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# Revelations expressed by preschool children with chronic diseases in outpatient treatment

Revelações manifestas por crianças pré-escolares portadoras de doenças crônicas em tratamento ambulatorial

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Ambulatory care; Pediatric nursing; Chronic disease; Play and playthings; Qualitative research; Child, preschool

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## Abstract

**Objective:** To identify and describe the revelations expressed by children with chronic diseases in outpatient treatment.

**Methods:** This was a qualitative study guided by the theoretical framework of symbolic interactionism and Bardin's thematic content analysis. Data was collected through therapeutic play sessions with four preschool children who live with chronic illness.

**Results:** Four thematic categories that characterize the daily life of these children were identified: "Interactions," "Fight," "Support" and "Doubt."

**Conclusion:** The children in this study seek to transform their daily interactions with a view toward being recognized as individuals with voices, desires, wills and opinions.

## Resumo

**Objetivo:** Identificar e caracterizar as revelações manifestas por crianças portadoras de doenças crônicas em tratamento ambulatorial.

**Método:** Tratou-se de uma pesquisa qualitativa, norteadas pelos referenciais do Interacionismo Simbólico e da análise de conteúdo temática de Bardin. A coleta dos dados foi desenvolvida por meio de sessões de brinquedo terapêutico com quatro crianças pré-escolares que convivem com a doença crônica.

**Resultados:** Identificaram-se quatro categorias temáticas que marcam o cotidiano destas crianças: "Interações", "Luta", "Apoio" e "Dúvida".

**Conclusão:** Estas crianças buscam transformar as interações de seu cotidiano com vistas a serem reconhecidas enquanto pessoas com voz, desejos, vontades, detentoras e formadoras de opinião.

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## Introduction

Children living with chronic illness often must live with timetables and routines that are imposed on them, marked by contact with different health care professionals, numerous procedures (hospitalizations and treatments, among others) and deprivations (food, play and social contact, among others).<sup>(1-3)</sup> This impacts their social conviviality, causing feelings such as fear, anxiety and tension that are amplified among preschool children, whose capacity for preparation and understanding is limited, along with their ability to express feelings and needs.<sup>(1-3)</sup>

Studies that explore the phenomenon of living with chronic illness in childhood are generally concentrated on the perspective of the family, with emphasis on the primary caregiver.<sup>(1)</sup> There are few studies that seek to understand the child's perspective. This study adopted the guiding question "What marks the daily lives of preschool children who live with chronic illness?", with the aim of characterizing the revelations expressed by children without cognitive impairment who are living with chronic diseases.

## Methods

This was a field study using a qualitative approach, which adopted therapeutic play as the strategy for data collection.

Therapeutic play is structured based on the cathartic function of play, and has been indicated as a resource to access the perspective and understand the needs of children, especially in the preschool phase.<sup>(4-6)</sup> This study and others have adopted this strategy for data collection.<sup>(7,8)</sup>

Given the objectives of this study, the theoretical framework of symbolic interactionism was chosen because it affirms that children are actors in their experience, and the meanings from which actions occur are established in their interactions. In this framework, a human being's interactions and actions are influenced by what is happening in the present, and at the same time aspects of an individual's lived past are applied.

In this sense, every phenomenon must be comprehended and understood from the perspective of the person who lives it.<sup>(9)</sup>

The study was developed in an outpatient care unit of the Sistema Única de Saúde (SUS), Brazil's public health care system, in a city in the interior of São Paulo state. The facility provides physical therapy, psychological counseling, occupational therapy and nursing care for chronically ill children and their families.

The study subjects were child users of this service who met the inclusion criteria: carrier of a chronic disease; treated exclusively in outpatient care for more than two years; no cognitive impairment; and preschool age (three to five years and 11 months). Seven children were potential subjects, but only four participated in the study. The other three were excluded for the following reasons: one for not attending scheduled meetings three consecutive times, who was considered as not wanting to participate; another due to transportation difficulties; and a third because the child refused to participate. A total of 29 therapeutic play sessions were conducted with the four remaining children, totaling 1,115 minutes.

Laurence Bardin's system of thematic content analysis was adopted as the methodological approach. This is part of a set of techniques for analysis of communication processes with a view to understanding the content transmitted.<sup>(10)</sup> It identifies three steps: (1) pre-analysis, which includes initial reading of the material to give order to the data; (2) exploration of the material, with the aim of coding and classifying what is revealed by the articulation of concepts and processes of the phenomenon in focus; and (3) treatment and interpretation of the outcomes obtained, which involves the process of critical reflection on the results.<sup>(10)</sup>

The development of study adhered to national and international standards for ethics in research involving humans.

## Results

Analysis of the data revealed that the children seek recognition as individuals with voices, de-

sires, wills and opinions. Their everyday experiences can be characterized by these thematic categories: “Interactions,” “Fighting,” “Support” and “Doubt.”

The thematic category “Interactions” reveals that the children’s social relationships, especially with professionals and caregivers, are marked by unidirectionality, imposition and valuing of results. They are relationships based on power over the children, sustained by the belief that the adults know what’s best for them. Commands for action predominate, and obedience is always expected.

In health care, professionals show little sensitivity and consideration, treating children according to protocol and in an impersonal manner, even when the children express suffering. The professionals in this study demonstrated that they were focused on implementation of interventions to achieve therapeutic results, while expecting the child to cooperate and obey.

Given this relational context, the coping mechanisms adopted by the child are to conform and incorporate the rationale that it is “for your own good.”

*While playing medical consultation, the child begins to examine the grandmother doll. The child “draws” the blood, and then immediately throws the grandmother doll into the corner and says, “Next.” In another session, this same child, in the same story plot, starts by crying, “Next.” [...] The child asks, “What have you got?” and, without waiting for the response, says, “You have to come back here on Wednesday, you have an infection.” The researcher responds, “That’s okay,” and that she will leave now. Superman replies “No,” pulls her arm to draw blood, and does the action of drawing blood, including “looking” for the vein, always with brusque movements, without eye contact, centered on the arm and the syringe. And he says dryly, “You have to drink plenty of water and come back on Wednesday. Go, you can go. It’s for your own good.” Superman – 3rd and 8th sessions.*

In daily interactions with their caregivers, it is reinforced that the health care professional is the absolute authority, always to be obeyed. The children suppress their affectivity and sensitivity in order to be able to carry out the professional’s recommendations.

*When playing giving medication to the baby, the child reproduces the drug intervention with skill, precision and sudden movements, and says, “I’m going to put in the medicine. I’m putting in a lot of medicine, take it, because the doctor said to, it is for your own good. Take it all. He said to.” The child sits in a chair, and with precise and firm handling gives the bottle to the doll, saying to the doll, “Very good, you took everything. It’s for your own good.” Wonder Woman – 2nd session.*

The thematic category “Fighting” shows the child’s attempts to become stronger in the face of anxiety and discomfort. All of the children incorporated fighting as one of the plots of the therapeutic play sessions, when objects, people and animals engaged in disputes and aggression, and the strongest dominated the weakest. Throughout the sessions, and with the development of their experiences, the children reduced their aggressiveness and fighting time, and incorporated the idea that they could both be strong and win. Concordant with this placement, it is emphasized that the fighting preceded the catharsis.

*Picks up the lion and simulates biting the alligator. Does the reverse, alligator bites the lion. [...] Grabs the cow, dinosaur and lion, lies down in the middle, the toys around him. Plays with these three animals for ten minutes, then the lion bites the dinosaur, now the dinosaur bites the lion. Both bite the cow, which falls down. [...] After various fights, the child feels confident expressing aggression without seeking eye contact with the adult to identify her judgment of the aggressive actions. As the session progresses, attacks with no concern for the others around him. Stone Man - 3rd session.*

Fighting in therapeutic play seems to be a resource by which the children are empowered to manage their experiences in relationships. The children appear to seek to be the dominators. Throughout the sessions, through fighting, the children gain the courage to explore their history and suffering with authenticity. Play fighting encourages the children to express their discomfort with their position of being dominated, but also allows them to appropriate their strength.(...) *Attacks the dinosaur, but says he is still alive. “There is still one life,” he explains. Soon after, he attacks and knocks down the dinosaur. He smiles and says, “I am*

*the strongest on earth,” and then begins the section of play in which he expresses his suffering. Superman – 4th session.*

The thematic category “Support” represents the children’s need to be accepted, which they experience in “differentiated” relationships, i.e., those with people sensitive to their situations, suffering and desires. In these relationships, the children perceive others’ efforts to welcome them, offer love and affection, and demonstrate care for them.

These people are most often family members who offer protection and advantages, and signal the child’s emotional fragility to others. These people are well-loved by the child, and to cease living with them, either by death or family separation, causes suffering and triggers the desire to reestablish contact. In this study, these people were the grandfather, mother and father.

*The session of one child who received emotional support from his grandfather is highlighted below.*

*Plays with the wheelchair, pushing it from one side to the other, opening and closing it. Is thoughtful, says he had two grandfathers, one died and the other is now under [...] The one who died was called P, and used a wheelchair, says the child. [...] Places the doll of the child (girl) in the wheelchair, and the dolls representing the father and mother behind it. Says this is how it was. Plays a little longer, and leaves it, turning to the sword, hitting the dinosaur with it. Hits the dolls on the chair with the sword. Squeezes her doll tightly (security object that she brings to the session). Is quiet. Wonder Woman - 1st and 5th sessions.*

The thematic category “Doubt” relates to social behavior imposed on the child that restricts the child’s authentic behavior. This makes the child fearful, with doubts and difficulties regarding how to act.

*Plays with the researcher, putting the blue lizard on her as if it was walking, the lizard “goes” to the neck and “bites.” Soon after, the child hugs the researcher, and smiles at her. He tosses the lizard away, and grabs the sword. He pushes the animals into a corner, gives the little dinosaur to the researcher, and asks what he should do. He shows how to act: hitting the big dinosaur. Researcher does what he asks. He smiles and hits too. Stone Man - 3rd and 6th sessions.*

In the initial social interactions, the children were unsure of how they could and should act, a result of their insecurity about being accepted. When they perceived that a given behavior was acceptable, they tended to reproduce it, even if they wanted to act differently. When in doubt as to whether the desired behavior was acceptable, the children expressed discrete, spontaneous and authentic manifestations, and waited for the impact of the behavior in order to decide whether or not to continue. However, finding the opportunity and permission to be authentic brought them joy, and they continued to manifest their own way of being.

Therapeutic play is a potential space for authentic behavior, which ends by expressing suffering. At the end of the sessions and/or termination of the study, the children stated that they would miss it.

*The researcher signals to the child that it is time to end the session. The child says he chose to play until he got tired, and the researcher again explains the rules. The child argues that he chose to play. (...) When the toys are put away, the child becomes quiet and thoughtful. He grabs the gun, handles it, faces the researcher, points the gun at her face and shoots. He also shoots to the side, and puts the gun next to the bag. Superman – 4th session.*

It was identified that these children expect commands about how they should or should not be. They discover in some of the interactions that they can be authentic, which encourages them to be who they really are, and express their wishes. They rarely experience such opportunities.

*Says that the doll was crying because she wanted her mom. “Makes” juice and is very involved with this act, looking from time to time at the researcher and observer. Looks at her stepmother, and gives food to the mother and father dolls. She-Ra - 1st session.*

## Discussion

This study was limited to a qualitative-interpretative approach to characterization of the manifestations of preschool children living with chronic illness. Therefore,

expansion of the experience is needed, with different methodological approaches and new sample groups.

The thematic categories revealed in the experiences of these preschool children with chronic illnesses provide a theoretical and practical basis to guide nurses' interactions with these children, from the perspective of care centered on the children as individuals, with a view towards recognition and support of their expressions, needs and autonomy. In this sense, this study can contribute to strategies for the development of advanced practice and application of ethical principles in pediatric care, according to the guidelines of the International Council of Nurses.

The children in this study revealed that their everyday experience is regimented, driven by relationships of command and imposition, and that they strongly seek to expand their opportunities to be authentic in their behavior. They seek understanding of their needs, valuation of their efforts and recognition of their capabilities. The children struggle for these in a scenario that tends to repress them.

Autonomy is essential to the empowerment of children living with chronic illness, and requires close, understanding relationships that offer possibilities of choice.<sup>(11)</sup> The children in this study seek autonomy in a shy and covert manner, questioning their power and possibilities.

Being heard is an acute need in the process of achieving autonomy,<sup>(8,11)</sup> and this need was identified in this study, particularly in the thematic category "Interactions." Yet similar to another study,<sup>(12)</sup> the professionals silence the children's voices and impose behavior. To transform this scenario requires listening to the child as part of care.<sup>(11,13)</sup> In this study and another, the professional-child relationship was focused on results centered on the disease and impersonality.<sup>(14)</sup>

This study confirmed that an affectionate and differentiated bond<sup>(7,15)</sup> brings a sense of security,<sup>(13)</sup> promotes confidence in oneself and others, and consequently relieves pain and increases resiliency.<sup>(16)</sup> Children experiencing hardships and unpleasant symptoms resulting from a chronic condition need social support "to create strategies that facilitate coping with stress and exhaustion".

<sup>(11)</sup> In this sense, social interactions can encourage the construction of new meanings for the elements of their history, thereby empowering them.<sup>(17)</sup> In the absence or loss of this bond, pain and depression may be present.<sup>(16)</sup> These observations are in conjunction with those presented in the thematic category "Support."

It is emphasized that living with chronic illness in childhood is pervaded by the possibility of social isolation, due to insecurity about being accepted.<sup>(11)</sup> Something similar was also revealed by the children in this study, who are faced with the fear of being inadequate, or not meeting the expectations placed on them.

It is noteworthy that support is usually found within the family,<sup>(7,11)</sup> as occurred in this study. Loving relationships and demonstrations of interest in the child generate care and authenticity, and promote comfort and relational security.<sup>(13)</sup> In contrast, in interactions with professionals, barriers are structured into the hierarchy.

Based on the above, it is clear that seeking to understand the children's experiences, as well as being respectful of their decisions and limits, are guides for relationships with them, and are basic to human care, where dialogue, affection and co-construction are paramount and amplify the children's satisfaction.<sup>(11,18)</sup> When the children can understand the place of the disease and its consequences in their lives, they tend to calibrate their own identity for coping.

Thus, it is a priority to invest in the full protection of these children, the first step being to respect them as individuals, regardless of their developmental stage. Listening to them and allowing them to be co-participants in their history needs to be the axis of relationships with, and care for, these children. The children in this study suffered from a lack of dialogue and explanations that go beyond "It's for your own good." This is vague, unsatisfying and uncaring.

It is noteworthy that therapeutic play proved to be a resource for listening and care. It should be incorporated into the actions of all those who have the knowledge, preparation and skill to use this methodology. The use of play/toys is recommended practice for nurses. The increased adoption of therapeutic play in pediatric nursing is urgent, and academia must incorporate knowl-

edge and discussion on this method into nursing training, as well as help provide education in scenarios of care.<sup>(5)</sup>

Based on the results of this study, training courses in health care need to incorporate opportunities to build knowledge and awareness of the experience of chronic illness in young children, as well as among older children and adults, with a view towards more humanized care.

Care needs to be designed as a *praxis*, mutually established among everyone involved: professionals, family members and children. In the absence of construction of care, respect for and appreciation of the autonomy of the children and their families are disregarded. In the present scenario, one wonders whether the relationship of care focuses on the diseases or the children and their families. This seems to be the first variable.

Giving voice to children and considering their grievances need to direct health care actions, both in health services and at home.<sup>(11,12)</sup> Further research that captures the voices of chronically ill children needs to be developed.<sup>(13)</sup> This study sought to contribute to this effort; however, it only made use of therapeutic play sessions to capture the voices of the children. Other strategies have the potential to broaden understanding of this context, such as integrated use of photographs and interviews.

## Conclusion

This study showed that chronically ill children strive to be subjects with rights, yet are conceived of by their social environment as subjects of duties. These children are “depositories” for achieving results, and their social interactions are thus unidirectional and authoritative, under the expectation that they will obey commands. Thus, their voices are almost silenced, and they struggle on a daily basis to be heard, and for their rights as individuals.

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## Collaborations

Matos APK; Canela PC; Silveira AO and Wernet M participated in the project design, analysis and interpretation of data, important critical review of the intellectual content, and approval of the final version to be published.

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