

Children in outpatient follow-up: perspectives of care identified in interviews with puppet

Crianças em seguimento ambulatorial: perspectivas do atendimento evidenciadas por entrevista com fantoche

Niños en seguimiento ambulatorio: perspectivas de la atención evidenciadas por entrevista con títere



Ana Carolina Andrade Biaggi Leite^a
 Willyane de Andrade Alvarenga^a
 Júlia Rezende Machado^a
 Letícia Falsarella Luchetta^a
 Rebecca Ortiz La Banca^a
 Valéria de Cássia Sparapani^b
 Rhyquelle Rhibna Neris^a
 Denisse Cartagena-Ramos^a
 Miguel Fuentealba-Torres^a
 Lucila Castanheira Nascimento^a

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ABSTRACT

Objective: To analyze the perspective of the child about his health condition and experiences related to outpatient hospital care and the use of the puppets as a playful strategy to collect data.

Method: A qualitative study included 16 children diagnosed with chronic diseases recruited in a pediatric outpatient clinic in the interior of São Paulo. Data were collected in October 2016 through a semi-structured interview and the puppet was used as a facilitator in communication. The interviews were analyzed through the inductive thematic analysis.

Results: Four themes were constructed: "children in ambulatory follow-up: what do they know?"; "Emotions that follow the outpatient follow-up"; "the outpatient clinic of my dreams" and; "the use of the puppets and the playful universe of the interview".

Final considerations: It was possible to identify the reason and main feelings of outpatient care, as well as the preferences of the children related to the physical and structural aspects of the outpatient clinic.

Keywords: Pediatric nursing. Ambulatory care. Chronic disease. Child. Play and playthings.

RESUMO

Objetivo: Analisar a perspectiva da criança sobre a própria condição de saúde, suas experiências relacionadas ao atendimento ambulatorial hospitalar e ao uso de fantoches como estratégia lúdica para a coleta de dados.

Método: Estudo qualitativo, incluiu 16 crianças diagnosticadas com doenças crônicas, recrutadas em um ambulatório pediátrico do interior paulista. Os dados foram coletados em outubro de 2016 mediante entrevista semiestruturada e utilizou-se o fantoche como recurso facilitador na comunicação. As entrevistas foram analisadas por meio da análise temática indutiva.

Resultados: Foram construídos quatro temas: "criança em seguimento ambulatorial: o que elas sabem?"; "emoções que perpassam o seguimento ambulatorial"; "o ambulatório dos meus sonhos"; e "a utilização dos fantoches e o universo lúdico da entrevista".

Considerações finais: Foi possível identificar o motivo e os principais sentimentos vivenciados durante o atendimento ambulatorial, assim como as preferências das crianças acerca dos aspectos físicos e estruturais do ambulatório.

Palavras-chave: Enfermagem pediátrica. Assistência ambulatorial. Doença crônica. Criança. Jogos e brinquedos.

RESUMEN

Objetivo: Analizar la perspectiva del niño acerca de su condición de salud y experiencias relacionadas al a atención ambulatoria hospitalar y el uso de los títeres como estrategia lúdica para recoger datos.

Método: Estudio cualitativo, incluyó a 16 niños diagnosticados con enfermedades crónicas reclutadas en un ambulatorio pediátrico del interior paulista. Los datos fueron recolectados en octubre de 2016 mediante entrevista semiestructurada y se utilizó el fantoche como recurso facilitador en la comunicación. Las entrevistas fueron analizadas por medio del análisis temático inductiva.

Resultados: Se construyeron cuatro temas: "niño en seguimiento ambulatorio: ¿qué saben?"; "Emociones que atraviesan el seguimiento ambulatorio"; "el ambulatorio de mis sueños"; y; "la utilización de los títeres y el universo lúdico de la entrevista".

Consideraciones finales: Fue posible identificar el motivo y los principales sentimientos del seguimiento ambulatorio, así como las preferencias, de los niños, relacionados con los aspectos físicos y estructurales del ambulatorio.

Palabras clave: Enfermería pediátrica. Atención ambulatoria. Enfermedad crónica. Niño. Juego e implementos de juego.

^a Universidade de São Paulo (USP), Escola de Enfermagem de Ribeirão Preto, Centro Colaborador da OPAS/OMS para o Desenvolvimento da Pesquisa em Enfermagem. Ribeirão Preto, SP, Brasil.

^b Universidade Federal de Santa Catarina (UFSC), Departamento de Enfermagem. Florianópolis, SC, Brasil.

INTRODUCTION

Sickness can cause several physical, emotional, and social changes during child development⁽¹⁻²⁾. Chronicity is multifactorial in nature with a slow progression and can lead to physical limitations, dependence on medication or restrictive diets, and an impaired social life⁽¹⁾. Chronic diseases generally last more than three months and they are recurrent and often incurable, which means sufferers require continued and/or regular treatment⁽¹⁾. Asthma, rheumatoid disease, kidney disease, epilepsy, cancer and type 1 diabetes mellitus are some pathologies considered chronic conditions in childhood⁽¹⁾. When children are diagnosed with these diseases, they face several challenges, such as the need to return to hospital regularly⁽²⁻³⁾, painful treatments⁽¹⁾, and changes in their usual activities⁽²⁾, which interferes with school attendance^(1,3).

Changes in the daily routines can make sick children fearful, especially when they are forced to stay in the impersonal hospital setting^(2,4) with large monochrome walls and quiet and dimly lit corridors. Theoretically, hospitals should provide more welcoming environments that support children's growth and development. Besides the actual structure and physical organization of the care setting of health workers, it is important to focus on the comprehension and sensitivity between caretakers and the people in care⁽²⁾.

To ensure the trajectory of children at the health service is less traumatic, they must know their health condition and its treatment and feel free to manifest their preferences with respect to the ambulatory environment. Moreover, health workers must learn to detect their main concerns that generally precede and accompany this type of care.

Although the families are considered the main sources of information^(3,5) on the health condition and experiences of children with chronic diseases, the influence of the disease on the child's life can also be learned by listening to their experiences during conversations, for example⁽¹⁾. However, it can be difficult to communicate with children using direct questions and answers, thus demanding the use of more attractive and familiar strategies to children, such as play⁽¹⁾. Some recreational resources used in qualitative research with children with chronic disease are puppets, drawing, therapeutic play, and photographs⁽⁶⁾. These strategies favor the approach and interaction between participants and researchers and enable informal conversation, which leads to better results in comparison with traditional interviews with straight questions and answers⁽⁶⁾.

The use of puppets as a communication strategy helps children better understand their health condition and the experiences related to outpatient hospital care. Further-

more, it makes children feel more comfortable and safe⁽⁷⁾ since they do not need to make eye contact or speak directly with the researcher. It also reduces stress, since the children can express their feelings, helps them feel less alone as they wait for their appointments, and encourages the children to learn about their disease⁽⁷⁾.

Literature reviews⁽⁶⁻⁷⁾ stress the use of play strategies with children for data collection and for educational simulations carried out by nurses. The studies included in these reviews demonstrate the perspective of children with cancer on their own disease and the impact of playthings such as therapeutic play and puppets. Although puppets have been used to collect data in other studies, we did not identify studies that specifically explore the experience of children with chronic diseases in relation to follow-up using this play resource. Therefore, this study was proposed to respond to the following questions: What is the perspective of children with chronic illnesses on their own health condition and outpatient follow-up? What is the perspective of children with chronic diseases on the use of puppets as a playful strategy in interviews? Thus, the objectives of this paper are a) to analyze children's perspective on their health condition and b) to analyze the experiences of children related to outpatient hospital care and the use of puppets as playful strategy for data collection.

METHOD

This is an exploratory study with a generic qualitative approach. In this type of study, the research question is presented according to the methodological design without adopting a specific theoretical assumption to guide the method⁽⁸⁾.

The children included in the study were between seven and 12 years of age, in outpatient care at a pediatric teaching hospital in the state of São Paulo. The hospital is a center of reference in the treatment of children with chronic diseases and it attends approximately 200 children and adolescents daily in 64 specialties. Children in the seven to 12 age group were selected because they are in the ideal stage of development for the use of puppets for data collection⁽⁷⁾. We excluded children who had some impairment that prevented them from expressing themselves or who were in their first two outpatient appointments. The subjects were selected by convenience, according to the order of arrival at the clinic for follow-up, and those who met the criteria for inclusion were invited to participate. When we observed repetitions in the information and achieved the proposed objective, new interviews were no longer scheduled due to saturation of theoretical data⁽⁹⁾.

Data were collected by means of semi-structured interviews conducted in October 2016, by four researchers; two nurses with experience in data collection and two nursing students trained to assist in this process. The researchers did not know the children and they were not involved in their care. The data were collected in a single interview based on a trigger question (“Can you tell me why do you come to the clinic?”) and other guiding questions (“Do you like coming here?”; “What do you feel when you know you are coming to the clinic?”; “What do you do while you’re waiting for your appointment?”; “What do you like or would like to do while you’re waiting for the appointment?”; “What would you prefer the hospital to look like, for example, the walls, chairs, and the doctor’s offices?”; “What did you think of our conversation with puppets?”), as well as questions to characterize the participants. The questions guided the conversation; however, the participants were free to talk about other matters. The interview script was previously tested in a pilot study conducted with three children.

In the interviews, we used six mouth puppets representing animals (giraffe, elephant and alligator), people (a girl and a boy) and an animal without defined features, all made by one of the researchers (Figure 1). These puppets have a hinged mouth that the person holding the puppet can open and close continuously with his or her hand, which enhances and facilitates communication. The puppets were carefully chosen to ensure the children felt comfortable, since they could pick the ones they preferred, and they came in varying sizes to fit the hands of the participants. The names the children gave the puppets were used to identify them in the study, and the children who chose to use their own names were represented by fictitious names to ensure compliance with ethical issues and guarantee anonymity of the study participants. The interviewer also chose a puppet. During the interview, this puppet was used both by the child and the interviewer as if it “spoke for them”. These strategies allow greater interaction between puppets and promote greater interest among the participants.



Figure 1 - Puppets used in data collection

The interviews and play activities with the puppets occurred in waiting room of the pediatric clinic. The room is divided into several environments and most of the seats are allocated in the center. The interviews occurred on the same day of the invitation in a side extension of the waiting room, away from the doctor’s offices, reception, and nursing station. Although the interviews were not conducted in a specific room for this purpose, we selected a space with privacy, minimal noise, and a limited flow of people. These precautions were taken to prevent losses, distractions, and participant exposure.

The interviews lasted for a minimum of seven minutes and a maximum of 32 minutes and they were recorded and transcribed in full. The shortest interviews were conducted with the younger children of the established age range due to the reduced eloquence of children in this development stage. In all cases, however, the use of puppets helped prolong the interviews. The people responsible for

the children were informed they could accompany the interviews, but some felt comfortable leaving the children alone with the researchers. We did not consider the statements of the persons responsible for the children who participated in the interviews in the analysis.

The data were subjected to qualitative analysis to capture the experiences of the participants. This stage consisted of six steps, according to the guidelines of Braun and Clarke⁽¹⁰⁾ for inductive thematic analysis, namely repeated reading of the interview transcripts; listing of ideas about the data; classification of data into main themes; review; nomination and construction of the result. Such a process was conducted by two researchers (first and second authors), who independently prepared a code structure and compared it to reach an agreement and consensus in a face-to-face meeting. Then, a third experienced researcher (senior author, research advisor) reviewed and validated the previously validated analysis. In the next step, the three

researchers jointly produced the themes. Finally, the team met to discuss the themes, review discrepancies, reach a consensus on the differences, and produce a final report.

The research was approved by the ethical committees of the proposing and co-participating institution (CAAE: 58516416.1.0000.5393). The legal tutors of the children were initially contacted in person to explain how the research would be conducted and asked to sign an informed consent statement, as determined in Resolution 466/12 of the National Health Council. Once the persons responsible for the children consented to the research, we approached the children and invited them to participate in the study. Those who accepted, signed an informed consent statement.

RESULTS

Sixteen children participated in the study, aged between seven and 12 (average of 9.77 years). Most of the children were girls (68.75%) and they all went to elementary school, with an average of 3.6 years of schooling. All the participants were from cities surrounding the treatment unit; nine (56.25%) lived in cities up to 100 km away from the unit and seven (43.75%) lived in cities more than 100 km from the unit.

The children had several diagnoses and some were being treated and doing follow-up for more than one dysfunction. They had all been attending the outpatient unit for more than a year and the majority (68.75%) had been attending the clinic for over six years, which indicates the presence of a chronic condition in childhood. The children attended the pediatric outpatient clinic at different time intervals and most (43.75%) visited the clinic every three months. In all cases, the mothers were the companions of the children during the consultations.

The interview analysis resulted in four themes: "Children in ambulatory follow-up: what do they know?"; "Emotions manifested in outpatient follow-up"; and "The outpatient clinic of my dreams". The use of the puppets was also assessed and presented under the theme: "The use of puppets and the playful universe of interviews". A description of the four thematic categories is provided below. The researcher's statements are in brackets and the children's statements are in italics. Some information that contextualizes the statements is presented in parentheses.

Child in follow-up: What do they know?

Some children were unaware of their diagnosis and the main reason they had to attend outpatient follow-up. Those who were aware of their health condition said they

knew why they were there. The following quotes show that, although they all acknowledged being in a hospital, some did not know the reason or were unaware of their own diagnosis. In an interview mediated by puppets, they said:

[Do you know why you come here?] Because I have hy ... hypo ... Oh! [Hypothyroidism] Yes, that's it. [Do you know what this is?] No! (Hanna).

[Researcher's puppet: Why do you come here?] I came here to do blood tests, x-rays, and I came to talk to the doctor. [Do you know what you have?] I don't remember (Jujuba).

In contrast, those who were aware of their diagnosis, health condition, and the reason they were in the waiting room of the children's clinic stated:

I have rheumatoid arthritis and it is when my arteries fill up, then my joints swell, and there is this water and I always have to remove the water (Bob).

I come here because of my leg. I was born this way; It's a stain and it is called "port-wine stain" [Flat Hemangioma]. I can't speak properly. My leg hurts when I move it a lot or when I stand up for too long (Grandona).

When questioned about their pathologies, they stated they had been diagnosed very early, when they were a few months old. Their curiosity regarding their own health condition made them seek answers with their parents, considered the closest source of information:

I was two or three months old when they discovered the cystic fibrosis. That's when I came to do the sweat test. And they found out it was cystic fibrosis. My mother told me (Florzinha).

I was born with this disease. I had a tumor. They found out because I had bad headaches and didn't like noise (Magali).

When talking about the long-term treatment of chronic disease, the children showed they had information on drug therapy and its consequences. In contrast, some had little knowledge about their drug treatment. It should be noted that chronic diseases might require non-medicated treatment:

[Do you take medicine?] Yes, but I don't know what for (Jully). You don't have to take medicine, I just have to use

a patch on my eye. Using a patch is annoying, but using glasses is nice (Mica).

Among the children who had knowledge of their treatment, some used words that are regularly used in the hospital routine and incorporated health care terms, which denotes involvement with this whole process. The participation of health workers and the mother in the child's integration with self-care became evident, as illustrated in the following snippet:

The tenckroff (referring to the Tenckhoff catheter) is a tube that goes in the belly. It fits into the dialysis machine and it helps the kidney function. If bacteria go in, you have to be hospitalized. You have to take good care of your Tenckhoff. [Who taught you that?] The doctors, my mother, and the nurse. (Lilica).

Chronic disease can cause limitations in the children's daily lives and requires adjustments in their routine and everyday activities. In this sense, the statements clearly express the sadness and impotence the children feel when they are deprived of certain games and food items. The statements also reveal how the disease interferes with their social lives and relationship with their peers, causing anguish and frustration. The limitations imposed by chronic disease, exemplified in several statements, raise questions about the differences between the children and their colleagues:

I'm alone, I have no friends. They (other students) go to places I can't go to. I can't see with one eye, I can only see forwards, I cannot see downwards, so I cannot use the stairs, where they like to be (Nick).

[What can't you do?] Swim, I cannot go into the water with my catheter because that water can give me an infection. On top of that, I cannot eat things my brother eats, like chips, stuffed cookies, and soda (Lilica).

Emotions pertaining to outpatient follow-up

During the interviews with the puppets, the children mentioned feelings of shame and hope. They felt hopeful about the possibility of healing and embarrassed to interact with health workers, especially the physician:

[Have you ever asked the doctor anything?] No, I am too embarrassed (Hanna).

When I'm cured, I'm going to do a transplant. He [doctor] told me, when I get better, I'll have my kidneys back (Lilica).

When asked about what they would say to other children with the same disease, the children stated they would tell them to be strong, have patience, courage, perseverance, faith, and trust in the health workers and in the treatment. They adopted the assumptions of normality to advise others to grow and develop while incorporating chronic illness in their lives:

I would tell him (referring to another child with the same disease) to be strong, which is not easy, but it is not impossible either" (Magali).

I've got used to it, so I don't feel anything. I'm used to coming to the clinic because I have been coming here since I was a baby (Florzinha).

During the interviews, they mentioned the relationship with other children who did not have chronic disease. According to the children, although they allowed their school friends to talk about the disease, they selected the ones with whom they shared their emotions and information:

[Do the other kids ask about the Tenckhoff catheter?] No, no one asks; no one sees it. Only one friend knows. If she wants to tell other people, she can, but she keeps it to herself (Lilica).

For the outpatient follow-up, the children must change their routine and, consequently, their school attendance. In this regard, they showed mixed feelings, as noted below:

[What do you feel about skipping school to come to the outpatient unit?] A little sad, a little happy. Because we didn't play with our friends and a little happy because we skip a day of school (Jujuba).

The chronic nature of their disease also forces the children to attend regular consultations at the hospital outpatient clinic. For many of the children, the trip between their homes and the clinic was long since they lived in other municipalities, sometimes more than 100 km from the unit. Moreover, although the trip was sometimes fun, it was also quite tiring:

Today, I woke up at 3:00 in the morning. I find it tiresome; it's 3 hours (trip). I sleep and then, in the middle of the trip, I look out the window. I like to travel! (Flash).

The outpatient clinic of my dreams

The children described a number of features they considered ideal in an outpatient clinic. One of the features was a unit exclusively for children and adolescents since some respondents, due to a longer diagnostic period, had also done follow-up in another unit that also attended adults. These participants used the puppets to describe their past experiences, which contrasted with the new outpatient scenario with exclusive pediatric care that was praised by everyone:

I thought it would be better to use a room only for adults and a room for children, I thought that was really good (Nick).

Before, we were all together, with the adults. I didn't like it when it was mixed with the adults. This is the children's outpatient clinic! (Lilica).

During the interviews, the children stressed that the playful activities and decoration of the new structure created a welcoming space. However, although they liked the color of the walls and seats, they dreamed of a more colorful and creative environment, including inside the offices, and more recreational activities. Furthermore, the children complained about the waiting time before appointments, the uncomfortable seats, and the loud noise. Therefore, their wishes included more comfortable chairs and a shorter waiting time:

I would like them to paint the doctor's offices to make them more colorful because I don't like things without color (Florzinha).

I have to sit on the chair waiting for a long time (Jully).

I think the chairs should have foam inside (Mica).

The outpatient unit had televisions exhibiting the order of consultations and the respective offices. Although the children believed the feature helped to organize care, they would have liked another television airing entertainment programs:

I think the televisions with the people's names are good, so you do not get confused (Magali).

They could have another TV for us to watch something as we wait to be attended (Bob).

When questioned about their dream clinic, the children showed anguish and fear regarding procedures such as blood collection, vaccines, intravenous medication and hospitalization after the consultations. Based on these perspectives, the hospital presented a characteristic of duality. While it caused them suffering due to painful procedures, it was also a place to maintain their health and perceived as a place they should frequent for their physical recovery.

[Is there something you don't like here?] The needles (...) because it hurts (Lilica).

It's for my own good (Flash).

The outpatient workers of their dreams were described as friendly, fun, knowledgeable, welcoming, good at communicating with children, and providers of qualified care.

[What does it take to be a good professional?] You have to study hard, go to school every day, you have to pay attention to the teacher, pay attention to the tasks, and what to do when healing someone and giving them the right medicine (Lilo).

The use of puppets and playful universe of the interview

During the initial approach, the researcher evaluated the children's interest in participating in the interview with the use of puppets, and the affirmative responses were unanimous. At the end of the interviews, they all said they wanted to handle the puppets:

[What would you like to do while you're waiting?] Stay here more often playing with puppets! (said with enthusiasm) (Flash).

[What do you think about coming here?] I think it is good, for example, now that I'm here playing with the puppets. I like it because it is rare! (Nick).

The puppet was an attractive method for the age group selected for the study and served as a dramatization tool that helped the children express their emotions verbally and non-verbally. Moments of joy, sadness, excitement and surprise were captured from the change of tone or silence of the participants. Experiences related to their medical condition, to friends, family members, health professionals and the ambulatory environment could also be explored more widely through the use of puppets.

In addition to aiding communication and interaction with the researcher, the puppet proved to be a resource that stimulates creativity by creating characters, games, and interaction between them. With the use of this recreational resource, the child created a character and assumed this new identity. The interviewer, also using the puppet that represented him or her, proposed the following to the respondent:

[Let's choose a nickname for you?] Call me Grandona (Big One)! (Child, without hesitation, replied using a giraffe puppet).

The children interacted dramatically, using different voice tones with their puppets and also with the puppet chosen by the researcher. Handling the puppets brought them comfort when they needed to express their feeling and minimized the passive nature of interviews based on questions and answers. In addition to creating attractive conditions that stimulate participation, this playful strategy reduced the chance of any discomfort.

The children showed no resistance or difficulty using the puppets, regardless of age or chronic condition. Our study did not include children with hearing impairment or upper limb motor deficit since these conditions can hinder the handling of puppets in the interview. Only one child had low visual acuity, which did not cause any difficulties.

For structural reasons, the interviews were carried out in the waiting room of the clinic and, therefore, it was not possible to use scenery for the puppets or conduct activities in a specific location for research interviews, which could motivate the participants even more. Throughout the data collection process, only one testimonial had to be interrupted because another child who was not participating in the research was interested in the puppets and disrupted the dynamics of the interview. However, after a break to play and the participant's privacy was reestablished, the interview continued.

■ DISCUSSION

With the use of puppets, it was possible to apprehend the perspective of children in outpatient follow-up on their health condition and experiences in outpatient hospital care. The knowledge of children and adolescents about their disease is a common subject in current literature⁽⁸⁻⁹⁾. While some children are aware of their diagnosis and treatment⁽¹¹⁾, the testimonies of the present study reveal that limited or insufficient knowledge of the pathology can lead to problems related to acute complications and in-

adequate adherence to drug treatment. Not knowing the diagnosis and the pathophysiology can affect the child's adherence to treatment and the treatment itself⁽¹¹⁾.

Communicating with the parents is a priority in the clinical practice since children are usually excluded from conversations with the health team and end up incorporating only part of the information provided, without fully understanding its meaning. Encouraging the child's understanding of the disease increases their involvement in treatment and can create a sense of co-responsibility⁽¹²⁾. In addition to being one of the international patient safety goals, communication is an inseparable phenomenon in children's nursing care and effectively communicating favors the participation of children in their care⁽¹³⁾. Nurses should be alert to the development of patients in outpatient follow-up and think about educational and playful strategies for the various pathologies and ages. Moreover, they must consider the preferences of children and plan interventions geared toward the individual needs of this population⁽²⁾. The family's involvement is crucial, and health workers should identify and meet the needs of the family in follow-up until the child can be the focus of educational interventions. Despite the implementation of structured programs for children with chronic illness⁽¹⁴⁾, fully effective interventions for children in primary care are non-existent⁽¹⁵⁾.

The results reveal that the children must cope with the restrictions imposed by the disease, such as diet, and the physical limitations that prevent them from playing and running. Furthermore, they must take extra care to prevent infections and cope with difficulties in socializing, especially in group activities at school. Corroborating the findings of this study, research conducted with children with chronic renal disease⁽¹⁶⁾ showed that they can recognize the changes imposed by treatment that affect school routines, diet, sleep/rest, and leisure in their lives and in the lives of their families. These limitations can cause fear of pain, infection, hospitalization and even death. Therefore, the children are constantly seeking comfort in normality and they try to adapt all the situations related to the disease and its treatment⁽¹⁶⁾.

The desire for the cure of the disease, according to this study, triggers feelings of hope in the children. A similar finding was also presented in a review⁽¹⁷⁾, in which hope for the cure was identified as an element that enables children to envision a better future in the context of chronic disease. Some cases show that children have a positive attitude and accept their current clinical condition⁽¹⁷⁾.

From the perspective of children, positive descriptions in relation to the ambulatory environment in this study were quantitatively higher than the negative descriptions.

This issue has also been investigated in a study that identified a predominance of positive reviews about the hospital, despite being an environment, according to the children, permeated by pain and diseases. Therefore, it is necessary to identify the aspects children consider unpleasant so they can be modified⁽²⁾. Waiting for a medical consultation is stressful for children because, besides missing a day of school, they often have to travel for hours for their appointment⁽¹⁶⁾. This corroborates the findings of the present study, in which the children mentioned the negative aspects of waiting such as delays, excessive noise and uncomfortable chairs.

According to the children, the outpatient clinic of their dreams should be painted in several colors, with toys and games, in a lively environment. A similar result was identified in a systematic review⁽²⁾ conducted to apprehend how ambience influences humanized care, in which the children dreamed of a hospital decorated with animal and nature themes in shades of blue, orange, and yellow. Moreover, educational practices such as storytelling and playrooms are included in the children's wish list and have been implemented in several hospitals. Lambert et al.⁽¹⁸⁾ stress the importance of using the floor for games, the ceiling for visual displays, of decorating the walls with drawings, and providing chairs, sofas with pillows, and colored furniture and windows in different geometrical shapes. Despite the desire to satisfy the preferences of children, the area planned for children's care must comply with standards of infrastructure and allow the proper functioning of health services, as established by RDC No. 50/2002⁽¹⁹⁾ and RDC No. 63/2011⁽²⁰⁾.

Puppets, used here to facilitate communication with the children, proved to be a potential resource for obtaining data. The use of playful strategies in communication has been incorporated by pediatric nursing through the Therapeutic Play (TP), used to minimize the negative effects of treatment and strengthen ties with the adults providing care in the specialized care model⁽⁴⁾. In a recent literature review, the use of puppets in TP sessions for interventions and interviews with children and adolescents proved potentially beneficial for this population since the use of puppets helped the children establish a relationship with the adults, especially with the nursing staff⁽⁷⁾.

FINAL CONSIDERATIONS

The present study explored the perspective of children in outpatient follow-up on chronic disease and their experiences in hospital follow-up. The results revealed that some children were aware of their chronic health condition and the main reasons they needed outpatient fol-

low-up, while others did not know their diagnosis or the reasons they were at the outpatient unit. Some feelings such as fear, shame and hope for the cure were mentioned, as well as the desire to advise other children with chronic diseases to have strength, courage, faith, and confidence to grow and develop, incorporating the chronic disease in their lives. The dream clinic was described as a playful and friendly environment in which health professionals could ensure the children were the main actors in their care.

Knowing the children's perspectives on outpatient follow-up and health condition creates a unique feature in nursing care because it helps workers plan and implement care according to the specific needs of this population. Furthermore, it is believed that the puppet, given its significant potential for data acquisition during interviews, can be incorporated in the consultations by health professionals to create a bond with patients, support communication and foster atraumatic care, as advocated by the National Policy of Humanization.

Future research can a) identify the experiences of families, health workers and children with chronic diseases regarding outpatient follow-up to compare results, plan care, and structure the outpatient setting; b) shed light on the perspective of adolescents using different data collection techniques that are attractive and consistent with the stage of development of this population, to learn about their experiences in ambulatory assistance; and c) explore, in a playful setting, the use of puppets with children with various health conditions. Conducting interviews in the waiting room can be considered a limitation of this study. In contrast, the use of puppets and the previous experience of the researchers with this feature were the strong points of the research.

By providing a welcoming environment that aims to improve the experience of children and their families, nurses and health managers will promote health care and enable increasingly healthier and more enriching experiences for children with chronic diseases.

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■ Corresponding author:

Lucila Castanheira Nascimento
E-mail: lucila@eerp.usp.br

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