

Impacts of recurrent partial hospitalization from the perspective of children and adolescents with mucopolysaccharidoses in a pediatric hospital¹

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Abstract: The present study had children and adolescents as participants, between seven and twelve years old, who live with Mucopolysaccharidoses. The main objective was to understand the meaning of weekly or fortnightly hospitalization at the day hospital of a Pediatric Hospital in Rio de Janeiro from the perspective of children and adolescents with Mucopolysaccharidosis. The specific objectives were to understand how children comprehend the disease process and to discuss possible interventions of Occupational Therapy in the day hospital ambient. The research has a qualitative character and for that, the observation, interview, and the construction were mediated by productions, using the drawing or the play as relevant ways of accessing the children-juvenile contents. From the interviews and other data, an interpretative analysis was performed that resulted in the following thematic nuclei: the reorganization of the daily life of the family, the disease's consequences, the local support networks, and the influence of humanization projects and Occupational Therapy in the hospitalization process. In view of the results, it is pointed out as a conclusion that when we listening to children, it is possible to understand the dimension that the disease has on their lives and as health professionals can offer comprehensive care in the face of hospitalizations. It is believed that Occupational Therapy has much to contribute to this space while it looks at daily life and acts on human doing.

Keywords: *Hospitalization, Day Care, Medical, Child, Adolescent.*

Impactos da hospitalização parcial recorrente sob a perspectiva de crianças e adolescentes com mucopolissacaridoses em um hospital pediátrico

Resumo: O presente estudo teve como participantes crianças e adolescentes, entre sete e doze anos, que convivem com Mucopolissacaridose(s). O objetivo geral foi compreender os significados da internação semanal ou quinzenal no hospital dia de um Hospital Pediátrico do Rio de Janeiro na perspectiva das crianças e adolescentes com Mucopolissacaridose. Os objetivos específicos foram apreender como a criança entende o processo de doença e discutir possíveis intervenções da terapia ocupacional no espaço do hospital dia. A pesquisa tem caráter qualitativo e, para tanto, foram privilegiadas a observação, entrevista e a construção das produções mediadas pelo suporte lúdico, utilizando o desenho ou a brincadeira como relevantes vias de acesso aos conteúdos infanto-juvenis. A partir das entrevistas e outros dados foi realizada uma análise interpretativa que resultou nos seguintes núcleos temáticos: a reorganização do cotidiano da família, as consequências da doença, as redes de apoio no local, a influência dos projetos de humanização e a terapia ocupacional no processo de hospitalização. Tendo em vista os resultados, aponta-se como conclusão que, ao ouvir as crianças, é possível compreender a dimensão que a doença tem em suas vidas e que vai além do aspecto biológico e como profissionais de saúde podem oferecer um cuidado integral diante das internações. Acredita-se que a Terapia Ocupacional tenha muito a contribuir com esse espaço ao passo em que olha para o cotidiano e age sobre o fazer humano.

Palavras-chave: *Hospitalização, Hospital Dia, Criança, Adolescente.*

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1 Introduction

The Day Hospital (DH) or “Partial Inpatient Service” is an organizational structure of a healthcare institution where outpatient programmed care is provided. This environment offers care for a period not normally exceeding 12 hours and does not require an overnight stay (LIMA; BOTEAGA, 2001).

Several pathologies are assisted in this DH. In this place, children and adolescents live with Mucopolysaccharidosis (MPS), which results from genetic factors. MPS is caused by inborn errors of metabolism, in which the production of glycosaminoglycan degradation enzymes (GAGs) is decreased or absent. GAG accumulation directly affects the functioning of all organs (NEUFELD; MUENZER, 2001).

MPS has no cure; however, there are treatments that slow the progression of the disease and provide improvement in the quality of life and functional capacity of these people, promoting development, participation in meaningful activities and social interaction. Specific treatments include Enzyme Replacement Therapy for replacement of the specific enzyme when it is absent or deficient. This treatment is held through periodic and pre-scheduled hospitalizations for medication, affecting the individuals’ functions in their daily activities for at least once a month, and can be up to four times a month.

Bury (1982) conceptualizes chronic disease as a particular type of event that promotes a break in the individual’s daily life. The experience of hospitalization, even if partial and pre-scheduled, brings the disruption of daily life with it (COSTA; LIMA, 2002) and changes in simple routines such as going to school, leisure activities and playing (MITRE, 2006). From this, it is necessary to consider the daily life of the family, needed to be aligned with the times and days of medication, causing an impact on the organization of the family.

The health-disease process is a singular and subjective experience and through the word, the individuals express their questions (AURELIANO, 2012, p. 240). For children and adolescents, hospitalization has consequences and limitations that go beyond physical signs and symptoms, even if scheduled. The perspective of children and adolescents who go through this process of hospitalization and have their daily life altered can contribute to their integral care. Some authors such as Vieira and Lima (2002), Mitre (2006), Mello and Moreira (2010) and Garcia-Schinzari et al. (2014) deal with the effects of child hospitalization on consecutive or long

days and emphasize the need to know the impact of hospitalization, starting from the perspective of children and adolescents and understanding them as individuals who greatly collaborate with this knowledge when experiencing this process.

Velho (1978), a classic author of Anthropology, support for the advantages of reviewing and enriching research results is sought, adding what was already known (scientific studies and also by one of the researchers, through the entries by the Project of Extension of “storytelling” in a public hospital DH) which can be taken back from the research. This process of strangeness about what is familiar to us as emphasized by Velho becomes possible while the posture and management of dialogue are rethought and altered to bring out the results of the field.

When conducting research and seeking the possibilities of interventions in the field of occupational therapy in this context, there was a lack of studies with significant outcomes on the impact of recurrent partial hospitalization on the lives of these children and adolescents. This fact prompted even more questions about how occupational therapy could contribute to the care of these individuals.

The objective of this study was to understand the meanings of recurrent partial hospitalization from the perspective of children and adolescents who live with mucopolysaccharidosis during hospitalization for Enzyme Replacement Therapy. Also, the objective was to understand how these participants understand the disease process and discuss the possible interventions of occupational therapy in this space.

2 Method

This study has a qualitative exploratory approach. The perspective of children and adolescents with mucopolysaccharidosis during their hospitalization for medication was considered, exploring their experiences and their possibilities of expression as subjects of knowledge.

Qualitative studies aim to value a deeper space of relationships, processes, and phenomena that cannot be operationalized into variables (MINAYO, 2001). Turato (2005) highlights that in the context of the qualitative methodology applied to health, the conception of the Human Sciences is considered, in which it is not sought to study the phenomenon itself but to understand its individual or collective meaning for people’s lives. The researcher is the research instrument and seeks to grasp the object and how it is manifested.

In the study, participants from 12 years old according to the Child and Adolescent Statute - ECA (BRASIL, 1990) were considered as adolescents. The ethical aspects of the research contained in Resolution 466/12 of the National Health Council were followed, and the project was approved by the Ethics Committee of the hospital selected under number 2,247,962 (CAAE: 69678417.2.0000.5264). All children and adolescents signed the Consent Form and their caregivers signed the Free and Informed Consent Form.

2.1 Field and participants

The fieldwork was carried out at the Day Hospital of a pediatric hospital in Rio de Janeiro between August and September 2017, totaling nine meetings. The referred DH had six beds divided into boxes. On Wednesdays, there is Enzyme Replacement Therapy in children and adolescents with Mucopolysaccharidosis. In the hospital, there were seven patients diagnosed with MPS, between 7 and 24 years old, treated in this space, which is one of the references in the municipality in medical genetics.

When the children and adolescents arrive at the hospital, before being referred to the DH, they undergo a medical evaluation in another sector. After release, they are sent to the Day Hospital where they await the arrival of the medicine to start the infusion. The children and adolescents assisted in this space are always the same, generating a familiarity between the families and the sector staff.

Children and adolescents aged 7 to 18 years old with MPS who were on Enzyme Replacement Therapy and knew of their disease were included. Considering the inability to understand the requests and agree to participate in the research, those with any neurological injury highlighted by the team were excluded, as well as those who eventually refused to participate. There was a cut-off based on the fact that children over seven years old are in the phase of logical and coherent thinking and can verbally communicate their ideas, giving meaning to the experiences (MELLO; MOREIRA, 2010) and under eighteen, as this is the adolescent age limit established by the ECA.

At the end of the selection process, the research participants were two children, Maria 7 years old and Felipe 9 years old, and a teenager, Eduardo 12 years old. The anonymity of the research participants was maintained and allowed to choose the fictitious name mentioned above as they would like to be mentioned in the paper.

The number of participants was based on the number of children/adolescents undergoing enzyme replacement therapy for MPS in the chosen Day Hospital and meeting the criteria of this study. There were seven patients in the sector being treated. Four of them met the criteria and only three agreed to participate. The refusal of one of them can be contextualized by the situation of the child (after surgery).

2.2 Data collection procedures

Before starting the research and after its approval by the Ethics Committee, the authors visited the service, presenting the proposal and the researchers to the professionals, families and children/adolescents. The head of Genetics and the Hospital had already given letters of support to the project that were duly forwarded for consideration by the Ethics Committee.

During the collection phase, playful activities such as free design were performed and the following questions were asked: "How is it for you to be here in the hospital?" and "What is the image that comes to your mind when you think about your illness?". The questions were not modified, but the explanation, when requested by the patients was adapted according to their age but respecting the central theme. The activities, interviews and routine observation of the place were recorded in a field diary during the interview. Later, materials such as craft sheet, colored pencil, crayon and modeling clay were made available. The researchers remained during the interview held in each child's box, noting that one of the children demanded that the box be closed with the curtain and that only one of the researchers remained, but the other remained in the sector (outside the box).

Due to the familiarity of the participants with one of the researchers due to their participation in an extension project that took place at that place, their presence was confused by the children/adolescents, being initially associated with extension activities. The white coat that was different from the color used in the extension and the presence of another researcher who was not part of the project featured to change this image. Proximity to children and space was a crucial factor in facilitating acceptance and openness for the study.

2.3 Data analysis procedure

The research material was organized following the analytical theoretical perspective (GOMES et al., 2005) with:

- a) The evaluation of available material from the field according to study objectives;
- b) The elaboration of analysis structures: a construction from the thematic nuclei obtained in the field and its foundation;
- c) The contextualized and triangulated analysis of the data, enabling to triangulate the interviews with field diary information, observation of child attitudes and hospital routine establishing a dialogue between different techniques and sources;
- d) The qualitative interpretation through the use of sense analysis, speech, drawing, and observation as a way to understand the meanings, which reveals more comprehensive logic and explanations on a particular theme (GOMES, 2016), which is presented in the article from occupational therapy, chronic illness, and hospitalization.

The analysis of the production took place interpretatively (GOMES, 2011), taking into consideration: how the children were represented by themselves, what aspects they value in their life, the language and the position of knowledge beyond the management of information about the disease process through their speeches and graphical representations.

The interviews lasted an average of 40 minutes and were held more than once with Felipe (9 years old), as he was drowsy at the end and asked to continue another day, and also with Maria (7 years), who during the first interview, she was shy and requested another day.

The analysis of the interview did not focus on their drawing, but on the meaning that the children gave to the process of drawing and what is possible to understand the reality from the image produced (NATIVIDADE; COUTINHO; ZANELLA, 2008). The researchers considered the behavior of the children/adolescents when drawing. As an example, what they reported about what they did, change in layout or physiognomy, emotion, if the drawing portrayed what was said in the interview; that is, behaviors considered relevant about the object of study.

Vygotsky (1998) understands children's drawing from the historical-cultural context in which the child is inserted. Thus, to understand the drawing, it is necessary to listen to what the child says about his production.

The interview was recorded at the same time, considering the presence of two researchers, one conducted it and both were writing. The answers of the children/adolescents were in short sentences, allowing annotation during the interview, and in a smaller amount, unlike what happens with adults in the same process. Records were also made in a field diary shortly after the interview ended from the researchers' memories. The drawings made were more prominent by the subjects of the field being emphasized in the analysis. It was possible to identify thematic fields or nuclei (GOMES, 2011; GOMES, 2016) brought by the children/adolescents that will be discussed later. Also, actions from the speeches and observation of the sector were identified that can be addressed by Occupational Therapy.

3 Results and Discussion

The results come from the data obtained in the interview, data analysis from the field diary and observation of the drawings and attitudes presented. To understand them, an interpretative analysis was performed to grasp the nuclei of meaning that were constructed: the reorganization of the family's daily life, consequences of the disease, support networks, the influence of humanization projects and occupational therapy in the hospitalization process.

3.1 The reorganization of the family's daily life

The discovery of a chronic disease produces changes in the daily life of both the individual who receives the diagnosis and his family. In the case of diseases in children, their parents/caregivers are the ones that most undergo changes in their routines (VIEIRA et al., 2008). Chronic illness can disrupt structures of daily life, such as relationships and work, which makes the expectations and plans that individuals have for the future be reevaluated (BURY, 1982).

The disorganization of the family's daily life is inevitable, especially when the child needs recurrent hospitalizations, a common fact when dealing with a chronic condition (SILVA et al., 2010). In the case of the interviewed children and adolescents, the medication is pre-scheduled, with a clear beginning and end. Thus, it does not require prolonged hospitalization.

During the interviews, the family's routine change appeared in the speeches of two of the three children interviewed. This change ranges from changes in the daily routine of the primary caregiver to changes

in plans, for example, traveling, always having to adjust them to the day of medication.

Although the theme of the question was about how it is for this child to be in the hospital and how he sees his illness, the answers were especially highlighting family relationships, especially with the mother. Chronic disease causes individuals, their families and closes social networks to face the purest form of relationship (BURY, 1982).

In all the speeches appeared the perception of the child focusing on their mothers who are always present, showing concern about the changes in their routine and the burden that the disease causes. In one of the interviews, the child brought up the fact that how discovering the disease changed the family routine, mentioning things such as having to get up early, spend the day in the hospital and wait for the medicine to arrive.

The production of Eduardo, 12 years old was a highlight in Figure 1. When asked what he thinks about his illness, he promptly answered: *"I think about my mother"*. When asked why he explained that his mother is a warrior because she takes care of him. Such speech demonstrates how much the adolescent is not oblivious to what happens around him.

Several studies have discussed how chronic diseases in childhood affect the mother's life. Gavazza et al. (2008) and Alves and Bueno (2018) bring data highlighting a prevalence of over 90% of care for children with disabilities/illnesses mainly under the responsibility of mothers or female figures. Even ten years from one study to another, the data remain current. Vieira et al. (2008) add that, in general, fathers assume financially part of the care while the care provided to the child, such as dressing, feeding and accompanying them to treatments and consultations are the responsibility of the mother.

Silva et al. (2010) stated that the title of caregiver is often implicit in the role of the mother as being responsible for caring for the children. Therefore, in situations of illness, it is up to the mother to reorganize her routine to meet the needs of her children. Given the interviews, the children and adolescents were sensitive to these repercussions in the mother's life, being aware of the changes, demonstrating the recognition, gratitude, and spirituality through the drawing (Figure 1, Figure 2 and Figure 3) and speaking. Santos et al. (2018) reaffirm the importance of spirituality as a positive point for self-esteem and strengthening resilience in everyday situations, favoring the involvement of these individuals in their occupations at home, at school and even at the hospital.

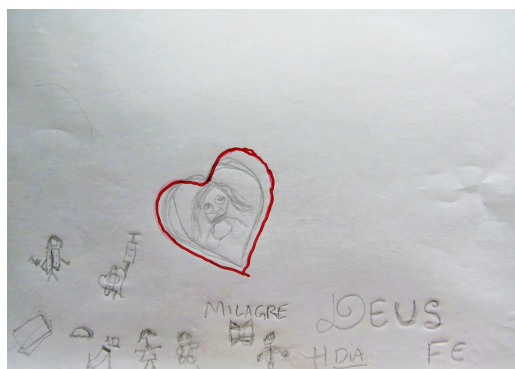


Figure 1. Drawing in which the child shows the mother within a heart. In the drawing appear words like "Miracle", "God" and "Faith".



Figure 2. Drawing in which the child shows the disease as a monster.



Figure 3. In the drawing, the child shows her family.

3.2 Consequences of the disease

As a progressive disease that affects the lubrication of the joints, its consequences are impaired connective tissue leading to loss of joint mobility, lag in the range of motion of various joints (especially shoulders and elbows), the loss of muscle strength, postural changes, changes in the peripheral nerves and carpal tunnel

leading to functional loss of thumb and claw hand (ROCHA et al., 2012). In some joints, such as knees, hips, and elbows, impairment becomes visible even in childhood (CARDOSO-SANTOS et al., 2008).

Faced with the need to live with the disease, which requires frequent hospitalizations, children and adolescents become familiar with the procedures, drug names, even appropriating a technical vocabulary (VIEIRA; LIMA, 2002). All the participants were knowledgeable about their clinical conditions, being able to explain the procedures and medications they use during treatment. Although one of the children faced with the question about what comes to her mind when she thinks about the disease answered that she does not understand very well, she had an understanding about the procedures performed by the nursing staff.

Given this, when asked about the disease, the patients brought both positive and negative aspects. Felipe, 9, described that he does not like the consequences on his hands because due to the disease, he cannot close them completely, pointing out that it is difficult to perform daily activities, for example, writing and eating. When asked what comes to his mind when he thinks about the disease, Felipe represented a monster, something that was bad (Figure 2).

The disease can sometimes be characterized as something negative since there is deprivation of daily activities and social participation (VIEIRA; LIMA, 2002; MELLO; MOREIRA, 2010). Faced with a chronic disease, the structure of daily life is transformed, requiring the patient to mobilize different resources to face and deal with the disease, so their life trajectory is traced according to his possibilities and limits (MITRE, 2006; ALVES, 2014).

Felipe highlighted that in his hospitalization process, the moment of puncture is the worst part due to fear of pain. However, for Maria, 7 years old, waiting for medicine is the moment that generates the most anxiety, because it is what determines how long she will stay in the hospital. Eduardo highlighted the fact that he understands that medication is good for his health, demonstrating to understand the importance and necessity of medication. Routine hospital care such as medication and punctures can influence social participation and end up being part of the impacts of hospitalization and chronicity even in the face of scheduled hospitalization.

Questions regarding the disease to Eduardo such as short stature do not affect him, defending it as a good feature. When asked what he thinks of the disease, he answered: *“the disease defines me,*

because she brought me to the hospital” (sic). Aureliano (2012) in his research debates how much the vision around the disease and treatment goes beyond the particular visions, built from the interactions it establishes with the surroundings.

Children and adolescents understood the need for treatment and hospitalizations but as reported by Eduardo and Maria, they would like to be at home, performing daily activities and playing. In Eduardo’s speech, he would like a miracle: that he could do the treatment at home or to be cured. However, while demonstrating this desire, he also says that he is afraid of losing the “Day Hospital family”. While making his report and drawing, Eduardo was agitated (he was trying to draw and handle the playdough), although he said calmly that he understood that he had to be in the hospital. Such behavior in drawing reinforced the contradiction he felt and acknowledged the interactions established with the people of the DH.

By playing as a resource, it is possible to observe the positive and negative repercussions through the child’s attitudes. This is a necessary strangeness when acting with playing. Even drawing is considered a pleasant moment, it has generated an agitated behavior, highlighting problems about the question that speech alone would not be able to convey.

In addition to the physical consequences in Eduardo’s speech, issues such as lack of significant spaces for him also appeared such as physical education and leisure classes, and the church. Although medication is considered a limiting factor that prevents him from regularly attending these spaces, he demonstrated the success in reconciling them with pre-booked hospitalizations. The school has knowledge about its clinical condition and reports having activities, such as content and tests adapted to his medication routine.

Maria did not comment on the disease. She said she knew what it was, but did not fully understand, she was reserved when questioned. When approaching children and adolescents, confidentiality is one of the main strategies for intervention adherence proposals (COSTA; BIGRAS, 2007). Although Maria requested total privacy during the interview, she spoke with little information about her health condition. In the end, she requested the presence of another researcher, who previously had not allowed entering the box, but she could not tell about the interview, she only showed her drawings.

Being aware of the disease as we were told in choosing the research participants did not mean knowing what was going on and giving the child

the right not to speak up about it. For Mitre (2006), the experience of illness occurs in different ways for children and adolescents, even if they share the same diagnosis and the same hospitalization space.

3.3 Supporting networks

The children and adolescents assisted on Wednesdays are always the same, which favors the emergence of the bond between the families and the hospital staff. In the speech of all children/adolescents, the importance of the people in that space emerged, from patients and caregivers to professionals. During the observation, it was possible to notice the existing friendship. In fact, during the research, there was a program of festive date for the following month and the researchers were invited to participate on the day of the event, including other mothers who did not participate in the study.

Costa and Bigras (2007) emphasize the importance of support networks at the treatment place. They discuss the importance of safety networks as the associations and institutions that support and offer them support, and the importance of social networks as the formation of the bond by interconnected people and groups, enabling the sharing of experiences. The identification of social networks, meaningful to the patient during treatment, can serve to help professionals, providing better direction of actions and care for the family and hospitalized patients (MENEZES; MORÉ; BARROS, 2015).

During the free drawings, all the children/adolescents wanted to draw the people who were present at Day Hospital and their closest family members. The importance of the nursing team care for treatment also appeared, highlighting the management differences during puncture.

Mitre (2006) emphasized the importance of establishing a bond and trust relationships between children and health professionals as a facilitator in the treatment process.

Also, the family has large participation in the process, which can be seen in the drawings. All of them stressed their importance for treatment. In Figure 3, the drawing by Maria stands out, showing her family. During the interview, she referred a lot to her family and the support she receives.

In Figure 2 presented earlier, the representation of family and friends is also possible to be noticed.

For children who live with a chronic illness, the hospital space often becomes part of their social space. It was possible to notice the importance of establishing a bond between children, professionals,

and caregivers as an efficient support network that facilitates treatment adherence.

3.4 The influence of humanization projects

Space is marked by the performance of humanization projects such as storytelling, clowning and Living Library. One of the days of the interview had the storytelling project.

Of the interviewees, the adolescent Eduardo is the one who has been treated at the hospital for the longest time, given his age. When asked how it is to be in the hospital, he replied that the conviviality is good, that at first he did not like, but he got used to it. When asked what has changed since the beginning of his treatment, he mentioned the storytelling project.

In all the interviews, humanization projects were mentioned as facilitators for their weekly hospital visits. The stories help to overcome fear, sadness and idleness (GARCIA-SCHINZARI et al., 2014) and by reducing the focus on the disease, it is possible to provide relief and better acceptance of treatment, as seen in the interviews.

The positive participation of these children and adolescents during the activities developed by the projects was possible to be observed as an opportunity not related to their illness, which seems to alleviate the discomfort caused by this hospitalization. Such meetings refer to a naturalness of play, which seemed not to be occurring within the hospital space. This was enhanced as children and adolescents exercised their right to choose whether or not to listen to stories and which book they wanted to enjoy.

These moments offer children/adolescents the possibility of moving from a passive position, of the condition of the patient, to a more active one, moving to action and developing their potentialities (VIEIRA; LIMA, 2002).

For Garcia-Schinzari et al. (2014), the hospital is still a space that causes fear and distress in many children/adolescents and their families, which is why humanization programs should be increasingly used as strategies to reduce the negative effects of hospitalization.

3.5 Occupational therapy in the hospitalization process

Defined by the American Association of Occupational Therapy (AMERICAN...,2015), the occupational therapist uses daily activities (occupations) to favor

or enable the participation of individuals cared for in the different spaces in which they live. During this study, there were possibilities of occupational therapy acting with these children and adolescents in the hospital space.

According to Carlo, Bartalotti and Palm (2004), the occupational therapist is the professional responsible for promoting the occupational life of the patient, by addressing physical conditions that are compromised by the disease and acting in the construction of their autonomy and independence for an active life. The occupational therapist is trained to help children and family members to cope with the hospitalization process.

The promotion of the quality of life of the patient who is hospitalized or whose routine is marked by recurrent hospitalizations is paramount, being necessary to address issues related to the hospital environment, school and leisure activities and family life (OTHERO; CARLO, 2006).

The playful activities performed with the children and adolescents during the research allowed access to the elaboration of their expressions and meanings about the treatment process (MELLO; MOREIRA, 2010). Through the interviews, it was possible to identify occupational roles such as being a child and being a student, which in many reports is hampered by the development of the disease or the compulsory hospitalization for medication.

Recurrent hospitalizations cause several changes in the routine of life of these children and adolescents, including school, as observed in the statements of Eduardo. In these children/adolescents, the medications are pre-scheduled, facilitating the organization of the routine. However, the importance of articulations with network devices is observed. In this sense, family, school, and hospital should establish dialogues and provide conditions for the continuity of school to be preserved.

There are situations that facilitate the school learning process, as Eduardo explained in his speech by saying that the activities are organized according to the days he is in school, and the opportunity for reinforcement classes, in an attempt to alleviate the difficulties of missing school.

It is necessary to understand that this clinical condition may limit the participation of this individual in educational activities, leisure and play and social participation (MITRE; PFEIFER, 2008). The health team should be aware not only of the demands brought but also those that are omitted (COSTA; BIGRAS, 2007). Eduardo in his speech brought issues of social participation, such as church activities and Physical Education classes, which he considered a loss due to the day of

medication. Both Felipe and Maria did not comment on specific losses, perhaps because they are younger than Eduardo and are in the early school stage that requires different demands as a student. This differs from what adolescents and children bring needs to be analyzed by professionals who work with these subjects and provoke to think about how to approach this topic in health care. Regardless of their level of development, the aspects brought by the participants were considered relevant.

Playful activity is inherent to children and is an essential element for motor, cognitive and social development and should be used as a resource and objective in the treatment of occupational therapy. Playing enables children to exercise their ability to experience what they are feeling, conveying their needs, anxieties, and desires (MITRE; PFEIFER, 2008).

The children/adolescents interviewed knew that they need to adjust to physical and social limitations in this treatment process. Thus, both parents and health professionals should encourage them to maintain autonomy and independence, typical of their developmental phase (VIEIRA; LIMA, 2002).

Given the fieldwork, the occupational therapist is seen as a promoter of actions that can enable the development of the child/adolescent, facilitating engagement in their occupations and supporting participation in the context in which they live. Their hospitalization occurs once a week, so the follow-up could be performed to identify specific intervention such as playful activities, which provide the elaboration of the understanding about the treatment, and use of assistive technologies such as prescription of orthoses mobility devices.

In general, the guidance on the importance of performing activities of daily living, playing and the school can be offered to children/adolescents and the family in this space, raising doubts and establishing strategies that will solve possible demands. Limitations related to the consequences of upper limb disease as brought about by Felipe may be addressed by the occupational therapist.

The daily reorganization that these children/adolescents and their families suffer must be carefully approached by the occupational therapist since the disease has no cure and treatment is performed in person. Articulating with the family and the hospital regarding medication schedules and day is critical for this task to have the least possible impact on the routine of these families. It is up to the occupational therapist to reinforce the importance of treatment, but also that there is more than that, to understand these patients, their rights and to act to promote active participation in their contexts.

4 Final Considerations

This study identified some of the changes that involve recurrent hospitalization in the lives of children/adolescents who experience a chronic condition in childhood. The reorganization of the family's daily life, the consequences of the disease, the local support networks, the influence of humanization projects and the occupational therapy in the hospitalization process appeared in the fieldwork.

When listening to children and adolescents, we realized the dimension of the disease in their lives, which is experienced in a unique way, that is, as a personal experience. Due to the treatment, the children/adolescents have their routines changed and the hospital assumes an important dimension during this process.

The feelings of fear of the moment of infusion, weekly hospitalization and loss of leisure time are highlighted and configure a scenario of rupture and suffering for these children and adolescents. Recognizing the changes in the daily lives of these people is an important step to initiate follow-up and differentiated care. At the same time, the relationships established in the hospital should be valued facilitating the bond between the family and the team.

Given the results, what is significant for these people is observed, contributing to new reflections on how the occupational therapist and other professionals can perform care for children and adolescents, who have the process of growth and development permeated due to recurrent partial hospitalizations.

There was no characterization of the history of children/adolescents and the option not to record or film during the field can be considered limitations of the study.

As suggestions for future research, the study in different institutions can be expanded, including the report of the caregivers who follow the recurrent hospitalization and who had prominence in the children's speech, besides the children's report.

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References

- ALVES, C. *As condições crônicas de saúde na infância e adolescência e as tessituras do cuidado*. Rio de Janeiro: Editora Fiocruz, 2014
- ALVES, S.; BUENO, D. O perfil dos cuidadores de pacientes pediátricos com fibrose cística. *Ciência & Saúde Coletiva*, Rio de Janeiro, v. 23, n. 5, p. 1451-1457, 2018.
- AMERICAN OCCUPATIONAL THERAPY ASSOCIATION – AOTA. Estrutura da prática da Terapia Ocupacional: domínio & processo. *Revista de Terapia Ocupacional da Universidade de São Paulo*, São Paulo, v. 26, p. 1-49, 2015.
- AURELIANO, W. As pessoas que as doenças têm: entre o biológico e o biográfico. In: GONÇALVES, M.; MARQUES, R.; CARDOSO, V. *Etnobiografia: subjetivação e etnografia*. Rio de Janeiro: 7 letras, 2012. p. 239-261.
- BRASIL. Lei nº 8.069, de 13 de julho de 1990. Dispõe sobre o Estatuto da Criança e do Adolescente e dá outras providências. *Diário Oficial [da] República Federativa do Brasil*, Poder Executivo, Brasília, DF, 13 jul. 1990.
- BURY, M. Chronic illness as biographical disruption. *Sociology of Health and Illness*, Boston, v. 4, n. 2, p. 167-182, 1982.
- CARDOSO-SANTOS, A. et al. Mucopolissacaridose tipo VI (síndrome de Maroteaux-Lamy): avaliação da mobilidade articular e das forças de garra e de pinça. *Jornal de Pediatria*, Rio de Janeiro, v. 84, n. 2, p. 130-135, 2008.
- CARLO, M.; BARTALOTTI, C.; PALM, R. A Terapia Ocupacional em reabilitação física e contextos hospitalares: fundamentos para a prática. In: CARLO, M.; LUZO, M. C. *Terapia Ocupacional: reabilitação física e contextos hospitalares*. São Paulo: Roca, 2004. p. 3-28.
- COSTA, J.; LIMA, R. Crianças/adolescentes em quimioterapia ambulatorial: implicações para a enfermagem. *Revista Latino-Americana de Enfermagem*, Ribeirão Preto, v. 10, n. 3, p. 321-333, 2002.
- COSTA, M. C.; BIGRAS, M. Mecanismos pessoais e coletivos de proteção e promoção de qualidade de vida para a infância e adolescência. *Ciência & Saúde Coletiva*, Rio de Janeiro, v. 12, n. 3, p. 1101-1109, 2007.
- GARCIA-SCHINZARI, N. R. et al. Caixas de histórias como estratégia auxiliar do enfrentamento da hospitalização de crianças e adolescentes com câncer. *Cadernos de Terapia Ocupacional da UFSCar*, São Carlos, v. 22, n. 3, p. 569-577, 2014.
- GAVAZZA, C. et al. Utilização de serviços de reabilitação pelas crianças e adolescentes dependentes de tecnologia de um hospital materno-infantil no Rio de Janeiro, Brasil. *Cadernos de Saúde Pública*, Rio de Janeiro, v. 24, n. 5, p. 1103-1111, 2008.
- GOMES, R. Análise e interpretação de dados de pesquisa qualitativa. In: MINAYO, M. C. S.; DESLANDES, S. F.; GOMES, R. *Pesquisa social: teoria, método e criatividade*. Petrópolis: Vozes, 2011. p. 79-108.

- GOMES, R. Análise e interpretação de dados de pesquisa qualitativa. In: MINAYO, M. C. S.; DESLANDES, S. F.; GOMES, R. *Pesquisa social: teoria, método e criatividade*. Petrópolis: Vozes, 2016. p. 81-93.
- GOMES, R. et al. Organização, processamento, análise e interpretação de dados e desafios da triangulação. In: MINAYO, M. C. S.; ASSIS, S.; SOUZA, E. *Avaliação por triangulação de métodos: abordagem de programas sociais*. Rio de Janeiro: Editora FioCruz, 2005. p. 185-221.
- LIMA, M. C.; BOTEGA, N. J. Hospital-dia: para quem e para quê? *Revista Brasileira de Psiquiatria*, Rio de Janeiro, v. 23, n. 4, p. 195-199, 2001.
- MELLO, D. B.; MOREIRA, M. C. A hospitalização e o adoecimento pela perspectiva de crianças e jovens portadores de fibrose cística e osteogênese imperfeita. *Ciência & Saúde Coletiva*, Rio de Janeiro, v. 15, n. 2, p. 453-461, 2010.
- MENEZES, M.; MORÉ, C.; BARROS, L. Redes sociais significativas de familiares acompanhantes de crianças hospitalizadas. In: CONGRESSO ÍBERO AMERICANO EM INVESTIGAÇÃO QUALITATIVA, 4., 2015, Aracaju. *Anais...* Aveiro: Ludomedia, 2015, p. 59-59.
- MINAYO, M. Ciência, técnica e arte: o desafio da pesquisa social. In: MINAYO, M. *Pesquisa social: teoria, método e criatividade*. Petrópolis: Editora Vozes, 2001. p. 9-31.
- MITRE, R. O brincar no processo de humanização da produção de cuidados pediátricos. In: DESLANDES, S. *Humanização dos cuidados em saúde: conceitos, dilemas e práticas*. Rio de Janeiro: Editora Fiocruz, 2006. p. 283-300.
- MITRE, R.; PFEIFER, L. Terapia Ocupacional, dor e cuidados paliativos na atenção integrada. In: CARLO, M. Q. *Dor e cuidados paliativos: Terapia Ocupacional e interdisciplinaridade*. São Paulo: Ed. Roca, 2008. p. 258-284.
- NATIVIDADE, M. R.; COUTINHO, M. C.; ZANELLA, A. V. Desenho na pesquisa com crianças: análise na perspectiva histórico-cultural. *Contextos Clínicos*, São Leopoldo, v. 1, n. 1, p. 9-18, 2008.
- NEUFELD, J.; MUENZER, E. The mucopolysaccharidosis. In: SCRIVER, C. R. et al. *The metabolic and molecular bases of inherited disease*. New York: McGraw-Hill, 2001. p. 3421-3452.
- OTHERO, M. B.; CARLO, M. M. A família diante do adoecimento e da hospitalização infantil: desafios para a terapia ocupacional. *Prática Hospitalar*, São Paulo, v. 8, n. 47, p. 100-104, 2006.
- ROCHA, J. S. et al. Avaliação do desempenho motor em crianças com Mucopolissacaridose II. *Caderno de Terapia Ocupacional da UFScar*, São Carlos, v. 20, n. 3, p. 403-412, 2012.
- SANTOS, W. et al. Terapia Ocupacional em oncologia pediátrica e cuidados paliativos. In: CARLO, M.; KUDO, A. *Terapia Ocupacional em contexto hospitalar e cuidados paliativos*. São Paulo: Payá, 2018. p. 145-158.
- SILVA, M. A. et al. Cotidiano das famílias no enfrentamento da condição crônica na infância. *Acta Paulista de Enfermagem*, São Paulo, v. 23, n. 3, p. 359-365, 2010.
- TURATO, E. Métodos qualitativos e quantitativos na área da saúde: definições, diferenças e seus objetos de pesquisa. *Revista de Saúde Pública*, São Paulo, v. 29, n. 3, p. 507-514, 2005.
- VELHO, G. Observando o familiar. In: NUNES, E. O. *A aventura sociológica*. Rio de Janeiro: Editora Jorge Zahar, 1978. p. 36-47.
- VIEIRA, M. A.; LIMA, R. A. Crianças e adolescentes com doenças crônicas: convivendo com mudanças. *Revista Latino-Americana de Enfermagem*, Ribeirão Preto, v. 10, n. 4, p. 552-560, 2002.
- VIEIRA, N. G. et al. O cotidiano das mães com crianças portadoras de paralisia cerebral. *Revista Brasileira em Promoção da Saúde*, Fortaleza, v. 21, n. 1, p. 56-60, 2008.
- VYGOTSKY, L. *A formação social da mente*. São Paulo: Livraria Martins Fontes, 1998.

Authors' Contribution

The authors were responsible for conducting the research and elaboration of the article together. Tainara Brites de Freitas worked on the conception and writing of the article. Olivia Souza Agostini worked on the text review, analysis and reasoning and she guided the first author in the development of the research. Both authors approved the final version of the text.

Notes

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