



## SCHOOL REINTEGRATION FROM THE PERSPECTIVE OF CHILDREN AND ADOLESCENTS WITH CHRONIC ILLNESSES

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### ABSTRACT

**Objective:** Analyze the experience of children and adolescents with chronic illnesses in the school reintegration process.

**Method:** Qualitative study with a descriptive-explorative design, conducted in a pediatric ward of a public hospital in the interior of São Paulo, with 15 children and adolescents with chronic diseases, who interrupted their school attendance due to demands associated with the treatment of the disease. Semi-structured interviews were conducted, and data was subjected to inductive thematic analysis procedures. The study followed all ethical precepts (opinion no. 2,911,290). **Results:** Based on the analyses, four themes were constructed: (1) "Social, academic and emotional impact of hospitalization"; (2) "Hospital routine: strategies to recover academic performance"; (3) "Challenges and joys resulting from returning to school"; and (4) "Support networks for children and adolescents with chronic illnesses in the school reintegration process". **Conclusion:** Children and adolescents with chronic illnesses who experience school reintegration need support in this process, especially to maintain the connection with school during the absence and in the reintegration phase. The results of this research can assist health professionals in planning care, considering the academic needs of this population.

**Keywords:** Qualitative Research. Chronic Disease. Return to School. Child. Adolescent.

### INTRODUCTION

Pediatric chronic diseases are considered a relevant public health problem, with a strong impact on the number of premature deaths and the quality of life of those affected<sup>(1)</sup>. In the last 50 years, worldwide, the number of families of children and adolescents living with these diseases has quadrupled<sup>(1)</sup>. In the child and adolescent population, the most prevalent and/or most demanding care include: cancer (CA), chronic kidney disease (CKD), type 1 diabetes mellitus (DM1), cystic fibrosis (CF), asthma and rheumatological diseases<sup>(2)</sup>. Particularly, children and adolescents with chronic illness face several difficulties and need to adapt to a life routine that demands care resulting from this

diagnosis<sup>(3)</sup>. Therefore, the collaborative work of an interdisciplinary team<sup>(4)</sup> with children and adolescents with chronic illnesses and their families during treatment is essential, to guarantee the right to schooling, access, formation of social and personal identity, as well as for the development of motor, cognitive and social skills<sup>(5)</sup>.

School reintegration is defined as a period in which the child or adolescent is away from school and later returns to classes, and, in the context of chronicity, this occurs due to the demands of therapy<sup>(6,7)</sup>. Children and adolescents with chronic illness face several difficulties in relation to schooling, such as: lack of information in the school environment about the disease, lack of interest on the part of

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hospitals regarding the academic situation of their patients, deficiency in communication between hospital and school and lack of commitment on the part of school management to improve the integration of sick students into the school environment<sup>(6,8)</sup>.

Two reviews summarized the main evidence available in the literature on school reintegration. The first, a systematic review carried out by English researchers, analyzed articles published between 1981 and 2000 regarding school absence, behavioral problems and social difficulties of children with cancer in the school reintegration process<sup>(9)</sup>. The results highlighted the concern about excessive absences due to the demands of the disease and treatment, although absences decreased over time. Furthermore, peers and teachers noticed a tendency for these children to be more isolated and demonstrate more sensitive behaviors than their healthy peers<sup>(9)</sup>.

The second, a systematic meta-review with children with chronic diseases, analyzed 172 studies published between 2001 and 2013 and found that the chronic diseases that trigger the highest rates of school absenteeism are asthma, cystic fibrosis, heart disease, gastrointestinal diseases, chronic kidney disease and cancer<sup>(10)</sup>. The results of this review highlight the diverse experiences of school reintegration of this population, with the negative ones being related to greater severity of the disease, greater number of signs and symptoms of the disease and treatment, and low socioeconomic status. On the other hand, effective models of support for school reintegration were associated with the success of this process for this part of the population<sup>(10)</sup>.

The literature also presents empirical research on the topic. In Belgium, a quantitative study carried out with parents of 60 children with chronic illnesses aimed to investigate their perspectives on school reintegration<sup>(11)</sup>. In the Brazilian context, few studies on the subject were identified<sup>(6,12,13)</sup>, and they aimed to understand the process of school reintegration, mainly in the context of oncological and renal treatment. However, the objectives are aimed at identifying the psychologist's acting strategies<sup>(12)</sup> in the context of school reintegration, as well as the mothers' perspective on this event<sup>(6,13)</sup>.

Therefore, although the studies presented have addressed the phenomenon of school reintegration, it is important to highlight the lack of research on the experiences of school reintegration of children and adolescents with chronic illness in the Brazilian context, from the perspective of this portion of the population. Given this, the question arises: What is the experience of children and adolescents with chronic illness in the process of school reintegration? Therefore, this study aimed to analyze the experience of children and adolescents with chronic illness in the school reintegration process.

## METHOD

Study using a qualitative approach and descriptive-explorative design. The Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines were used as a guide for the development and description of the present study<sup>(14)</sup>. This research was submitted to the ethics committee for research with human beings and approved under opinion number 2.911.290, CAAE n° 91370718.8.3001.5440, on September 24, 2018. All ethical precepts to obtain consent from those responsible and assent of children and adolescents were properly monitored.

The invitation to new participants took place in the pediatric ward of a public university hospital in the interior of the state of São Paulo. Data were collected before the start of the Covid-19 pandemic, between October 2018 and August 2019. This study included 15 children and adolescents between the ages of 7 and 18, diagnosed with chronic diseases (diabetes, cancer, chronic kidney disease and cystic fibrosis), who had the experience of school reintegration, that is, returning to school attendance, after interruption due to demands associated with chronic disease therapy. Children and adolescents who had pathologies that affected verbal communication were excluded from this study. This assessment was carried out through observation by the researchers during the first contact with the potential participant and through information collected from the health team.

Semi-structured interviews were carried out with guiding questions regarding the history of

the diagnosis, living with the chronic disease, absence and return to school, in addition to the support of parents, friends and health professionals. Some questions were: “How has your daily life been since you started treatment?”; “How did you leave school?”; “How did you go back to school?”; “How did your family help during this time of returning to school?”; “How your family made it difficult to return to school?”; “How could health professionals help you when you return to school?”.

The invitation to new participants was interrupted when the set of data collected proved to be sufficient to achieve the objective of the study<sup>(15)</sup>. The data were analyzed concomitantly with collection, according to guidelines for inductive thematic analysis, in accordance with the recommendations of Braun and Clark<sup>(16,17)</sup>. The audio-recorded interviews were transcribed and inserted into the QDA Miner Lite® software<sup>(18)</sup>, which helps in the organization and analysis of qualitative data. Data familiarization occurred through repetitive reading of the transcribed interviews, in the first stage of analysis. In the second stage, initial codes were constructed inductively and aggregated by similarity to form themes, in the third stage of analysis. Subsequently, the constructed themes were reviewed, in accordance with the objective of the study. In the fifth and sixth stages, there was refinement and validation of the names of the themes, with consequent production of the final synthesis, presented in the results session.

## RESULTS

15 participants aged between 8 and 16 years old were included (mean of 12). Of these, 2 were diagnosed with chronic kidney disease, 5 with cancer, 3 with cystic fibrosis and 5 with type 1 diabetes mellitus, 7 of whom were male and 8 were female. The mean absence from school was 150 days.

From the analysis of the interviews, four themes were constructed: ‘social, academic and emotional impact of hospitalization’; ‘hospital routine: strategies to recover academic performance’; ‘challenges and joys resulting from returning to school’; and ‘support networks for

children and adolescents with chronic illnesses in the school reintegration process’.

### Social, academic, and emotional impact of hospitalization

The departure from the usual context generated a deficit in the social interaction of children and adolescents with chronic illnesses in relation to individuals of the same age, with whom they had previous emotional bonds. At times when they needed hospitalization due to therapeutic demands, participants reported feelings of sadness due to the interruption of their school routine.

Ah, a little sad. Because on my first day of school I already had to go to hospital (E10, 8 years old, female, FC).

A little sad about being away from my friends and my teacher (E5, 8 years old, female, CA).

Missing people was the term they used to express the impact generated by social isolation due to hospitalization. They missed, mainly, their school friends and the games they used to play in the school context.

“I miss my colleagues” (E7, 14 years old, male, DM1)

“I missed my friends and playing” (E3, 13 years old, male, CA).

In addition to missing people, reports emerged about fear, resulting from delays in subjects and the possibility of failure, due to the lack of participation in school activities associated with “points” and “grades”.

“I also fell behind in my subjects. Then I “had to get” (the content) from my sister. I was worried about not passing the subjects” (E4, 13 years old, female, DM1);

“I was afraid of failing and not being able to go to school anymore” (E12, 16 years old, female, DM1).

### Routine in the hospital: strategies to recover school performance

The participants' school reintegration began in the hospital context, as pedagogical activities were developed during hospitalization to make up for the absence of regular education. Children and adolescents reported that their mothers were the

main source of connection and communication between the school and the hospital. They often informed the school about the hospitalization and requested teaching materials and educational activities for the school, in order to help monitor school subjects, learning and return to activities after hospitalization. Mothers also delivered school assignments and controlled the impact of these activities on the final academic assessment.

"I'm doing schoolwork here at the hospital." My mother is going to get the books and notebooks from school, and then she will teach me. I also clear my doubts with my mother" (E1, 14 years old, male, CKD).

My mother tells the school when I have to go to hospital. The teachers already know my case and prepare tasks for me to do. Generally, teachers give assignments for two weeks and, if I only stay in hospital for that long, when I return home the next day, I go to school and take it. But if I stay longer, my mother will go there (at school) to take me and pay more (E12, female, DM1).

When asked about their school routine during hospitalization, children and adolescents reported using internet resources, such as e-mail, video classes, Google, and WhatsApp as tools to facilitate the teaching-learning process.

"I watch video classes, sometimes I search on Google" (E12, 16 years old, female, DM1).

Furthermore, family members, such as mothers and older siblings, and friends from school also helped to clarify doubts regarding carrying out educational activities.

My mother will pick up (school assignments). The exercises in the books. My mother receives the exercises I have to do via email, she doesn't go to school. The principal takes it from the teachers and sends it to my mother. My mother calls them and says I'm hospitalized. The tasks are for a whole week and, if I stay here for more days, they will do it (E14, 11 years old, male, FC).

Then my friends send me the tasks they have to do via WhatsApp and, when I have any questions, I ask them or watch video classes on my cell phone (E8, 14 years old, male, CA).

In addition to internet resources, the hospital class was cited as a strategy to facilitate the teaching-learning process, specifically education professionals who work in this space. However, participants reported that the activities proposed

in this context were often limited to drawings, simpler exercises, or exercises at previous levels than what children and adolescents did at school, before hospitalization. Participants classified these tasks as a consolidation of knowledge previously constructed in schools and not as a strategy for developing new knowledge. Often, the activities offered in the hospital class were also classified by participants as recreational activities.

The teachers here give me drawings. {And exercises like the ones you did at school?} No, just drawings (E3, male, CA).

I've been to the hospital class; I even have tasks there. [...] I think it's cool because, at least, I won't sit still, I won't stop studying. It's possible to practice the things I've already learned. {Do you learn new things too?} No, just the exercises you had already learned at school (E4, 13 years old, female, DM1).

### Challenges and joys resulting from returning to school

Chronic diseases are generally associated with repercussions on diet and physical appearance, with these aspects cited as challenges to returning to school. Because they had dietary restrictions, it was common for participants to not be able to eat school lunch, just like others. The change in physical appearance was uncomfortable, as it drew the attention of other students due to the use of a mask, oxygen, medication, and the presence of alopecia, for example. Furthermore, being away from school resulted in consequences such as difficulty in resuming the rhythm of studies and, therefore, in recovering academic performance.

I can't eat things with sugar. So, I bring snacks from home. Oh, I'm a little sad because I don't eat the same things as my friends, but my mother makes delicious things for me to take (E6, 12 years old, female, DM1).

I felt a little strange because I was wearing a mask. {What was it like for you to wear a mask at school?} Oh, some people kept looking at me. {How did you feel?} At first, I was sad, but then everything became normal (E8, 14 years old, male, CA).

Ah, I felt a little difficult because I saw that others already knew a little more like this. But I asked for

help and tried to clear up any doubts. But I had a little difficulty with some exercises (E11, 14 years old, female, CA).

In contrast to the challenges, there was satisfaction in being welcomed by friends and teachers. Participants reported joy at having been discharged and being able to return to their school routine, with their peers, as is expected for children and adolescents their age.

"I felt a little strange, because I was wearing a mask, but I was happy to go back to school" (E8, male, 14 years old, CA).

### **Support networks for children and adolescents with chronic illnesses in the school reintegration process**

Children and adolescents with chronic illnesses have weakened social interactions during hospitalization but seek support to overcome the demands related to school reintegration. For the participants in this study, family, friends, and hospital class teachers were part of this support network. However, the majority did not identify health professionals as support in the reintegration process, although they believed they could perform this function by liaising between hospital and school, for communication and guidance to teachers and colleagues about the current health situation.

Everyone in my family welcomed me, helped me, especially my sister. They asked if I was okay to go to school, that sort of thing. My sister helped with the chores. (E4, 13 years old, female, DM1)

When the class teacher corrects my assignments, she helps me, so I don't fall behind. (E11, 14 years old, female, CA)

The desire for health professionals to become part of the support network was mentioned, creating coordination between the hospital and the school.

If they talked to the teachers and sent me a task to do here. {Why do you think this would help?} Because then I would do my schoolwork here and when I came back it would be easier to follow up. (E9, female, CA).

## **DISCUSSION**

The results of this study describe the experience of children and adolescents with chronic illnesses in the process of school reintegration. The first theme presented in the results highlights how hospitalization impacts the emotional, social, and academic aspects of this population.

Participants reported, mainly, a feeling of missing their friends and playing. Another study demonstrated the recognition of families and nurses that the restrictions imposed by treatment lead to separation from friends and usual recreational activities, as well as the importance of promoting these moments of interactions with friends<sup>(19)</sup>. Nurses specializing in CF state that it is essential to provide socialization for adolescents with CF with their peers, as social restrictions can generate feelings of dissatisfaction and, consequently, abandonment of treatment<sup>(19)</sup>.

Because they were away from school due to hospitalization, participants reported feeling afraid, for fear of not being able to follow the activities when they returned to school and, therefore, failing. There is evidence that the school reintegration process is a challenge for this population, capable of generating anguish, especially when there is high therapeutic demand, and this is not adequately managed by health professionals and families. This compromises the time available to carry out school activities and, consequently, school performance<sup>(19-21)</sup>.

The results of this research also highlight that children and adolescents are concerned about how they will interact with friends and teachers when they return to school. They wonder whether there will be differences in relationships in relation to their healthy peers, and what challenges they may face in this process, due to changes in physical appearance and eating habits, for example. Another study shows that parents of children with chronic illnesses are also apprehensive about these aspects, so that, throughout the school reintegration process, this becomes a common concern, experienced by both parents and children<sup>(19)</sup>.

During the hospitalization period, children and adolescents identified the hospital class as a strategy to recover school performance. However, some considered that the activities were not up to the level of those previously carried out at school. Furthermore, the majority reported a lack of

communication between the hospital and the school, and that the activities carried out in the hospital were not accepted upon return to school. This, it is worth highlighting, differs from what is foreseen in Brazilian legislation on the rights of children and adolescents and the requirements related to the Ministry of Education (MEC), since Brazilian law guarantees, among the rights recognized to children and adolescents<sup>(22)</sup>, the right to education. However, the living conditions of children and adolescents with chronic illnesses and their families often make it difficult to realize this right<sup>(23)</sup>. The education to be provided to children who are sick and hospitalized, undergoing frequent outpatient treatment or home treatment, has also been covered and regulated for more than two decades in the country<sup>(24)</sup>.

In 1995, Resolution 41 of the National Council for the Rights of Children and Adolescents listed, among the rights of children and adolescents, that of "...enjoying some form of recreation, health education programs, monitoring the school curriculum during their hospital stay"<sup>(24)</sup>. Although this document refers to hospitalized children and adolescents, later documents expand the idea, as they defined as hospital class the specialized care offered to students unable to attend classes due to health treatments that involve hospitalization or outpatient treatment. The documents also cover home care for those who, due to health problems, must remain at home for long periods<sup>(25)</sup>.

It is the duty of the hospital class teacher to coordinate the hospital's health team with the state or municipal Department of Education and with the school, in order to contribute to the restoration of health and guarantee, through compliance with the curriculum, the continuity of studies and approval of the child for the next school year<sup>(26)</sup>. However, what we identified in this study is the lack of intersectoriality with the school and, furthermore, that the activities carried out by children and adolescents during the hospitalization period did not contribute to the academic curriculum.

In addition to the hospital class, children and adolescents used internet resources such as video classes, e-mail, and instant messaging on platforms such as WhatsApp as a strategy to recover their academic performance, which gave them access to activities carried out at school so

that they could achieve indirectly follow the teaching-learning process, but without pedagogical support. This reinforces the importance of professionals working in the hospital profession providing support to this population<sup>(27)</sup>, guiding and assisting in the use of technological tools effectively.

Children and adolescents who experience chronic illness need to be heard, so that their real care demands are highlighted. Living with the challenges imposed by the disease is less painful when they have an effective social network, capable of offering support in all phases of the chronic disease<sup>(6,28)</sup>. In this study, participants reported that their support networks were family and friends. Family support is present in the child's daily life and can be demonstrated in the care and attention in relation to treatment, and through the bridge between the contexts of health and education. However, for family members to build this knowledge, health professionals must be available to talk, listen and support them, exchanging information and providing guidance<sup>(29)</sup>.

It is noteworthy that the reports of the participants in this study highlighted the lack of recognition of hospital professionals as part of the support network for the school reintegration process. In this sense, one can reflect on the importance of professional educators and health professionals in developing articulation between the two contexts, so that they can have support to face the challenges associated with the school reintegration process.

Faced with a growing number of students with chronic health conditions that require management during their attendance at school, and the need to promote the development of the relationship between the contexts of health and education, the presence of the school nurse is important. The school nurse has a crucial role in the continuous provision of services, being a member of the school team, whose role is to provide preventive services and early identification of problems, interventions and referrals that favor the joint promotion of educational success and health, as well as coordinated work between health and education professionals<sup>30</sup>.

Furthermore, it is important to highlight the importance of coordination between schools and

basic health units, to promote continuity of care for children and adolescents with chronic illnesses and the development of health education activities, in view of the proximity to the community. Furthermore, this articulation helps these children's peers understand their health needs and are able to act as care collaborators, ideally becoming part of the support network in the school reintegration process<sup>(6)</sup>.

## CONCLUSION

By analyzing the perspective of children and adolescents on school reintegration, it was possible to identify their needs, weaknesses, and potential throughout the process. In view of this, it is necessary for health professionals to reflect on their practice, to plan care that considers the demands related to school reintegration, as one of the results of this study highlighted, precisely, the absence or failure of dialogue between school and hospital.

The hospital class is a resource that, when used effectively, can strengthen the connection with the school of origin. The continuity and academic performance of hospitalized children and adolescents occurs through educational activities and reports sent from the hospital class to the school of origin. Furthermore, the multidisciplinary team plays an essential role in overcoming the walls of the hospital and promoting coordination between hospital and school.

Care management must also be promoted with the family to balance health and education demands. It is suggested that health professionals work together with the school to promote school reintegration through care guidelines and the promotion of reliable information. In this way, it will be possible for teachers and healthy peers to understand and assist in the school reintegration process for children and adolescents with chronic illnesses.

We consider the inclusion of participants with different chronic diseases to be a strength of this study, as it allowed the identification of similarities in experiences in the process of school reintegration in the context of chronicity. However, the fact that most of the participants study in public schools prevents the results on screen from representing the phenomenon for those who experience school reintegration in the context of private schools, which can be considered a limitation of this study.

Based on this investigation, it is suggested that future research explore different perspectives on the phenomenon, such as the perception of parents, health professionals, teachers and peers who live and experience the school reintegration process of children and adolescents with chronic illnesses. Knowing different perspectives can help to strengthen the available evidence and, therefore, help health professionals to implement evidence-based care, according to the specific needs of this population during the school reintegration process.

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## REINserÇÃO ESCOLAR NA PERSPECTIVA DE CRIANÇAS E ADOLESCENTES COM DOENÇAS CRÔNICAS

### RESUMO

**Objetivo:** Analisar a experiência de crianças e adolescentes com doenças crônicas no processo de reinserção escolar. **Método:** Estudo qualitativo, de natureza descritiva-exploratória, conduzido em uma enfermaria pediátrica de um hospital público do interior paulista, com 15 crianças e adolescentes com doenças crônicas, que interromperam a frequência escolar por demandas associadas à terapêutica da doença. Entrevistas semiestruturadas foram conduzidas e os dados submetidos aos procedimentos da análise temática indutiva. O estudo seguiu todos os preceitos éticos (parecer nº. 2.911.290). **Resultados:** Com base nas análises foram construídos quatro temas: (1) "Impacto social, acadêmico e emocional da hospitalização"; (2) "Rotina no hospital: estratégias para recuperar o rendimento escolar"; (3) "Desafios e alegrias consequentes ao retorno à escola"; e (4) "Redes de apoio à criança e ao adolescente com doença crônica no processo de reinserção escolar". **Conclusão:** Crianças e adolescentes com doenças crônicas que vivenciam a reinserção escolar necessitam de apoio neste processo, principalmente para manutenção da conexão com a escola durante o afastamento e na fase de reinserção. Os resultados desta pesquisa podem auxiliar os profissionais de saúde no planejamento do cuidado, considerando as necessidades acadêmicas dessa população.

**Palavras-chave:** Pesquisa qualitativa. Doença crônica. Retorno à Escola. Criança.

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## REINserCIÓN ESCOLAR EN LA PERSPECTIVA DE NIÑOS Y ADOLESCENTES CON ENFERMEDADES CRÓNICAS

## RESUMEN

**Objetivo:** analizar la experiencia de niños y adolescentes con enfermedades crónicas en el proceso de reinserción escolar. **Método:** estudio cualitativo, de naturaleza descriptiva-exploratoria, conducido en una enfermería pediátrica de un hospital público del interior paulista, con 15 niños y adolescentes con enfermedades crónicas, que interrumpieron la frecuencia escolar por demandas asociadas a la terapéutica de la enfermedad. Fueron conducidas entrevistas semiestructuradas y los datos sometidos a los procedimientos del análisis temático inductivo. El estudio siguió todos los preceptos éticos (dictamen nº. 2.911.290). **Resultados:** con base en los análisis fueron construidos cuatro temas: (1) "Impacto social, académico y emocional de la hospitalización"; (2) "Rutina en el hospital: estrategias para recuperar el rendimiento escolar"; (3) "Desafíos y alegrías consecuentes al retorno a la escuela"; y (4) "Redes de apoyo al niño y al adolescente con enfermedad crónica en el proceso de reinserción escolar". **Conclusión:** niños y adolescentes con enfermedades crónicas que experimentan la reinserción escolar necesitan apoyo en este proceso, principalmente para mantener la conexión con la escuela durante el alejamiento y en la fase de reinserción. Los resultados de esta investigación pueden ayudar a los profesionales de salud en la planificación del cuidado, considerando las necesidades académicas de esa población.

**Palabras clave:** Investigación Cualitativa. Enfermedad Crónica. Regreso a la Escuela. Niño. Adolescente.

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