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Educational care in a hospital environment: a student's view of cerebral palsy about rights and training[1]

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ABSTRACT

This article is the result of a research carried out in 2020 that investigated the views of five hospitalized students with cerebral palsy, about the educational assistance they received, their rights, the hospital space, and the role of the teacher in training. For the investigation, the qualitative approach was chosen, whose data were collected through semi-structured interviews and activities mediated by the researcher, in the light of legal documents and studies on educational assistance. The results showed that students recognized their rights to this pedagogical-hospital assistance, but believed that this service needed to be improved. Concerning the teacher's performance, they realized that he has contributed to continuing their learning processes, but that, as a rule, they lack quality training for hospital educational service.

KEYWORDS: Right to hospital education. Teacher training. Cerebral palsy.

Atendimento educacional em ambiente hospitalar: visão do estudante portador de paralisia cerebral sobre direitos e formação

RESUMO

Este artigo é fruto de uma pesquisa realizada em 2020 e que investigou o olhar de cinco estudantes portadores de paralisia cerebral hospitalizados sobre o atendimento educacional que recebiam, os seus direitos, o espaço

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do hospital e o papel do professor. Para a investigação, optou-se pela abordagem qualitativa, cujos dados foram levantados por meio de entrevistas semiestruturadas e atividades mediadas pela pesquisadora, à luz de documentos legais e estudos sobre o atendimento educacional. Os resultados mostraram que os estudantes reconheciam seus direitos a essa assistência pedagógico-hospitalar, mas acreditavam que esse atendimento precisava ser melhorado. No que diz respeito à atuação do professor, afirmaram que ele tem contribuído para dar continuidade a seus processos de aprendizagem, mas que, via de regra, carecem de formação de qualidade para o atendimento educacional hospitalar.
PALAVRAS-CHAVE: Direito à educação hospitalar. Formação docente. Paralisia cerebral.

La asistencia educativa en el ámbito hospitalario: la perspectiva de los estudiantes con parálisis cerebral sobre los derechos y la formación

RESUMEN

Este artículo es fruto de una investigación realizada en 2020, que indagó en las opiniones de cinco estudiantes hospitalizados con parálisis cerebral sobre la asistencia educativa que recibieron, sus derechos, el espacio hospitalario y el rol del docente en la formación. Para la investigación se optó por el abordaje cualitativo, cuyos datos fueron recolectados a través de entrevistas semiestructuradas y actividades mediadas por el investigador, a la luz de documentos legales y estudios sobre asistencia educativa. Los resultados mostraron que los estudiantes reconocieron sus derechos a esta asistencia pedagógico-hospitalaria, pero creían que este servicio necesitaba ser mejorado. En cuanto al desempeño del docente, manifestaron que ha contribuido a continuar con sus procesos de aprendizaje, pero que, por regla general, carecen de una formación de calidad para la atención educativa hospitalaria.
PALABRAS CLAVE: Derecho a la educación hospitalaria. Formación de profesores. Parálisis cerebral.

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Introduction

Educational assistance in a hospital environment represents the continuity of a service responsible for the student's schooling when undergoing health treatment. In this article, we report the research, carried out from January to March 2020 by one of its authors, on the experience of pedagogical-educational care received by five students with cerebral palsy[4]admitted to a hospital in the city of Campo Grande, MS. The question that guided the investigation was the following: what do students think and feel about the educational hospital care they receive with regard to their rights, the hospital space and the role of the teacher?

To help the investigation, we chose the qualitative approach, as it help the understanding and interpretation of social events, providing a chance to understand the interactions carried out during the research. The investigation was developed in complementary stages: the first one had as a starting point the bibliographic review, for be considered the fundamental phase to get the theoretical foundation of the study, while the second took care of the documentary analysis, as it is also an important procedure to build the initial regulatory frames for the institutionalization of educational hospital care, such as laws, reports and national normative guidelines.

Then the field research was carried out with students with cerebral disabilities who had or still have successive experiences of hospitalizations and who were attended to and / or knew the structure of said school attendance. Among 12 hospitalized students, five of them chose to participate in the research; the selected ones are of both sexes, aged between 15 and 25 years old, who at that time attended regular schools and / or universities. Participants are

[4] The World Health Organization (1999) describes cerebral palsy (CP), or chronic non-progressive childhood encephalopathy, as a result of static injury, which occurred in the pre, peri or postnatal period, and which affects the central nervous system in phase of structural and functional maturation. The term CP is comprehensive, as it presents a variety of causative factors and describes the evolution of the motor function disorder secondary to the non-progressive pathology of the immature brain (HARE; DURHAM; GREEN, 2000).

identified here in a numerical sequence from 1 to 5, as a way of preserving their identities: Student 1, Student 2 and soon.

The investigation objectives were explained to the participants, when the importance of voluntary participation was also emphasized, highlighting that there would be no exposure or damage to the participants.

The survey of data was done through semi-structured interviews, according to a previous script. According to Lakatos (2003, p. 195), "[...] the interview is a meeting between two people, with the objective of gathering information about a certain subject, through a conversation of a professional nature".The interviews, previously authorized by students and their families, took place in 2020, during hospital visits, and each of them lasted an average of two hours.

The article is showed in three phases, in addition to this Introduction and the Final Considerations. The phases bring the discussions from the students' interviews, with which they initially said their understanding of their right to receive educational care at a hospital. The intention was to show how this right is guaranteed by legislation. Then, there was a conversation about the space and functioning of hospital care and, finally, about the assistance provided by the teacher with the objective of to reflect on his role and his training.

1 The student's right in legislation

Art. 205 Federal Constitution of 1988 (CF / 1988) defines education “[...] as everyone's right and duty of the State and the family and in collaboration with society” (BRAZIL, 1988), guidance that brings the opportunity for hospitalized students to also take educational assistance. Studying is not only being enrolled, but also a chance for the student to keep contact with teachers, friends and content, expanding their knowledge, improving their social relationships, training themselves to live with others and develop citizenship.

The beginning of the study took place based on the student's knowledge of Brazilian law, aiming to illustrate and raise awareness about their rights, because if education is everyone's right, it is necessary that it is actually carried out, through the guarantee that all student will have access to specialized educational assistance. For sure, educational assistance should preferably be offered in the regular school system, but CF / 1988 does not prevent it from occurring in other places, such as the hospital.

Thus, the first question of the interview - "What do you know about your right, about the laws that support your schooling"? - aimed at broadening the understanding of students who are in school, but undergoing prolonged treatment and / or hospitalization, about their right to continue their studies.

Among other legal documents, the interview with the students that made up the universe of research was included in Law nº. 7,853, of October 24, 1989, which provides for support for people with disabilities, their social integration and establishes, among others, judicial protection of collective or diffuse interests of these people. Said law confirms attendance in the hospital environment as an inclusive education modality and legalizes the performance of the teacher on the spot, as long as he / she has adequate training for that.

Throughout the study, it became clear to everyone - researcher and students -that kids and adolescents have the right to education, aiming at their full development and their preparation for the exercise of citizenship and their qualification for work. Thus, it was also understood that one of the supplementary programs is the pedagogical hospital care, because of the fact that it allows the continuation of school education simultaneously with health care.

The right to hospital care continued with a part of the interview and was based on Resolution MEC / SEESP No. 2, of September 11, 2001, which expressly determines the implementation of school hospitalization, with the "[...] purpose of pedagogical assistance to students with needs transitory specials, with the organization of academic courses designed to meet this

new demand, thus reinforcing [...] the right to health" (BRASIL, 2002). According to CF / 1988 (Art. 196), the right to health must be guaranteed through economic and social policies that aim at universal and equal access to actions and services, both for their promotion and for their protection and recovery (BRAZIL, 1988). Thus, the quality of health care directly refers to an expanded conception of this service, which must be extended to the needs of housing, work and education, among others.

It was also analyzed with the students the Law of Education Guidelines and Basis 9.394 / 1996, which establishes the guidelines and bases of national education (LDBEN / 1996), to remember that this document, in its Art. 58, defines special education as a modality of Basic Education that should be offered to students with special needs, especially in the regular school system. Paragraph 1 of LDBEN / 1996 recommends that the regular school make available "[...] specialized support services" [...] to attend to the peculiarities of the special education clientele ". This means that all this legal apparatus must be applied, as it reflects positively on the student, as stated by Student 2:

> *Today, from what I've learned, I think that [the presence of] teachers in the hospital should be everyone's right. We cannot let our colleagues stay on the sidelines, apart, without studying. It's very important. I don't even know what to say to you. It is valid, useful, helps a lot in development, in learning.*

About the right to education, Student 4 said that "[...] governments need to increase attendance and free up resources for attendance". This means that, no matter the structuring and provision of educational services in hospital and home environments are legitimate, there is still a need to call for rights so that public policies are implemented with more quality.

In this situation, it is understood that both students understand their rights, but at the same time recognize that they still lack the full guarantee for their effectiveness. It is necessary, meantime, to continue the search for partnerships between hospitals and the departments of Education, Health and Social Assistance to guarantee the sick student more humanized care, about to

what the legislation establishes. This mean that their studies should not undergo a solution of continuity during their treatment, especially when one considers that this withdrawal from the daily routine of school can be, sometimes, traumatic and painful.

2 Hospital environment

The meaning of the hospital environment was another point addressed in the interview with the students. The second question - "What is this place that the educational service is proposed?" -, was based on the understanding that, in the hospitalization process, there is a tendency for the student to leave or abandon out of school when he / she is sick and, therefore, not to get this service.

Aiming to show each student many ways of providing this service, after their responses, we seek to talk with them about the space and possible ways of providing this hospital educational service, as recommended by different authors. The issue also brought explanations, such as that school attendance in hospitals, due to illness and / or any other need for hospitalization, may be provisional. The same occurs when students in a state of illness are treated at their homes.

The interest that guided the question was to make the student able to understand his right to educational assistance when he was away for health reasons and about the transience of this service. It is an alternative process of continuing education that goes beyond the formal context of the school. When done multi / inter / transdisciplinary and with their own educational characteristics, respecting the time of sickness, the schooling situation, and also the other developments in the social and family life of the student being served, this assistance shows to be quite effective.

From there, educational care in a hospital or home environment should be individualized, respecting the identity of each child / young person, raising all their difficulties and respecting their trajectory and development. Then, this

assistance must occur when the question is in a different situation from the one in which the other students are. To this end, the school must get an education program integrated with school activities in the hospital, which will contribute to reducing the dropout, repetition and lag of age / series of children and young people served in relation to their peers.

To González, E. and González, C. (2007), this clientele compose a heterogeneous group of students with psychological, medical, social and educational needs that are different from those experienced by children in a regular education class. Barros (2007), on the other hand, argues that this type of service does not need to be reduced to the use of a circumscribed physical space. According to the author, it is possible to use the hospital library, the idle moments of the cafeteria, the verandas of the infirmary and even the beds.

Also according to Barros (2007), what is called a class, in a pediatric ward, is actually an open group with a intensive structure, which allows the attending student to enter and leave it relatively frequently. So, the structure is always variable, since, for each student attended, the length of stay in the hospital will be different and, then also the duration, extent and nature of the pedagogical / therapeutic investment received (BARROS, 1999). About the profile of the group served, it appears that this is also variable, since hospitalized patients have different academic demands and socioeconomic origins.

Sandroni (2008) defends that the teacher can act not only with activities related to school content, but also with others that aim at the psychic and cognitive development of the illness. The playful aspect, according to the author, is also a good option for working with hospitalized kids and adolescents, as it instigates curiosity, creativity and the search for knowledge. For her, this is more visible when using electronic resources, such as video, CD-ROM, computer and games.

To analyze this service, it is important to highlight the warning made by Matos and Mugiatti (2009) that it is not possible to look at the patient just for

his physical case, but to take into account the psychosocial factors behind the disease. For the authors, "[...] it is about caring for a person, in all its dimensions, and not, simply, caring for a certain disease" (p. 20). The authors point out that the patient's condition is often multifactorial, so it is necessary to understand him in all aspects. They also add that children hospitalized more than once are frightened by the routine of a hospital, which can cause difficulties in the teaching and learning process.

With on the analyzes made so far, it is possible to understand that this assistance is possible to be performed as long as the conditions of the student-patient are considered and that there is a space adapted for the development of the teaching and learning process. Then, the experience with these patient-students who participated in the research showed us to verify their insecurities about what could actually happen with their lives without the warmth of home, a feeling that could be realized in their frightened eyes and, above all, because they were always feeling alone, depressed because they are forced to stay in a hospital environment.

An example of this is the condition signaled by Student 3 to to highlight that his admission to the hospital was quite painful, because, in addition to undergoing three complex surgeries, he had to remain hospitalized for many days, taking different medications, some of them to relieve pain. During the time he was hospitalized, he says he did not receive educational assistance and told that he missed his routine and being at school very much:

> *During this period that I was in the hospital, I lost a lot of content, school material! Lesson really! At the time, school attendance was not talked about, nor did I understand all of it. I lost an academic year several years! Whenever I was hospitalized, I stayed in a wing without much color, there was no activity, no games, no playroom, no class as there is today! It would be very different if you had! I see how important this is.* (Student 3)

In general, the fact of being in a strange environment and subjected to a hard routine of contact with doctors and nurses, without knowing about their

health status, interferes with the psychological structure of the sick person. In the statement above by Student 3, it is clear that educational assistance would have greatly improved its improvement in many aspects.

For Student 4, educational assistance took place at different times, which became a positive point in your learning process:

> *As for school attendance, I had it while I was undergoing treatment in São Paulo, it was very good! Every day, a teacher came and brought activities for me to do. I did it with her and my mother after she left. I took a shower every day, took my banana smoothie and cookies and was all ready, waiting for the teacher! And one thing, see ?, I learned a lot. When I returned to the state, I was hospitalized several times, and I also had a teacher at the hospital. Was good! I even had a birthday there. I felt, very important. It was the teacher and the hospital staff who encouraged me to continue my studies.* (Student 4)

In addition to learning, 4 feelings and emotions are perceived in the Student's conversation that promoted the satisfaction of being in the hospital environment, which reduced his suffering experienced at the time of the disease.

The right to education in the hospital is still a problem of concern for some students,as Student 5 points out: "[...] laws must be made. You need, you know, to charge government officials, it has to be something real, that doesn't end, that happens ..." His speech signals, for the managers who are in charge of the implementation of public policies, the need to rethink about the importancethis hospital educational assistance, which represents both the act of educating and humanizing, promoting actions that contribute to expand the process of teaching and include comprehensive care, that is, assistance and care for the other, with the student.

3 Teacher's role in hospital care

Ceccim (1999) states that, in order to attend the hospitalized student, the teacher need to understand that his role is not only to creatively occupy the student's time, but that he can show and elaborate the feelings brought on by

sickness and hospitalization, and learn new feelings. On the contrary, according to the author, it is up to the teacher: to open get spaces, with an emphasis on pedagogical leisure, so that the student may forget for some moments that he is sick or in a hospital, and operate with the affective processes of building cognitive learning, allowing school acquisitions. Ceccim (1999) also shows that the contact of the teacher with a "school in the hospital" is an opportunity to connect with the standards of everyday life of the common kids, that is, it represents a link with life at home and at school.

The educational assistance in a hospital environment is supported, according to Fonseca (1999), in educational-school proposals that are different from the recreational and recreational activities that may exist in the hospital. Explainsthe author that, even if playfulness is a learning strategy in the hospital environment, the pedagogical-educational intervention is more specific, as it is individualized, based on regularity and having responsibility for the child's formal learning. This mean that it is an inclusive activity for parents and the child's home schools, as having classes during their hospitalization, in addition to maintaining school learning, is an incentive for the student to return and reintegrate into the school space after discharge hospital.

Maia-Vasconcelos (2010) states that, with educational assistance in a hospital environment, the teacher can compensate for the gaps and back the student to a little of normality to their way of life. He can be the total guardian of the student's development, respecting his sickness, and do not forgetting his needs as a person. Another issue highlighted by the author refers to the maintenance of affective bonds that help students find their way back to their world through language.

Another orientation made by Maia-Vasconcelos (2010) to the teacher is that he must seek to become a kind of educational agency so that the hospitalized student can make activities that help him to build a cognitive, emotional and social path, in order to maintain a connection with your family life and the reality in the hospital. It also highlights the need for teachers to get

recognition of the student's identity, providing them with a cognitive path appropriate to their age, so that they can understand the reality of the hospital. In addition, it should also provide you with moments for games and diversions, in order to ensure educational continuity with the school of origin and help you and your family to undertake new rhythms and new projects, in case the project previously planned has become impracticable.

In this context, there are many attributions that belong to the teacherand a hospital class, among them, to diagnose the student's specific learning difficulties and apply strategies to remedy such troubles; and to elaborate recommendations for the parents to return home from the hospital to the home and school of origin at the end of the hospitalization. Therefore, acting as a teacher in a hospital class means, as pointed out by Zombini et al. (2012), promote dialogue, explore the hospital environment together with the hospitalized child, perceive in the student their vision of life, their needs and their problems, so that, based on them, they can develop a pedagogical practice appropriate to their reality, thus contributing to the construction of the necessary knowledge for an active action in favor of the restoration of their health.

Regarding the role of the teacher, Fontes (2002) says to be the one who promotes a link between the hospital world and the daily life of the hospitalized child. To do so - says ela -, it is necessary for the teacher to receive training, first, because this activity, by activating the ludic as a communication channel with the hospitalized student, seeks to make him forget, for a few moments, the aggressive environment in which he finds himself, rescuing sensations experienced before entering the hospital. Second, because, by knowing and demystifying the hospital environment, giving a new meaning to its practices and routines - which is one of the proposals for pedagogical assistance in hospitals -, "[...] the fear that paralyzes actions and creates resistance, tends to disappear, appearing in its place the intimacy with the space and the trust in those who take care of it" (FONTES, 2004, p. 4).

To play his role in the right way, according to Ortiz and Freitas (2005, p. 55), the teacher must "[...] implement the continuity of teaching the contents of regular schooling or even invest in school work with programmatic contents specific to the age group age of the child", as it should seek to remedy the learning difficulties and promote the acquisition of new knowledge. Still according to the authors, it is also the role of the teacher "[...] to get the appropriation of school skills and learning, strengthening the return and reinsertion of the child in the context of regular education", because, by providing protection to affectivity as a phenomenon that guarantees acceptance and respect for the uniqueness of the patient-student, it is possible to strengthen "[...] the subjective construction of living, supported by psychological overcoming of sickness and fostering social relationships as a vehicle for the learner's instrumentalization". In this way, the teacher becomes a "[...] socio-interactive agent and stimulator of socio-affective development" (p. 55).

Finally, it is necessary to say that, for Sandroni (2008), the teacher must have a good knowledge about the human development process in each school phase and the respective contents of each level, and understand the special needs and deficiencies be they: visual, auditory, physical, intellectual and / or multiple, of the student-patients and have sensitivity to dialogue with the hospital and family. This statement coincides with Student 2's view, when stating: "The teacher, for this service [hospital teaching assistance], needs to have a lot of knowledge, goodwill and love for others". Therefore, the teacher responsible for educational assistance in the hospital environment has the function of maintaining school activities during the hospitalization period of the hospitalized child or adolescent, but should not only consider cognitive development, with school activities and contents, but also the psychic and emotional development.

When realize that the conditions of vulnerability and fragility of student-patients are sensitive, the teacher becomes an important element to ensure the establishment of a desirable relationship of trust. An example of this is the

following statement by Student 1: “Everything I am I owe to them [teachers]. I had a lot of teachers who didn't give a damn about me, but I also had those who helped me. I owe everything I am to them. They are my great examples, my inspiration”. It is seen in this speech that the teacher's action provides conditions of well-being, because, by stimulating the student's autonomy and, especially, by creating an affective bond with him, it certainly contributed to the improvement of the student's learning conditions.

The educational assistance in a hospital environment is therefore responsible for sustaining the student's return and reintegration into his school and social group, as he may feel excluded from his social environment due to the time he needed to be away. In this context, although one of the assumptions of educational assistance in a hospital environment is the encouragement to get linguistic and logical-mathematical skills and competences, the space allows the educator to develop other activities, among which those aimed at health education not only hospitalized children and adolescents, but also their relatives. This activity can become a motivating element for the adoption of attitudes conducive to health. Thus, the aim is to overcome the logic of compartmentalization of knowledge, making possible the different ways of learning, doing and knowing. (BARROS, 2007).

Therefore, the student's stay in the hospital should not represent the breaking of his / her link with the school and the loss of the right to schooling. The educational services in a hospital environment guarantees kids and adolescents hospitalized the chance to continue to experience pedagogical experiences. In addition to not interrupting contact with knowledge, which stimulates the cognitive and developmental processes, it also allows the continuity of interpersonal relationships.

Due to daily contact with the patient and his family, the hospital class teacher assists in interactions with the health team, because it can identify, thanks to the experience acquired in the classroom, patterns of behavior that may not have been realized by the team. The teacher of educational assistance in a hospital environment must articulate with the hospital's health team, with the Department

of Education and with the school of origin of the student, thus collaborating for attention to the restoration of their health and ensuring, for through the fulfillment of the curricular matrix, the continuity of learning and the approval of the child or adolescent for the next school year (ZORBINI et al., 2012).

When talking about this process, it is clear that that according to Ceccim (1999), the opportunity to attend a hospital class gives the child or adolescent the pleasure of contact with the school environment, privileging their learning achievements and detaching them, albeit momentarily, from the restrictions that hospitalization imposes. This way, the result of this attention is to make the hospitalization experience a positive event for the student's growth and development.

Finally, with the research done with hospitalized students, it was found that, almost all the teacher's duties to work in educational care in a hospital environment are to offer emotional and cognitive assistance to the student, a conclusion that they also reached other researchers. As one learns from the speech of the interviewed students, the formation of the teacher be it initial or continuous is necessary so that he can develop his activities with more quality. As Caiado (2003) points out, universities that are committed to social reality and understand education and health as social rights have no problems with teacher training, appreciating the multiple spaces and times of education, including the class hospital.

Because of this, the role of the teacher goes through his training, and the university, when preparing the pedagogue, must excel in a training that enables a pedagogical practice that understands hospital care as a new educational alternative. Teacher training enables political and pedagogical commitment and strengthens professional competence.

Final considerations

The study showed here brought up the debate on educational care in a hospital environment, which aims to give the curricular monitoring of the

hospitalized student, to ensure the maintenance of their link with the school. This process is a student's right, as stated in the legislation, but it is important to highlight that this offer is still small and that, according to the students who participated in the research that supports this article, it still needs to be guaranteed to everyone who needs it.

Regarding educational assistance in a hospital environment, it was realized, with the contribution of students, that the hospital can be both a place of discomfort, because of medical procedures, which cause pain and fear, as a transitory, necessary environment, which is part of life and which contributes a lot to human and dialogical training based on the development of knowledge and skills. These can be shared with other hospitalized colleagues, with the attendant team and with hospital care, teachers and those assigned to their home school. However, for that, the space to beimplemented needs to be in conditions to carry out the necessary actions to attend.

The teacher, still through the eyes of the student, has played a role that contributes to perfect the learning process and broaden the students' worldview. And for this reason, it is necessary to dialogue about the need to implement more effective public policies for the training of the teacher who will provide hospital educational assistance, and, above all, so that the current policies and legislation are complied with. This academic training, especially in the different degrees, should enable a pedagogical practice that understands hospital care as a new educational alternative and bearing in mind that a political-pedagogical commitment strengthens professional competence.

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