

HOSPITAL SCHOOL CARE TO ADOLESCENTS WITH CHRONIC RENAL FAILURE: THE VOICE OF USERS

ATENDIMENTO ESCOLAR HOSPITALAR AOS ADOLESCENTES COM INSUFICIÊNCIA RENAL CRÔNICA: A VOZ DOS USUÁRIOS

ATENCIÓN HOSPITALARIA ESCOLAR A ADOLESCENTES CON INSUFICIENCIA RENAL CRÓNICA: LA VOZ DE LOS USUARIOS

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ABSTRACT: The objective of this research was to understand how transplanted adolescents with chronic renal failure perceive hospital school attendance. It is a qualitative study, which was based on the phenomenological method. Data were collected through interviews with a semi-structured script with three adolescents and those responsible for two of them. The data showed that only one teenager had hospital school assistance. They also indicated the importance of this service for the continuation of schooling. However, the data indicated that outpatient care for student-patients, such as hemodialysis and consultations, does not guarantee them attendance by Hospital Classes. It is concluded that, although the legislation guarantees the right to hospital school attendance of student-patients, such service is still restrictive and does not cover all cases of students who are away from school activities due to health problems.

KEYWORDS: Hospital school attendance. Hospital class. Right to education. Schooling of hospitalized student.

RESUMO: O objetivo desta pesquisa foi entender como adolescentes com insuficiência renal crônica transplantados percebem os atendimentos escolares hospitalares. Trata-se de um estudo qualitativo, o qual teve por base o método fenomenológico. Os dados foram coletados por meio de entrevista com roteiro semiestruturado com três adolescentes e os responsáveis por dois deles. Os dados mostraram que apenas um adolescente dispôs do atendimento escolar hospitalar. Indicaram, também, a importância desse atendimento para a continuidade da escolarização. Contudo, os dados assinalaram que os cuidados ambulatoriais de alunos-pacientes, como hemodiálise e consultas, não garantem a eles o atendimento pelas Classes Hospitalares. Conclui-se que, apesar de a legislação garantir o direito ao atendimento escolar

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hospitalar dos alunos-pacientes, tal serviço ainda é restritivo e não abrange a todos os casos de alunos afastados das atividades escolares por problemas de saúde.

PALAVRAS-CHAVE: *Atendimento escolar hospitalar. Classe hospitalar. Direito à educação. Escolarização de estudante hospitalizado.*

RESUMEN: *El objetivo de esta investigación fue comprender cómo los adolescentes con insuficiencia renal crónica trasplantada perciben las visitas a la escuela hospitalaria. Se trata de un estudio cualitativo, basado en el método fenomenológico. Los datos fueron recolectados a través de una entrevista con guión semiestructurado con tres adolescentes y los responsables de dos de ellos. Los datos mostraron que sólo un adolescente tenía atención hospitalaria. También indicaron la importancia de este cuidado para la continuidad de la escolaridad. Sin embargo, los datos indicaron que la atención ambulatoria a los estudiantes-pacientes, como la hemodiálisis y las consultas, no les garantiza la atención de las clases hospitalarias. Se concluye que, si bien la legislación garantiza el derecho a la atención hospitalaria de los estudiantes-pacientes, este servicio sigue siendo restrictivo y no cubre todos los casos de estudiantes retirados de las actividades escolares debido a problemas de salud.*

PALABRAS-CLAVE: *Atención escolar hospitalaria. Clase hospitalaria. Derecho a la educación. Escolarización del estudiante hospitalizado.*

Introduction

This study is constituted in the field of Special Education and has as its central theme hospital school care (COVIC, 2003). Part of the recognition of education as the right of all citizens and the duty of the State to promote it by offering it (BRASIL, 1988, 1996; CURY, 2008). Thus, the understanding of Education is assumed as a social right and for all, guaranteed from the access and permanence of the subjects in the school environments, extending, therefore, to hospitalized students (FANTACINI, 2018).

With these assumptions, the present article aims to understand how adolescents with transplanted chronic renal failure perceive the hospital school care experienced in their trajectory.

Students, with health problems and hospitalized, prevented from attending regular school, also have the right to educational care in the hospital environment. According to Gonçalves, Pacco and Pedrino (2019, p. 2, our translation), "hospital educational care aims to minimize the effects of hospitalization, as well as to offer continuity to the schooling process". In this sense, hospital classes, as one of the school care services in the hospital environment,

can continue the process of schooling of hospitalized students, thus collaborating with the treatment of the disease and with the recovery of health.

Gonçalves, Pacco and Pedrino (2019) point out that the hospitalization period causes many changes in the lives of the hospitalized individual and his/her family members, who require proper coping. Thus, it is salutary to ensure that students in hospitalization can find care that provides experiences similar to those experienced in the educational context, an environment that stimulates the desire to act with knowledge and follows the schooling process. However, it is important to emphasize that, as a modality of care, hospital classes are still little present in Brazilian hospitals, and there is little research on this scarce in the area of education.

In Brazil, the Hospital Classes date back to 1950, in the city of Rio de Janeiro-RJ, at the Hospital Municipal Jesus. Initially, care was made in the children's beds, because there were still no specific facilities for the educational service in the hospital. Pedagogical practices aimed to know what the student was learning in his home school or even what they already knew, thus enabling the planning and sequence of the schooling process (SANTOS; SOUZA, 2009). Later, in 1960, another hospital in the city of Rio de Janeiro-RJ, Barata Ribeiro, implemented hospital pedagogical care. The service did not have support from the State of Rio de Janeiro, but had the support of the hospital's management, thus being possible its implementation and operation (SANTOS; SOUZA, 2009).

Specifically, in the *locus* hospital of the research that underlies this text, hospital classes were created in the 1970s and, from creation to the present day, assumed different forms of organization and functioning.

It was only from the 1980s that this service expanded to other hospitals in the State of São Paulo and other regions of Brazil, causing a gradual increase in the supply in such hospital and the demand for this care by the sick and their guardians (CAVALCANTE; GUIMARÃES; ALMEIDA, 2015).

According to Araújo (2017), Brazil had, in 2017, 148 hospitals with hospital school care, in various regions, states and municipalities. This study shows that two states (São Paulo and Rio de Janeiro) from the southeast region and one from the Midwest region (Distrito Federal) were the pioneers in hospital school care. Moreover, the data analyzed indicate that most programs/policies happened between 1999 and 2009.

From a legal point of view, hospital care was provided for in the Law of Guidelines and Bases of National Education No. 9,394/1996, Article 4, which determines that

Educational care is ensured, during the hospitalization period, to the basic education student hospitalized for health treatment in hospital or home for a prolonged period, as available to the Public Power in regulation, in the sphere of its federative competence (BRASIL, 1996, art. 4, our translation)

The hospital classes were considered as the modality of Special Education in Resolution No. 2 that instituted the National Curriculum Guidelines for Special Education in Basic Education (BRASIL, 2001). According to this resolution

Art. 13. The teaching systems, through action integrated with the health systems, should organize specialized educational care to students unable to attend classes due to health treatment that implies hospitalization, outpatient care or prolonged stay at home.

§ 1 - Hospital classes and home care should continue the development process and learning process of students enrolled in Basic Education schools, contributing to their return and reintegration to the school group, and develop a flexible curriculum with children, young people and adults not enrolled in the local educational system, facilitating their subsequent access to the regular school.

§ 2 - In the cases of this Article, the frequency certification must be carried out based on the report prepared by the specialized teacher who assists the student (BRASIL, 2001, p. 4, our translation).

According to the document Hospital class and home pedagogical care: strategies and orientations (BRASIL, 2002, p. 13, our translation), the hospital class is defined as

[...] pedagogical-educational care that occurs in health care environments, either in the circumstance of hospitalization, as traditionally known, or in the circumstance of the service in hospital-day and hospital-week or in comprehensive mental health care services.

Thus, it aims to create conditions for the student to continue the schooling process, as well as to promote the integration between the school and the hospital classes. According to this document, such resources, such as network computer, television, VCR, camera, adapted materials, etc., used in the care, are essential for the teacher's planning, the development of meetings and the evaluation of the pedagogical work performed.

The National Policy of Special Education in the Perspective of Inclusive Education (BRASIL, 2008, p. 14, our translation) recognizes hospital classes as a space for professional activity of teachers in the area of special education, who must have a solid education, that is, "[...] to have as a basis for their initial and continued training, general knowledge for the exercise of teaching and specific knowledge of the area".

More specifically, Resolution No.4, of October 2, 2009, which Establishes Operational Guidelines for Specialized Educational Care in Basic Education, Special Education modality (BRASIL, 2009), also guarantees hospital care for the target audience of Especial Education,

i.e., "Art. 6º. In cases of Specialized Educational Care in a hospital or home environment, special education will be offered to students⁴, through their respective education system in a complementary or supplementary way" (BRASIL, 2009, p. 2, our translation). Thus, it will be extended only to the target public students of special education, having its practice in the Multifunctional Resource Room of the school in which the student is enrolled or in another regular educational institution, happening in the period after schooling in the hospital environment.

According to the above, the hospital class aims to continue the schooling process (teaching/learning) favoring the student to return to school in a condition of continuing his schooling process. This modality, therefore, "resource important for maintaining the bond between sick children and school" (TINÓS *et al.*, 2018, p. 240, our translation).

Regarding the forms of organization and functioning, the hospital classes serve children, adolescents and adults enrolled in basic education. Given the diversity of this audience, it is assumed that such service is guided by the principle of flexibilization and considers the particularities/needs of each student (SOUZA; TELES; SOARES, 2017) aiming at welcoming the restrictions imposed by the hospital and its conditions (CECCIM, 1999). In view of this, as the teachers of the hospital class work with human diversity, they should therefore verify the educational needs of each of the students present there, as well as think and use various teaching methodologies and resources to meet the specificities of school curricula. It should be added that the visits can be in a specific space or in beds, individual or in groups (BRASIL, 2002). As for the planning of the work of the hospital class, this should happen due to the different educational contexts, aiming to ensure the progression of the schooling process, promoting accessibility and means for the student to learn and acquire the conditions to reinsert themselves in the common class, when released from hospitalization (FONSECA, 2008; SCHMENGLER; FREITAS; PAVÃO, 2018). For this, it is essential that teachers have solid initial and continuing education, a training that provides means to organize the care of students with different ages and levels of education and from different schools and educational networks.

According to Ceccim (1999, p. 42, our translation), "The hospital class, as educational pedagogical care, should be based on educational-school proposals, and not on proposals for playful education, recreational education or health education." This means that the planning of hospital class care should be guided by the curriculum of the regular school where the student

⁴ Segundo the resolution in its fourth paragraph, the target public students of Specialized Educational Care, are children and adolescents with physical, intellectual, mental or sensory disabilities, with global developmental disorders and with high abilities/gifting.

does not attend. Thus, hospital care, although being developed within the hospital, is linked to the work/curriculum articulated in the regular school in which the student is enrolled, which implies interaction of the hospital class with the common classes for the development of planning and pedagogical practices (BRASIL, 2002).

The approximation between hospital care and regular school, from the perspective of multidisciplinary work, favors the continuity of the schooling of these students (MATOS; MUGIATTI, 2014). In this case, multidisciplinary work is configured by the articulated performance of health and education professionals, in favor of the development and continuity of the student's treatment and schooling process.

Studies have demonstrated that pedagogical care for the sick has helped in the recovery of health, since the mediation of the education professional provides adaptation, motivation and continuity in the schooling process, thus cooperating with the effectiveness of the education law also in the case of hospitalized students (FANTACINI, 2018; GONÇALVES; PACCO; PEDRINO, 2019; PACCO, 2017). This positive result is possibly due to the fact that such care provides the link between the hospitalized student and the world outside the hospital.

A study by Pacco (2017) indicates that, in the various hospital classes in Brazil, care is individually or in groups. Individually, there is a total focus on the student and his/her particularities, and, in a group, he proposes socialization and exchange of experiences with the other. With regard to the organization of these hospital classes, the study emphasizes that they follow some guidelines – in relation to organization, curriculum, material resources, etc. – and that they are produced by the state school system, noting that some follow municipal or national documents.

According to the above, it is evident that there are guidelines that guide the work of teachers in hospital classes; however, they do not snore the care, which should consider the specificities and needs of their students. For Mazer-Gonçalves (2013), there is no single way to develop work in the hospital environment, there is a multiplicity of ways, since it must be organized according to the students and their particularities.

In order to guarantee the right to education in the hospital environment, the spaces inside the hospital need to be planned, designed and organized to offer the minimum conditions so that children and adolescents can fully enjoy the care, according to the needs of each one (COVIC, 2003; FONSECA, 2008).

Thus, some of the care can take place in specific classrooms, in playrooms, in wards, in bed or in an isolation room according to the specificities of the students (COVIC, 2003). The activities, material resources and organization of the environments will be demanded by the

specificities of each case; however, since 2002, a minimum number of audiovisual resources has been provided, including: "network computer, television, VCR, camera, cam recorder, digital satellite dish and stereo with CD and k7, as well as telephone" (BRASIL, 2002, p. 16). These resources aim to support the teaching and learning process and provide the contact of these hospitalized students with their colleagues and teachers of the regular school.

Regarding the training of the teacher responsible for hospital school care, the State Department of Education and The Board of Education - Ribeirão Preto Region, Accreditation Notice, establishes the following order of preference of accreditation:

- I - Holders of full degree in Pedagogy, with qualification for teaching, accompanied of certificate of specialization course in Hospital Pedagogy;
- II - Holders of full degree diploma in any discipline, accompanied by certificate of specialization course in Hospital Pedagogy;
- III - Holders of diploma of Full Degree in Pedagogy, with qualification for teaching, accompanied by certificate of course of updating in Hospital Pedagogy of at least 60 (sixty) hours;
- IV - Holders of full degree diploma in any discipline, accompanied by certificate of course of update in Hospital Pedagogy of at least 60 (sixty) hours;
- V - Holders of a Full Degree in Pedagogy with qualification for teaching;
- VI - Holders of full degree in Psychology;
- VII - Holders of full degree diploma in Pedagogy, with qualification for teaching the pedagogical disciplines of the Magisterium Course;
- VIII - Holders of high school diploma, with qualification in teaching, accompanied by certificate of course of updating in Hospital Pedagogy, with a minimum duration of 60 (sixty) hours;
- IX - Holders of full degree diploma in any discipline (SÃO PAULO, 2018, p. 1-2, our translation).

More specifically, the document Hospital class and home pedagogical care: strategies and orientations (BRASIL, 2002), recommends that the teacher working in the hospital space be preferably graduated in Special Education, but can be graduated in Pedagogy or other teacher training courses, with "senses about the diseases and psychosocial conditions experienced by the students and the characteristics of them arising, clinically, from an affective point of view" (BRASIL, 2002, p. 23, our translation). With these trainings recommended by Brazil (2002) and São Paulo (2018), it is believed that the teacher is able to adapt and adapt the activities, materials and the environment, as well as create strategies for flexibility and adaptation of the curriculum.

Studies such as those of Abreu (2014), Carvalho (2015) and Schneider and Martini (2011) discuss these changes highlighting treatments that do not require prolonged hospitalizations, but rather from the frequency of the hospital on a few days a week or hours a day, resulting in the suppression of the right of the student to hospital school care. This situation

includes patients with Chronic Renal Failure, who leave school as very often, for example, on several days of the week when they go to the hospital for hemodialysis treatment. This type of treatment is not offered in all hospitals, which often requires students to travel to hospitals in large centers in search of this resource. For these reasons, chronic disease can be a stressful factor in the development of adolescents, as it directly interferes in many individual and social aspects. Silva *et al.* (2017) state that chronic diseases do not simply include organic or physical alterations of the patient, but promote emotional and important changes throughout the family, which require constant care and adaptations. Moreover, the daily routines of the patient need to undergo adaptations, through consultations, tests and daily treatments that, in the case of Chronic Renal Failure (IRC), usually include specific treatments for the maintenance of renal function.

In view of the previously discussed questions about the right to hospital school care for students and the conditions of supply, this article seeks to understand how patients with transplanted Chronic Renal Failure perceive hospital school care experienced in their trajectory.

Methodological Procedures

This research is based on the qualitative approach (LUDKE; ANDRÉ, 1986) and the phenomenological method, according to the proposal of Martins and Bicudo (2005). According to the authors, it is a method that focuses on the phenomena found from the research, so the analysis and understanding of the phenomenon only happen through the subjects' statements. The analyses were undertaken according to Moreira's phenomenological perspective (2002) and in the steps presented by Giorgi (1985), therefore, following the following trajectory:

- Preparation of the interview script;
- Performing the interviews (they were recorded and transcribed);
- General reading of the transcribed interviews, to broadly understand the school trajectories described;
- Rereading the transcriptions, aiming to discriminate "units of meaning" according to the research's objective. These units of meaning are spontaneously perceived discriminations within the subject's description and according to the researcher's intentional posture (MOREIRA, 2002);
- Finally, to obtain the understanding of the researched phenomenon, analyses of the units of meaning were made through the thematic categories unveiled. These categories contain

the essence of the phenomenon, which, in turn, means the processing of the subject's everyday language in scientific language.

The study was carried out in the premises of a state public hospital in a medium-sized city in the countryside of the State of São Paulo. Regarding ethical aspects, the Research Project was first referred to the Research Ethics Committee of the Faculty of Philosophy, Sciences and Letters of Ribeirão Preto of the University of São Paulo and obtained a favorable opinion⁵, that is, approved by the committee. With the approval of the project, I contacted a professional appointed by the hospital and this made it possible to approach patients who could participate in the research in view of the objectives of the study and the criterion of being in treatment for at least five years.

The participants of the research were, therefore, three student-patients (Anna Beatriz, Luiz Otávio and Bernardo⁶), aged 12 to 18 years, diagnosed with Chronic Renal Failure (IRC)⁷, and the parents of two of them. The following table shows the characteristic of these three participants, specifically regarding age, level of schooling and diagnosis of the disease:

Table 1 - Age, level of schooling and diagnosis of the disease

Participants	Anna Beatriz	Luiz Octavio	Bernardo
Age and year of schooling	17 years and 3rd year of high school	17 years and 3rd year of high school	14 years and 8th grade of elementary school
Diagnosis and treatment (Transplant Period)	Chronic Renal Failure - Hemodialysis and Transplantation (2012-2013)	Chronic Renal Failure - Peritoneal Dialysis and Transplantation (2003 - 2006)	Chronic Renal Failure - Hemodialysis and Transplantation (2003). *The adolescent has other diseases.

Source: Prepared by the authors

As a data collection procedure, the interview with the participants was used in order to understand their perceptions about the realization of the right to education during the hospitalization period. It is also emphasized that the collection happened during the second semester of 2017 and the experiences of hospital school care reported and reflected by the participants occurred in hospitalizations in the period from 2000 to 2017.

⁵ Opinion of CEP No. 2,173,056.

⁶ Fictitious names.

⁷ Chronic Renal Failure – IRC is a disease that affects the renal functions of the subject, that is, it is characterized by renal dysfunction, to different degrees, and may evolve to the renal failure disease (RIYUZO *et al.*, 2003).

Initially, the interviews were arranged with the three adolescents and, later, with the guardians of two of them, the father and mother of one and the mother of the other. The interview with the adolescents was based on the following semi-structured script: 1. Tell a little about you, your family and your routine; 2. Tell us which schools you have attended to date; 3. Tell us what it was like to study in these schools; 4. Tell me how your schooling was after the discovery of the chronic disease.

To start, contact was made by telephone with the parents of the adolescents to explain the work and make the invitation to participate. Then, the invitation to the adolescents was also made and, from the acceptance, the first meeting was scheduled. In this first meeting with each of the adolescents, the data collection procedure was presented and the interview was re-interviewed.

It is emphasized, again, that the analysis of the interviews, based on the phenomenological method (MARTINS; BICUDO, 2005), was carried out using in principle the units of meaning proposed by Moreira (2002) and Giorgi (1985), initially made only with adolescents, the need for a dialogue with parents was discovered to obtain greater detail of school trajectories. Thus, another telephone contact was made to invite them to participate in an association. The parents of two of the participants accepted (Anna Beatriz's mother and Luiz Otávio's parents), but Bernardo's parents did not, in view, the particular moment they were going through. The interview with the parents was guided by the following script if misstructured: 1. Tell a little about your child; 2. Tell us how was the process of discovery and treatment of chronic disease; 3. Tell them which schools your child attended and how he/she went to school. Why did they opt for the private network?; 4. How the school dealt with chronic disease in relation to adaptations, activities, contents, evaluations, etc.; 5. Tell us how your child's schooling process was with chronic disease. The interviews with the adolescents and their parents were recorded and, after it, transcribed by one of the researchers. Finally, it is worth mentioning that parents and/or guardians signed the Informed Consent Form, related to the participation of adolescents and their own participation, as well as, from the authorization of those responsible, the adolescents signed the Free and Informed Consent Term - TALE.

Results and discussions

Data analysis showed that the presence of hospital school care occurred in a punctual manner, according to the experiences lived by the three participants of this study. In addition, the study showed varied forms of organization and functioning.

Of the three participants, only Bernardo had care in the Hospital Class during hospitalization periods due to his comorbidities. He points out that the activities performed in the hospital were related to the work of the school, as can be seen in the speech below:

"I've done a lot of activities related to what I'm doing in school [...]" (Bernardo).

In view of this,

This aspect of the experience is in line with the Law of Guidelines and Bases of National Education No. 9,394/1996 (BRASIL, 1996) and law no. 13,716 of September 24, 2018, which amends the current LDB (BRASIL, 1996) to ensure educational care for basic education students hospitalized for health treatment in hospital or home for a prolonged period (BRASIL, 2018). According to the document "Art. 4^oa. Educational care is ensured, during the hospitalization period, the basic education student hospitalized for health treatment in hospital or home for a prolonged period" (BRASIL, 2018, our translation).

It should be clarified that this care by the hospital classes presupposes that the hospitalized student is enrolled in the regular school system (public or private). In addition, it turns only to those who are hospitalized. As previously stated, students in treatments that do not involve hospitalization are not considered public of hospital classes. However, some treatments require the student to be absent from school for several days a week, as is the case with hemodialysis in specialized nephrology services whose average duration is three to three hours, three times a week (BARBOSA; VALADARES, 2009). This is the case of Luiz Otávio and Anna Beatriz who, because they were not hospitalized for long periods, did not receive hospital school care, so it can be observed in their statements.

*"[...] I had no follow-up outside of school [...]" (Anna Beatriz).
"I don't think so." (Luiz Octavio).*

In addition, Luiz Otávio's manager reaffirms the non-provision of hospital school care and when returning to regular school the teacher struggled to work all the contents of the semester in which the student was away.

"With nothing. Because then, it was when he came back in August that she gave everything he had to learn..." (Amanda).

In this respect, we identified a serious problem in ensuring the right to education of these students. Even if they do not remain hospitalized in the hospital, they leave school on the days of the procedure, with this suffering considerable and systematic interruption of school

activities with evident losses to school achievement. This problem worsens even more considering that the regular school teacher works alone and does not have assistants to help him recover the contents for these students on the days when they attend the school. In addition, these students have a very stressful routine of attendance to hospitals on several days of the week, including in many cases, commuting to other cities; therefore, receiving some care in the hospital could minimize the suffering routinely imposed on these children and adolescents. In the understanding of this study, students in this situation should be contemplated by hospital school care, as this would minimize the disadvantages experienced in the school trajectory.

Anna Beatriz mentioned in her report that she received a care during the three weekly days of hemodialysis for a while, however, it was not hospital class care, but rather a volunteer work of a pedagogy student, as shown in the excerpts below:

When I started doing hemodialysis that I was hospitalized, so I was more or less like this, had the school, then the teachers offered help, if also, when I was at a vacation (Anna Beatriz).

There was, I don't know who it is[...] I don't know what college she does, if it was pedagogy anyway, but she called M., she even daughter of a colleague of my mother's, she was going to college at the time, and she was getting the research work, so she went to talk to Dr. I., and started visiting us, bringing something for us to do, talk about school, how i was, and she helped me a lot in that part, sometimes I had some difficulty doing something, she helped me, and just like all the other patients who did with me (Anna Beatriz).

Although relevant, voluntary work, in this circumstance, does not guarantee the permanence of the service or the necessary relationship with the regular school for the link between the school curriculum and the work developed in the hospital.

Reis (2017) states that hospital school care (hospital class) is part of formal education, has the potential to contribute to the continuity of schooling and to improve the possibilities of school dropout, or even student failure. In this sense, depending on the forms of organization, it may be directly related to the development and learning of the student-patient.

According to the report of Luiz Otávio's mother, he, as a child, underwent a kidney transplant and never had care during post-transplant recovery. When she returned to regular school, the teacher created some conditions to recover and supply her absence during the semester and in which the transplant was done and favor the continuity of the year.

In view of the above, it was clear that hospital school care is a very important service for children and adolescents who are in health care, because it strengthens their identity as students, ensures the learning process, as well as contributes to express their feelings and experiences within the hospital, as Gonçalves consider, Pacco and Pedrino (2019).

In this perspective, Albertoni (2014, p. 34, our translation) argues that

By maintaining the rights of the child to education, the care provided in the hospital classes contributes to coping with the stress of hospitalization, thanks to the meaning and symbolic value of the school in the composition of the experiences of children and youth who, then rescued despite the condition of hospitalization, rebalance the psychic development of children and adolescents.

Thus, the guarantee of the right to education in the hospital environment, in addition to contributing to the continuity of the schooling process, "[...] it is capable of reviving the student, weakened by the process of illness and treatment, leading him to seek healing, stimulated by the desire for continuity to life" (REIS, 2017, p. 94, our translation), that is, it helps in coping with the disease and all the challenges caused by the situation in which it finds itself.

In the trajectories constructed, it was found, both in the reports of adolescents and those of their parents, that they do not recognize the continuity of school processes as a right in the case of students with chronic diseases, possibly because they are unaware of the laws that ensure the right to this care, which points to the lack of information and the need for dissemination of school services in hospital environments. In addition to this ignorance, who would be responsible for the patients and guardians on hospital classes? Trying to answer this question and reflecting on the importance of the link between the hospital class and the regular school student, in the understanding of this study the function of guiding them on this right, it would be up to the regular schools and the professionals responsible for the hospital classes.

Melo and Cardoso (2007, p. 115, our translation) value the performance of hospital class teachers in this period. For such authors,

The teacher enters as a link in the relationship between the child and the hospital environment, between the child and the family member, and, mainly, between the child/adolescent and the regular school, opportunistic interaction between these three institutions, contributing to the child/adolescent's adaptation to changes in their daily lives.

Given these considerations, the bond established between the hospital teacher and the regular school teacher makes possible the interaction between the world that is outside the hospital and the hospital environment, thus benefiting the students, regarding the guarantee of curricular follow-up and preparation for returning to regular school at the appropriate time (BRASIL, 1994; REIS, 2017).

Listening to the adolescents participating in this and their families gave room for recognizing how significant the bond between the teachers responsible for the hospital classes

and the teachers of the regular school, especially for the qualified mediations with these students and their families, essential in the organization of care, in the school and in the hospital. This interaction between teachers can even avoid a possible disarticulation between these segments, besides providing conditions for the maintenance of the schooling process.

Finally, in addition to the issues already discussed, it is worth mentioning that the three adolescents exposed in the interview their pertinent longings to schooling. Anna Beatriz expressed her claim to study medicine.

My focus, my dream is medicine, I always wanted dentistry until the eighth grade, then I went to a trade fair and I saw that it was not what I wanted, it was not what I would like to do every day, then in my head when I started doing hemodialysis I saw that, so, I lost a lot of things because I went only twice a week at school, then Monday, Wednesday and Friday I had to go to the tertiary hospital in the region of Ribeirão Preto and there was no way I could go to school, then in my head I get into medicine was very ... A thing very distant, then I thought I'll do nursing because it is a very noble area too, and my focus is to help people [...] (Anna Beatriz).

In view of the passage, it is observed that Anna Beatriz has the dream of being able to help people, just as she received the care of health and education professionals. In addition, he stressed the importance of education and continuation of his schooling, for having contributed to his life in some way, even with chronic disease. Luiz Otávio also revealed his dream of being chef, that is, he wanted to study gastronomy.

"I'm looking to go to gastronomy college." (Luiz Octavio)

Thus, your goal is to realize your professional dream. Because the transplant occurred when he was 6 years old, his literacy process occurred late; however, during his life, he had no greater complications regarding school experience. Bernardo mentioned that he would like to follow the branch of communication.

"Maybe... Journalism." (Bernardo)

"Or Economy, or politics... Political commentator." (Bernardo)

It is noted that Bernardo does not have something specific to future plans, therefore, his plans are not considered unique and immutable. Due to the other diseases, at various times in his life, he had to move away from school routines, but, with the help of his family, friends, school and hospital school care, he continued his schooling process. Similar issues show that students, even living school processes marked by systematic and even prolonged interruptions, do not fail to dream of the prospect of following schooling to the most advanced levels of teaching.

Final considerations

This study aimed to understand the perceptions of adolescents with chronic renal failure transplanted about hospital school visits.

At first, it is worth noting the validity of studies that, like this one, prioritize the voice of users of educational services, since their perception is essential for the improvement of educational services and policies. In this case, the reports of the study participants initially showed the diversity of the experiences experienced. Therefore, the suggestion to bring up, in the results and discussions section, some excerpts from these reports, of these statements of the subjects. Only one of the three students interviewed was awarded the right to hospital school care. All three were treated in the same hospital due to the same pathology, Chronic Renal Failure. However, only the constant trips to the hospital for hemodialysis do not guarantee the right to hospital school care, even when this condition requires frequent and systematic absences from the regular school. This suggests, therefore, the review and improvement of policies related to the functioning and organization of hospital classes so that students who, although not subjected to hospitalizations for long periods, have the school trajectory interrupted by the treatments to which they are submitted as users.

Although the legislation guarantees hospital school care to the student, the right to enjoy this service and to continue the scholar process during the removal from school is not known by them (students) or by their parents in the case of the participants of this study. This exposes the lack of guidance of users both by the regular school and by the hospital service itself.

The study pointed out the importance of hospital school care both for the students' schooling and for the very constitution of the identity of these subjects as students, and above all, for the preservation of their educational expectations. In this sense, it was also verified that it is necessary to improve educational policies to ensure the interaction between the regular school and the hospital school service.

We conclude this study, therefore, recognizing that there is still a way to go in order to safeguard the right of students to hospital school care. We also found that, in this process, there is a need for other studies that focus on the school experiences of these subjects and the needs of teachers, both from the regular school and from hospital care, thus seeking to improve public policies and practices performed in the hospital environment by teachers with their hospitalized students.

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