



Lola had one thing: building an educational book for children with cystic fibrosis

Lola tinha uma coisa: construção de um livro educativo para crianças com fibrose cística

Lola tenía una cosa: construcción de un libro educativo para niños con fibrosis cística

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ABSTRACT

This work describes the experience of constructing a story book with the objective of helping health professionals and families to share with children less than 5 years about their diagnosis of cystic fibrosis. The book tells the story of Lola, a child who discovers she has cystic fibrosis and creates an imaginary monster as a representation of the disease. The experience emerged out of professional practice in an outpatient multidisciplinary service for these patients, translating the importance of reconciling theory and practice, and interdisciplinarity for the construction of innovative and creative strategies in the development of comprehensive care.

Keywords: Cystic fibrosis; Health education; Child; Narration

RESUMO

Este trabalho descreve a experiência da construção de um livro de história com o objetivo de auxiliar profissionais de saúde e familiares a contarem para crianças menores de 5 anos sobre seu diagnóstico de Fibrose Cística. O livro traz a história de Lola, uma criança que descobre que tem Fibrose Cística e cria um monstro imaginário como representação da doença. A experiência emergida da prática profissional em um ambulatório multiprofissional de atendimento a esses pacientes, traduz a importância de conciliar teoria e prática, além da interdisciplinaridade para a construção de estratégias inovadoras e criativas no desenvolvimento do cuidado integral.

Descritores: Fibrose cística; Educação em saúde; Criança; Narração

RESUMEN

Este trabajo describe la experiencia de la construcción de un libro de historia con el objetivo de auxiliar a profesionales de salud y familiares a contar a los niños menores de 5 años sobre su diagnóstico de Fibrosis Cística. El libro muestra la historia de Lola, un niño que descubre que tiene Fibrosis Cística y crea un monstruo imaginario como representación de la enfermedad. La experiencia emergida de la práctica profesional en un consultorio externo multiprofesional de atención a esos pacientes, traduce la importancia de conciliar la teoría y la práctica, además de la interdisciplinaridad para la construcción de estrategias innovadoras y creativas en el desarrollo del cuidado integral.

Descriptorios: Fibrosis quística; Educación en salud; Niño; Narración

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INTRODUCTION

Cystic Fibrosis (CF) is a hereditary, autosomal and recessive chronic illness with systemic effects. Its physiopathology is intracellular and, until date, it is incurable ⁽¹⁾.

According to neonatal screening data, incidence levels in Brazil correspond to approximately 1: 8,500 liveborns ⁽²⁾. As 1,787 mutations have been registered for the disease until date ⁽³⁾, countless clinical forms are found. Thus, there is no standard disease, although there is a triad of characteristic effects: sudoriferous glands, digestive and respiratory systems ⁽¹⁾.

Telling the diagnosis of a chronic and incurable illness to a child's family is not easy and becomes even more complex when this disease is genetic. In literature, reports about the feelings of fear, guilt and anger the moment of the diagnosis entails for these patients' relatives are common ⁽⁴⁾, but data are missing when we look for the children's experience when they discover this diagnosis.

Children are frequently excluded from explanations about their health conditions, as it is considered that they have no cognitive skills and specific knowledge to understand these explanations. Difficulties emerge in the establishment of relations and dialogue between health professionals and these children, aiming to protect the child from unpleasant news that can cause emotional trouble ⁽⁵⁾. Contradictorily, these children stay with their family during these conversations, listening to what is said and reaching their own interpretations and conclusions about their disease and treatment.

An earlier study involving child and adolescent CF patients evidenced that most of them have mistaken knowledge about the disease, relating it with other genetic conditions like Down Syndrome, or with the signs and symptoms they present. The consequence of this mistaken knowledge is non-positive coping with the disease and its concealment in social relations, which together end up interfering in the socialization process and in these patients' quality of life ⁽⁶⁾.

Another study investigated knowledge on the cause of the disease in children between 5 and 9 years old, hospitalized at a pediatric nursing ward of a teaching hospital in the interior of São Paulo State. Results showed that 24% of the children did not know the cause of their disease and that 18% associated it with their signs and symptoms ⁽⁵⁾.

A study aimed at understanding the meaning of health and illness in school children's perspective identified that children in this age range think about health and disease as separate events, instead of components of a process. Besides, they link their definitions of disease with previous experiences, and not with the multi-

causal and multi-factorial definitions of this condition. This acknowledgement is important to enhance health education and orientations to this population ⁽⁷⁾.

Lola has a thing: the construction of the book

In this experience report, the construction of the storybook *Lola had a thing* is presented. The idealization of the book was based on results available in literature, in combination with experiences at the Multidisciplinary Cystic Fibrosis Outpatient Clinic (MCFOC) of the University of São Paulo at Ribeirão Preto Medical School *Hospital das Clínicas*. The goal of this instruction material is to help professionals and family members to tell children under five years of age about their disease.

Children's knowledge about diseases depends on a range of factors, including their experience with the disease, their education level, the development phase they are in, social class, culture, nature of the disease, among others ⁽⁵⁾. Considering cognitive development and understanding, we attempted to elaborate material for children younger than five years.

Children of that age were chosen because of the large number of patients with CF in that age range at the service where the study was developed, and because of mothers' complaints that they did not know how to tell these children about their disease. The fact also contributed that, at that age, when education starts, children with CF start to perceive that they are different from their schoolmates, that they go to the doctor more often, arousing questions about the disease ⁽⁸⁾.

The development phases, which range from the end of the first childhood to the second childhood, are characterized in cognitive and emotional terms by gradual sophistication in symbolic thinking (comprising identity, cause and effect, ability to classify and understand figures), besides the ability to give meaning to words, numbers or images. The attribution of meanings and the understanding of symbols represent important advances in child development, as they allow the child to think of objects and their qualities without their actual presence ⁽⁹⁾.

In this phase, children can already give meaning to an unknown word like genetics, although, often due to a lack of explanation and/or association with the known world, this can be disjointed and confusing. Hence, it becomes important to clarify the concepts, words, signs and meanings that permeate the world of health, disease and treatment, with a view to the development of correct concepts and meanings for children to understand themselves as CF patients.

In the preoperational stage (2 to 7 years), children are already centered or able to center on one thing at a time and mix up appearance with reality, besides their

exacerbated egocentrism⁽⁹⁾. Therefore, we sought a strategy, put in practice in the book, which would at the same time withdraw the child's focus from him/herself and transfer it to another person (Lola), be easy to access and, with little external interference, centered on the core character, would further approach the reality these children experience, facilitating the association between the real and the imaginary.

We built an illustrated story, considering that *"for a story to truly catch children's attention, it should entertain and arouse their curiosity. But to enrich the children's lives, their imagination should be stimulated: help them to develop their intellect and clarify their emotions; be in harmony with their anxieties and aspirations; fully acknowledging their difficulties and, at the same time, suggesting solutions for the problems that disturb them..."*⁽¹⁰⁾.

Besides, we decided to use a playful health education strategy, taking into account child development and evidence appointed in literature that these strategies enhance learning and changes in child concepts and behaviors, influencing quality of life⁽¹¹⁾.

Also, in line with other authors, it has to be considered that health education in chronic conditions demands innovative attitudes, distinct from traditional adherence-centered ones. Thus, it requires a combination of knowledge and strategies that involve self-knowledge, values and needs that enable patients to set their own targets, i.e. their empowerment⁽¹²⁾.

Hence, the history *Lola has a thing* presents the history of a girl with CF who starts to ask her mother questions about the disease. When asking her mother what CF is, the mother answers: "It's a thing you have..."

Based on that phrase, Lola starts to imagine Cystic Fibrosis as a thing, a large and hairy animal, due to its complicated name. Therefore, she decides to keep it in her cupboard, because she's afraid of it and, at the same time, knows that she should take good care of it.

As her mother provides daily care, giving her medication, physiotherapy and inhalations, Lola asks her about why she needs all that and, as her mother always answers her briefly that it is because of the Cystic Fibrosis, she starts to imagine that she needs to get strong to keep the animal inside the cupboard and that the physiotherapy and aerosol are necessary because the Cystic Fibrosis joins a lot of dust.

During a medical appointment, Lola meets other children with Cystic Fibrosis and decides to ask her friends where their Cystic Fibroses are. Each of them answers, associating the disease with a body part that is more affected, like the nose, lungs... and that, initially, they also thought the Cystic Fibrosis was an animal.

The nurse explains the children about the disease as something they were born with, that is neither caught nor transmitted and that should be taken care of, so

that they can continue to grow and play, just like their other friends.

Lola understands that Cystic Fibrosis is the name of a disease instead of an animal. She imagines that she is strong and the animal gets very small, and she keeps him in her pocket, metaphorizing that the problem, the animal, which used to be big and unknown, becomes something smaller she can face.

At school, she tells her friends about her confusion, who find it very funny! They also tell that they have other illnesses, with different names, like asthma, rhinitis, arthritis... The history ends with all children with their pocket animals, which only they can see and that, at each piece of knowledge they gain about their disease, the animal got smaller, until it disappeared completely.

The storytelling strategy is an important communication tool in pediatric nursing, as it facilitates dialogue and relationships, broadens the diagnostic and therapeutic process and values the development process of the child, relatives and the health team⁽¹³⁾.

The educational potential of child storytelling has also been acknowledged, and that these stories serve as food for the soul, arouse curiosity and stimulate the search for explanations. Besides, they can value different alternatives to overcome challenges⁽¹⁰⁾.

We used orientations for the elaboration of educative materials in health, including the literature review, adaptation of contents to the target population and validation involving expert professionals in the area⁽¹⁴⁾.

The construction of the book departed from an initial idea, complemented, adapted and, thus, validated by a multidisciplinary health team. Through the combination of distinct knowledge and experiences, this permitted the production of adequate material for the target age range, addressing actual experiences and taking care to deconstruct mistaken concepts, revealing adequate knowledge and demystifying the disease.

FINAL CONSIDERATIONS

We consider this research relevant for the target population, in view of the disease's little public visibility, difficulties to understand it due to the complex physiopathology and systemic effects and the small number of educative actions and research on this theme specifically directed at children.

When considering chronic conditions in childhood, greater emphasis has been put on the prevention of problems and the treatment of the disease itself, while little has been invested in health promotion, working to stimulate and enhance child growth and development, as well as children's autonomy and empowerment. In that sense, health education is an important tool for

health promotion, permitting comprehensive care and children's protagonist role.

This research also reveals the importance of articulation between theory and practice, interdisciplinarity and creativity as essential elements to plan and put in practice innovative care for chronic conditions, especially in childhood.

Given the limitations of this paper to draw conclusions on the telling and/or use of stories as effective

health education tools in pediatric nursing, and especially in Cystic Fibrosis cases, as it is an experience report, further research is due, applying the history to children and assessing their understanding after reading, the relatives and professionals' experiences when telling the story and their assessments, among others, besides encouraging the production of new materials with similar goals for other chronic conditions in childhood.

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