice, aiming at a place that does not intend to dictate rules but rather to invest in the subjectivity of each individual[8].

Freud[9] reports the need to look at the suffering individual and listen to them, not reducing them to a medical approach and classifying them according to a disease, but listening case by case, as individuals are unique. Therefore, healthcare professionals must consider the child as more than a body to be made functional, but as a bearer of a history that precedes the moment of hospitalization[10].

Purpose

To understand the context of childhood illness and hospitalization, tracing a path from the physical marks to the symbolic marks.

Method

This is a qualitative, exploratory study involving participant observation of a theoretical-clinical nature in the field of psychoanalysis, motivated by inquiries arising from listening to children with chronic illnesses in a hospital context.

As a specificity of the method, clinical facts derived from cases attended throughout the researcher's experience were used as minimal fragments to give consistency to the theoretical and practical concepts presented. Clinical facts are a way of investigating human phenomena in psychoanalysis and will be generated from the researcher's work, in their role as a psychoanalyst, related to the research theme, in order to illustrate issues related to psychoanalytic theory.

The clinical facts consist of a post-factum documentary reflection of what was produced by the analytic duo, meaning the production of scientific knowledge occurred based on clinical facts a posteriori and are the result of the researcher's memory notes in their work as a psychoanalyst.

The clinical facts are not an in-depth, extensive case analysis, but minimal fragments of the cases which trigger a problematic situation.

The concept of data analysis does not apply to this study because the notion of psychoanalysis as a science with its own method was used. Therefore, the reading of the clinical facts was carried out according to the psychoanalytic method, based on floating attention from free association and the interpretation of unconscious contents.

Results and discussion

Childhood Illness

According to Quayle[13], illness is a state of exception from which we seek to flee, distance ourselves, and escape, as it brings suffering and damages our fantasy of omnipotence. Moretto[14] corroborates the view of illness as an unconscious dimension of the individual's relationship with their ideals, illusions, and even with immortality.

The word 'illness' is related to the Latin term *morbus*, from which derive 'morbid' and 'morbidity'. Illness originates from *dolentia*, which refers to 'pain', 'affliction', and 'bitterness', effects of *morbus*[13].

Moretto[14] defines illness as an event in the body, not just in the organism, requiring a psychic effort on the part of the patient to accommodate it in their psychic life, transforming it into a unique experience It also highlights a distinction between event and experience: the event is the illness itself, the object of medical intervention; and the experience, of interest to the psychoanalyst, is the subjective dimension of the event. Illness is an event that can transform into a traumatic experience depending on how it is integrated or excluded within the realm of relationships[15].

Hospitalization is an intense and complex experience, which includes invasive procedures, changes in routine, loss of social and educational contacts, and stressful situations. Some emotional reactions from children are present in the face of these experiences: irritability, fear, uncertainties, anger, and anxiety[16].

Thus, the unpredictability of events experienced in the body can trigger intense feelings of anguish. The destabilization of the body/organism often leads to an encounter with a traumatic situation, making it impossible to find words to name what presents itself as unbearable.

Upon entering the pediatric inpatient unit, we hear incessant screams and cries, and, as we approach, we realize that a child is undergoing nursing interventions, screaming that she wants to die, that she doesn't want to be pricked anymore. We encounter a girl with wide-open eyes, trembling, who immediately asks for my hand for support. We notice that the child expresses, through her gaze, a mix of sadness and perplexity – perhaps a mirror of the feelings stirred by such an invasive and powerless situation. Without words to express, we hold hands until we can emotionally recover.

In an attempt to understand the meaning of the child's words, we listen and are surprised by her narrative that she is hospitalized for kidney issues and that two of her siblings had already died from kidney problems. This is in line with Mathelin's ideas that the child carries a history even before their hospitalization process[10].

We observe that the suffering is expressed in a raw state, with manifestations of anger, crying, and silence, as if the subject experiences a short-circuit leading to emotional overload, paralyzing and hindering the flow of significants, which can cause disorganization and suffering.

Moretto[14] reports that illness is a disruptive factor in the life of the patient, which can lead to a series of consequences and feelings such as shame, fear, loneliness, and helplessness.

In the clinical experience of the first author, certain words and expressions are characteristic of the pediatric chronic disease unit: renal insufficiency, sickle cell anemia, diabetes mismanagement, immunocompromised patients, cystic fibrosis, transplant recipients, among others. These are all forms of illness that refer to inadequacies and impairments, almost synonymous. Illness/hospitalization poses challenges related to self-image, confronting the child with feelings of powerlessness and helplessness, which generate anguish and fragility, along with a lack of control and uncertainty[4].

Children in whom biological aspects and illness overlap are aware of their temperature, medication, blood pressure, saturation, and discuss details of their clinical condition. They are "associated" with the signifier of their illness, reproducing the medical and family discourse, and only exceptionally manage to talk about their illness in its symbolic aspects. Moretto[14] points out that submitting oneself to the medical approach and occupying the position of an object of medical investigation causes the subject to identify with these signs, losing their own frame of reference and identifying with the illness itself. Often, this identification becomes a solution, saving the subject from anxiety and psychic work[14].

On another occasion, when we arrived at the pediatric ward, we encountered a patient known to the team, with numerous previous hospitalizations since his diagnosis of Crohn's Disease. During this hospitalization, the team noticed that he was tearful and very irritable, unlike other times he had been in the unit. In the consultation, the teenager stated that he wanted to go home and eat whatever he wanted. His remarks were very intense with a tone of irritability, justified by him stating that people with Crohn's are very irritable.

The psychoanalyst considers that illness is connected to the child's bodily imagination, which will be affected by the approach and narrative about their history. Thus, interventions occur in listening beyond the inscription of the biological body, as proposed also by Mathelin[10], meaning that one moves from diagnosis – marking the body and illness – to the entrance of the subject – symbolic constructions and integration of experiences in the process of illness.

The organ's incapacity, its malfunction or absence become incorporated into subjective aspects. It is perceived that physical vulnerabilities and incapacities are transferred to the mental aspects and often assumed by the child who, instead of being a carrier of chronic illness, becomes a true chronic patient; that is, there is an incorporation. In clinical settings, these patients always present themselves as "incapable" of drawing, or when they do, they alert us to its incompleteness and their inability to please us, fearing to disappoint what they believe to be others' expectations.

Another child, who was admitted for medical treatment of Cystic Fibrosis, has appointments permeated by descriptions of their clinical condition, such as saturation, oxygen levels, and medications; but when asked about issues outside the scope of illness, they have difficulties expressing

themselves and constructing a narrative about their experiences, claiming they don't know how to draw, or that everything they do is not good. One can see a subject subjected and identified with the signs given by their medical condition, concerned with the practical implications of their treatment and describing the affectation of their body, with little implication regarding what they say, showing a detachment from their suffering, which aligns with Albuquerque's ideals[17], who believes that the process of illness and hospitalization provides more than just a change in routine, but a change in self-experience.

Hospitalization as a place where illness persists

Children with chronic illnesses have recurrent and long-term hospitalizations; patients are familiar with the hospital environment and the multidisciplinary team, and it's not uncommon to hear comments from the team and other patients: *"Have you seen who's here? Did you see who came back?"* referring to re-admitted patients. Hospitalizations contribute to overall clinical improvement and symptom management, but rarely to cure. In the experience of the first author, each return to the hospital demands symbolic re-hospitalizations of their inadequacies and deficiencies from the children, aspects that are painful and often disintegrating, generating a lot of anguish[13,14].

The hospital environment extends beyond its geographic space, becoming a locus where illness insists on remaining, with symbolism of deficiencies, inadequacies, deformities, lack of control, which give rise to absences and situate the subject in a place of powerlessness. Quayle[13] defines the hospital as a sign of threat to narcissism and omnipotence, a symbolic place marked by losses and mourning.

Approaching psychoanalysis in the hospital goes beyond situating this practice in a physical location but implies analyzing the signifiers that place the psychoanalyst's action in this space.

Carrijo[18] suggests that:

> The meaning of the environment is not always the same in terms of literal perception of value and function, as environments present symbolic communication, referring to what is expected of it and self-assessment in relation to it This characteristic of the environment provides people with a sense of "place identity," which in turn helps define the role the subject plays in society.

Psychoanalytic treatments conducted with hospitalized children must consider in their practice that the hospital extends beyond its physical space but needs to analyze the signifiers surrounding this place and belonging to it.

The medical team requests support for a 10-year-old girl diagnosed with cystic fibrosis, who will remain hospitalized for an extended period for stabilization of her condition. During psychoanalytic sessions, she discusses her diagnosis and clinical condition of severe shortness of breath. Her words make it clear that she is aware of the disease's progression due to prolonged hospitalization, that her improvement is not occurring as before, and she fears staying in the hospital forever. In this sense, she lists things she is unable to do because of hospitalization, expressing a desire to go home and see her siblings.

She expresses concern about her clinical state and understands that the hospital is no longer a place for treatment and recovery of health conditions, but rather a place where the disease persists. The hospital has become a space marked by uncertainties about the future, the certainty of perpetuation, and the aspects of illness. The family dynamics has given way to uncertainties, loss of control they thought they had, making room for the emergence of feelings of fear, fantasies, and helplessness. The only possibility of gaining control of the situation and escaping this place is by longing to return to what is familiar: their home and siblings. It is not uncommon for children to request discharge from the hospital, even knowing that their clinical condition still requires care and attention from the medical team.

Losses, mourning, and death

The experience of illness can be linked to situations of concrete and symbolic losses, temporary and definitive, causing suffering, mourning, and struggles[,12,13,]. According to Freud[19]:

Mourning is the normal reaction triggered by the loss of a significant object of love, which can be a loved one, an abstraction that held the place of a loved one, such as country, freedom, someone's ideal, and so forth.

The loss of a healthy condition is felt by the child as an inability to fulfill the narcissistic aspirations of their parents, losing the place of the idealized child by them, and the place of a child by doctors and society.

The feeling of frustration and weakening of their self-esteem inherent in this moment directly affect their relationship with themselves and with the world.

In "Civilization and Its Discontents," Freud[9] identifies three sources of human suffering:

> We are threatened with suffering from three directions: from our own body, which is doomed to decay and dissolution and which cannot even do without pain and anxiety as warning signals; from the external world, which may rage against us with overwhelming and merciless forces of destruction; and finally, from our relations with other human beings.

These aspects described by Freud are present in childhood illness, as children with chronic diseases have their own bodies affected, subjected to medical procedures that may signify an imposing and destructive external world; their relationships with other human beings, both peers and significant others, are also impacted.

Children with chronic illness perceive themselves as different from others, a perception reinforced by society, which fails to embrace their differences and often accentuates them. As part of the world of the chronically ill, they are unable to engage in and attend places typical of childhood, thus being removed from their rightful place as children. During consultations with these children, it is not uncommon to hear reports of losses due to hospitalization and illness, such as missing school, being unable to participate in recreational activities, missing out on celebrating birthdays with friends and family, and experiencing social isolation.

Hospitalized children with chronic illnesses inevitably face physical changes, bodily pain, limitations in daily activities, dietary restrictions, loss of mobility, and learning difficulties[20]. Some authors[13,14] point out that one source of anguish and consequently suffering arises from a body that lacks something, and is incomplete, deficient in its image, functioning, shapes, and deformities.

In the pediatric unit, we encountered an 8-year-old boy hospitalized for a urinary tract infection, who discovers during the hospitalization the absence of one kidney and reduced functioning of the other. He is always restless, a change noted by his mother as stemming from the illness process. During a session, he asks for a sheet of paper to draw, and, before starting, he checks if he has all the materials needed for it. Upon realizing some materials are missing, he expresses disappointment that he won't be able to complete the activity. The mention of lacking materials shifts from his own lacks and incompleteness due to the absence of one kidney, and reduced functioning of the other, which cannot alleviate his physical and psychological suffering. The illness is perceived as a threat to the ego, demanding the individual to undergo a true mourning process. According to Gomes and Próchno[5]: *"The sensation of finitude deprives the patient of the realm of certainties and thrusts them into a deterritorializing condition, which produces division and suffering."*

The process of chronic illness places the individual in a subjective drama requiring the elaboration of mourning and dealing with narcissistic wounds, even confronting thoughts of death directly. When the progression of the disease is acknowledged, intense feelings of fear and helplessness arise, leaving the child with profound emotions of abandonment. In the treatment of her medical condition, the child diagnosed with cystic fibrosis acknowledges that her physical symptoms of shortness of breath are not improving, despite the efforts of the medical team, leading to an awareness of the disease's limits and the presence of death. The child expresses her fears through intensified physical symptoms such as fatigue, shortness of breath, and difficulties sleeping at night. Through listening, she was able to verbalize her fears, anxieties, reports of losses, frustrations, and especially uncertainties about the future, moving from bodily aspects to symbolic ones when she voices her fear of dying. Faced with the complexity of these experiences, we encounter issues that extend beyond the suffering body to include anguish-generating suffering.

Bolsson[21], in turn, reports that, considering Freudian theory, anxiety is a response to the imminence of danger, a reaction that occurs whenever such a state is repeated or as a signal that such a situation may occur, posing a threat to the real ego. Anxiety arises due to the ego's inability to cope with danger through appropriate reactions. Manifestations of anxiety in childhood can therefore constitute intense psychic suffering and require a

sharp and attentive reading, "...allowing the suffering hidden behind the symptom to be heard..."[8].

In a clinic marked by pain, suffering, tears, and a lack of words for everyone involved – children, families, and professionals – hospitalized children trigger an unbearable reality: faced with organ failure that may lead to imminent risk of death, mental processes and defenses collapse, unleashing anxieties in the patient, family, and team[6]. For Gomes and Próchno[5]:

In the hospital, listening is also listening to this lack that deterritorializes, which tends to be articulated through a demand. Demand for pain, for knowledge, demand for love, demand for listening that the subject undergoes in trying to maintain the illusion of completeness; and the body, in its fundamental incompleteness, reveals the painful emergence of the subject of desire (...).

Final considerations

The context of childhood chronic illness and hospitalization is a significant event that evokes daunting and persecutory emotions and fantasies, conflicts, impasses, and emotional conditions to cope with the disease that persists, involving components beyond the biological, cognitive, and emotional dimensions.

Children's narratives point to reflections on the child as the protagonist of their process, as well as to the need to hear the child's voice beyond their childhood condition and a body affected by illness, demanding the inclusion of symbolic dimensions that guide how the individual will deal with their diseased body. This underscores the need for comprehensive care that goes beyond mere prescriptions and guidance, prioritizing the listening to the significations, different meanings in the subject's history.

Psychoanalytic practice in the hospital reveals a child-subject who, in narrating their suffering, experiences the subjectivation of the process of illness, makes sense of this experience, allowing the finding of necessary words for naming and psychic elaboration, finding a place in the discursive plot, and enabling the shift from the position of patient to that of subject of desire.

All professionals involved in childhood, whether in the realm of the body or language, need to consider that the child also needs to be listened to, recognizing that the symbolic expresses itself through words when it can be spoken.

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