



Revista da Escola de Enfermagem da USP

ISSN: 0080-6234

reeusp@usp.br

Universidade de São Paulo

Brasil

Rolim de Holanda, Eliane; Collet, Neusa

As dificuldades da escolarização da criança com doença crônica no contexto hospitalar

Revista da Escola de Enfermagem da USP, vol. 45, núm. 2, abril, 2011, pp. 381-389

Universidade de São Paulo

São Paulo, Brasil

Available in: <http://www.redalyc.org/articulo.oa?id=361033309012>

- How to cite
- Complete issue
- More information about this article
- Journal's homepage in redalyc.org

redalyc.org

Scientific Information System

Network of Scientific Journals from Latin America, the Caribbean, Spain and Portugal

Non-profit academic project, developed under the open access initiative

The difficulties of educating children with chronic illness in the hospital context*

AS DIFICULDADES DA ESCOLARIZAÇÃO DA CRIANÇA COM DOENÇA CRÔNICA NO CONTEXTO HOSPITALAR

LAS DIFICULTADES DE LA ESCOLARIZACIÓN DEL NIÑO CON ENFERMEDAD CRÓNICA EN EL CONTEXTO HOSPITALARIO

Eliane Rolim de Holanda¹, Neusa Collet²

ABSTRACT

The objective of this qualitative study was to understand the perception that families of hospitalized children with chronic illness about their being away from the process of education. The empirical material was produced by means of interviews performed with families of hospitalized children with chronic illness. The data was analyzed based on the principles of thematic analysis. Among other aspects, the data showed the lack of systematized pedagogical actions in the studied hospital, in a way that the educational activities that were developed were seen as a moment of leisure. We understand that the hospital class is becoming an important health care technology for hospitalized children. Therefore, it requires support, especially from the Departments of Education, in terms of providing the necessary human resources, funding and materials. This is a pioneer study, capable of helping improve the quality of life of children with chronic illness.

RESUMO

Pesquisa qualitativa que objetivou compreender a percepção da família de crianças hospitalizadas com doença crônica acerca do afastamento do processo de escolarização. O material empírico foi produzido por meio de entrevistas com famílias de crianças hospitalizadas com doença crônica. Os dados foram analisados a partir dos princípios da análise temática. Dentre outros aspectos, revelaram a ausência de ações pedagógicas sistematizadas, no hospital em estudo, de modo que as atividades educacionais desenvolvidas eram compreendidas como um momento de recreação. Consideramos que a classe hospitalar vem se constituindo em uma importante tecnologia de cuidado na assistência às crianças hospitalizadas. Para tanto, precisa de apoio, principalmente, das Secretarias de Educação, no que concerne à provisão de recursos humanos, financeiros e materiais. Esse é um trabalho pioneiro, capaz de auxiliar a criança com doença crônica a ter uma melhor qualidade de vida.

RESUMEN

Investigación cualitativa que objetivó comprender la percepción de la familia de niños hospitalizados con enfermedad crónica respecto al alejamiento del proceso de escolarización. El material empírico se produjo mediante entrevistas con familias de niños hospitalizados con enfermedad crónica. Los datos fueron analizados a partir de los principios del análisis temático. Entre los aspectos, se reveló la ausencia de acciones pedagógicas sistematizadas en el hospital estudiado, de modo que las actividades educativas desarrolladas eran entendidas como momentos recreativos. Consideramos que las clases hospitalarias están constituyéndose en una importante tecnología de cuidado en la tecnología de cuidado en la atención de los niños hospitalizados. En consecuencia, la misma necesita de apoyo, principalmente por parte de las Secretarías de Educación, en lo concerniente a la provisión de recursos humanos, financieros y materiales. Este es un trabajo pionero, capaz de ayudar al niño con enfermedad crónica a tener una mejor calidad de vida.

DESCRIPTORS

Child, hospitalized
Education, special
Family
Comprehensive health care

DESCRIPTORES

Criança hospitalizada
Educação especial
Família
Assistência integral à saúde

DESCRIPTORES

Niño hospitalizado
Educación especial
Familia
Atención integral de salud

* Taken from the thesis "Doença crônica na infância e o desafio do processo de escolarização: percepção da família", Graduate Program in Nursing, Universidade Federal da Paraíba, 2008. ¹RN. M.Sc. in Nursing from Universidade Federal da Paraíba. Faculty, Nursing in Infant, Child and Adolescent Health Nursing Course, Universidade Federal de Pernambuco - UFPE. Vitória de Santo Antão, PE, Brazil. elianerolim@yahoo.com.br ²RN. Ph.D. in Nursing, University of São Paulo at Ribeirão Preto College of Nursing. Faculty, Undergraduate Nursing Program and Graduate Nursing Program at Universidade Federal da Paraíba. João Pessoa, PB, Brazil. neucollet@gmail.com

INTRODUCTION

Hospitalization is a reality in the lives of a significant part of the child population. Accepting and taking care of children with a chronic illness is a very difficult experience for families, even more when the illness is accompanied by a closed prognosis or low life expectancy, as it not only entails lack of control over the situation, but also causes anxieties on the child's actual perspectives for the future⁽¹⁾.

What makes this situation worse is the predominance of clinical and curative care, accompanied by highly interventionist technology, in care delivery to hospitalized children. Rules based on discipline, efficiency and knowledge hierarchization produce routines that generally leave little room for users to express their singularity and autonomy. In work process organization at pediatric units that follow these standards, health professional are prepared for disease treatment, relegating the emotions and subjectivity of the child-family binomial⁽²⁾.

This model, however, has showed to be insufficient and has undergone transformations. Hence, in a more up-to-date perspective, professionals should aim for the children's comprehensiveness, responding to diagnosis and treatment prerogatives based on their needs⁽³⁾.

Comprehensiveness should be understood not only as a constitutionally defined concept, or a mere guideline of the Unified Health System (SUS). On the opposite, it is a polysemic principle, whose meanings are at the same time correlated, distinct and mutually articulated. Defending comprehensiveness means defending the fine-tuning of health action supply with the specific context of each meeting, through intersubjective practices and a dialogical dimension, in which health professionals relate with subjects, and not with objects⁽⁴⁾.

Also, these subjects have *ways of leading their lives* that emerge from the way itself in which life is collectively reproduced and on the singularities inherent in each person⁽⁵⁾. This understanding results in the achievement of a more human professional care, which cannot be fragmented, technicist or without dialogue, and should be concerned with a broader view on the needs for health actions. When considering care delivery for hospitalized children from a comprehensive care perspective, one cannot remain limited to medication interventions or rehabilitation techniques.

Sick children or adolescents cannot understand the hospital as a place of pain and suffering only. They always need to find a space there that can be used for play, pedagogical and recreational activities, as the hospitalization should not interrupt child development⁽²⁾.

Literature appoints that, in child hospitalization, the main source of stimulus for children to develop is

the person who every day involves them in their care, either for meals, hygiene, playing, a technical nursing procedure. The personal involvement of who takes care transmits an essential experience, human contact to the sick child⁽⁶⁾.

Based on this understanding, health care delivery to the child-being needs to cover his/her expanded health needs, whether: emotional, social, family, cultural or environmental. Thus, it becomes fundamental to include a care proposal that can comprise pedagogical and educational actions during the hospitalization period.

School is a space where children not only learn cognitive skills, but also develops and establishes different social bonds. Being left at the margin of this space for experiences can be painful for hospitalized children or adolescents, who need to see that they are productive and involved in activities similar to their peers⁽⁷⁾. In cases of chronic illnesses, these young people spend months and sometimes years without going to school, far from the education process. Thus, the youth give up school and school gives up the youth⁽⁸⁾.

Thus, with a view to avoiding that these children interrupt their education due to the hospitalization, as from the 1990's, the Child and Adolescent Statute – ECA⁽⁹⁾ and Resolution 41/95 on the Rights of Hospitalized Children and Adolescents⁽¹⁰⁾ started to conceive hospitalized children and adolescents as subjects with rights, starting a debate process on public policies for these citizens.

In 1994, the Ministry of Education and Culture (MEC), through the National Secretary of Special Education, defined responsibilities for the execution of hospitalized children and adolescents' right to education, through the formulation of the National Special Education Policy⁽¹¹⁾, which legally established the *hospital class* service.

The hospital class is a Special Education teaching mode, regulated by specific legislation, aimed at pedagogical-educational attendance to hospitalized children and adolescents. Hence, it departs from the acknowledgement that these young patients, if distanced from the academic routine and deprived of community life, are at risk of school failure and possible developmental disorders. During hospital classes, teachers attempt to adapt the program to the contents being offered in students' original classes, so as to help them reintegrate in school after discharge from hospital⁽¹¹⁾.

Considering children as citizen-beings, with rights and duties, was a historical and socially constructed conquest. Childhood gained new meanings, based on cultural, economic, political determinations and structural changes in society across the centuries. As for hospital classes, however, although legislation exists, ignorance on this attendance mode is still considerable at various Brazilian hospital institutions.

...health care delivery to the child-being needs to cover his/her expanded health needs, whether: emotional, social, family, cultural or environmental.

In this sense, the research problem in this paper derived from the reflection that the care offered to children hospitalized with a chronic illness at the Pediatric Clinic of a federal teaching hospital in João Pessoa-PB did not offer systematic actions that are officially recognized as pedagogical-educational.

OBJECTIVE

According to the above context, this study aimed to understand how families of children hospitalized with a chronic illness perceive distancing from the education process.

METHOD

A qualitative, descriptive and exploratory research was carried out, which attempts to understand reality by moving beyond the phenomena perceived by the senses and can include the subjective and the objective, the social actors and the context they are inserted in inside the analysis⁽¹²⁾.

The field research was accomplished at the Pediatric Clinic of a public teaching hospital in João Pessoa-PB, with 32 beds distributed across 32 nursing wards. This clinic is a referral center for clinical and/or surgical treatment of chronic and/or rare diseases in the entire state of Paraíba. Care is delivered to pediatric patients between 0 and 19 years old, who are hospitalized in different specialties.

Approval for this research project was obtained from the Institutional Review Board of the institution where data were collected, under protocol No 140/07, in compliance with Resolution No 196/96⁽¹³⁾ on research involving human beings. Before data collection, all research subjects were consulted on their desire to participate and signed the Free and Informed Consent Term.

The criteria for inclusion in the research were: being a companion/relative to a child or adolescent hospitalized with a chronic illness; child in the age range for compulsory primary and secondary education; accepting to participate in the research. These families were identified through indication by the health team and consultation of the patient registration book at the study unit.

Ten families participated. Data were collected between January and May 2008. The technique used to produce the empirical material was the semistructured interview. The interview script contained aspects to identify the subjects and a guiding question on the family member's perception regarding the child's distancing from school activities due to the hospitalization. To finish data collection, the data saturation criterion was adopted, which is when the researcher discovers, in the field, that he/she managed to understand the logic of the group that is being analyzed⁽¹²⁾.

To guarantee the participants' anonymity when displaying the testimonies, their names were replaced by the follow-

ing specification: the letter *E*, followed by a number from 1 to 10, according to the order in which the interviews were held.

For the sake of descriptions, the terms hospitalized child, sick student or patient will be used interchangeably to designate hospitalized school-age children and/or adolescents, between 07 and 18 years of age.

The analysis of the empirical material followed the principles of thematic interpretation, with the following methodological steps: ordering, classification and final analysis of data⁽¹²⁾. In data ordering, the material produced during the fieldwork was organized, the interviews were transcribed and read repeatedly to put them in a specific order. The data classification phase was constructed departing from inquiries about these data, based on theoretical foundations and re-reading of the collected material, starting to group the data according to themes, so as to construct the empirical categories. In the final analysis, articulations were established among the empirical research material, thematic interpretation and the theoretical framework. In this paper, we will present and analyze part of the information obtained from the study's social actors.

RESULTS AND DISCUSSION

A short characterization of the participating families' profile reveals that users at the HULW pediatric clinic mostly come from poorer social classes. As for the family relation, 06 interviewees were mothers, while the remainder was: father, sister, aunt and grandmother, with 09 women and only 01 man. The relatives' ages ranged from 18 to 55 years, with 41 years as the predominant age range. Six out of ten companions lived in the rural area and the others in urban areas, with 07 interviewees from small interior cities in the state of Paraíba, and only 03 in the state capital João Pessoa-PB.

The children whose family members participated in this research were 05 boys and 05 girls, who attended Municipal or State public schools, except for one who was not studying. Considerable variation was found in the duration of hospitalization but, in general, ranged between 05 days and 09 months. The mean hospitalization period ranged between 15 and 30 days, except for patients with thalassemia, who were hospitalized each month for a mean period of 8 days. The children suffered from the following chronic illnesses: *hematological*: idiopathic thrombocytopenic purpura (01), thalassemia (03), acute lymphoid leukemia (01); *rheumatologic*: rheumatoid fever (02), juvenile rheumatoid arthritis (01); *nephrological*: nephrotic syndrome (01) and *endocrine*: pheochromocytoma (01). These chronic conditions imply periodical and sometimes extended hospitalizations, but do not impede studying.

Regarding the children's age, the age when their illness was diagnosed and the school level in course, six out of ten children showed an education lag, i.e. they were in an inappropriate year for their age range, according to the Ministry of Education's parameters established in Law 9.394/

1996, which sets the guidelines and bases for Brazilian education⁽¹⁴⁾. The other children either discovered the diagnosis/disease recently or their hospitalization frequency and duration was minimal, so that they were managing to control and live well with the limitations and implications the chronic illness imposed.

Even when offering care to sometimes incurable diseases, in a deep connection with life, the health team can recompose not only the children's organism, but also their forgotten subjectivity, to the extent that it adopts comprehensive care behaviors⁽¹⁵⁾.

Thus, to promote humanization in care delivery to hospitalized children, behaviors need to be changes, breaking with the power relations among health professionals and with the biomedical and technicist model, which discredit comprehensive care strategies for children, such as pedagogical activities in the hospital environment.

According to the families' reports, the study hospital is not prepared to welcome the intellectual and educational needs of children with chronic illness.

Look, my daughter, it's been 18 years that I'm here, inside this hospital, [...] the whole time there were just these toys, drawing, parties, those things... There has never been a teacher to teach other things from school (E2).

It would be good if, during the time he is hospitalized here, he could study because he stops studying over here! (E5).

Some people have been here for 4 months! Four months! And where's class? Imagine 4 months of class lost! You end up losing the year because you lose a lot! [...] I think there should be a classroom here, where they'd teach at least the necessary because, when they leave here and get there [in school] there's difficulty and a lot of accumulated homework (E9).

Since 2001, at the pediatric clinic where the empirical data were collected for this research, a community service has been developed that involves college students in Pedagogy, Languages, Psychology and Nursing. Its main goal is to offer child patients opportunities to have school and play experiences during the hospitalization period, and also provide Pedagogy and Teaching Diploma students an alternative to work in non-formal Education spaces.

Although this work exists, coordinated from Education professionals, the interviewed families do not manage to see it as a school curriculum follow-up activity. Their testimonies reveal that these practices have prioritized the play aspect, which is significant for hospitalized children and adolescents, but insufficient to see to their needs for education and socialization.

Hence, the testimonies appoint that systemized pedagogical activities, in accordance with the Ministry of Education and Culture's for organization and administrative functioning recommendations, do not exist at the study hospital, so that the activities developed there happen sporadically and the teachers/pedagogues inserted in that context are generally seen as recreation monitors.

radically and the teachers/pedagogues inserted in that context are generally seen as recreation monitors.

Therefore, aware that comprehensive health care delivery for children/adolescents implies attending to their indissociable needs – physical, mental, social and learning, the researchers suggested the educational strategy, taking the form of *hospital classes*, according to the parameters determined in the National Special Education Policy⁽¹¹⁾.

In this paper, the term *hospital class* was chosen, as disseminated by the MEC⁽¹¹⁾, at the same time recognizing the legitimacy of other names for this attendance mode, such as hospital pedagogy, school in hospital, school intervention in hospitals or pedagogic listening. This choice was made at random and perhaps tradition-based, but implies no ideological foundation and, therefore, does not endorse any theoretical affiliation exclusive to any of the possible branches in research on the theme.

Cooperation agreements between the hospital and schools should be closed through the Municipal or State Secretaries of Education and Health. Although the law establishes that hospitalized children and adolescents need pedagogical follow-up, public entities, educators, hospitals and society in general still know very little about these educational spaces as an official teaching mode in Brazil. Few Education Secretaries set up these educative practices in hospitals, guaranteeing support and assistance⁽¹⁶⁾.

Unfortunately the above mentioned community service project does not receive any stimuli from local political and institutional powers, working without funding or partnerships and with donated didactical material. It has not received any formal recognition from the Secretaries of Education as a hospital class.

The families demonstrated that they perceived the lack of pedagogical-educational actions in the hospital context under analysis, showing their concern with the continuity of these children's education during their hospital stay. Thus, the families themselves propose strategies that could be used to guarantee the children's access to education inside the hospital. The report transcribed below clarifies this aspect:

The hospital could set up a classroom to complement the classes hospitalized children lose. To give an example, this painting, OK, it's important, but combine the painting with normal class, you see! Because just painting, painting doesn't get you anywhere either! I think it would be important to have a classroom here because, in the same way as they paint, they could do other things too! Isn't that right? Like, that day is for painting, and two days per week for classes, about Portuguese, mathematics. [...] If the child is using a drip, put it in the arm where she doesn't write so that the other is free or let her participate orally, by answering questions (E9).

The fight for further cognition, quality of life and health are traits associated with the role of pedagogical work in

hospitals. It represents a singular initiative for the humanization and comprehensiveness of care delivery to hospitalized children and adolescents. This strategy, however, should not remain restricted to demands to follow the academic curriculum solely for approval at the end of the school year, which was interrupted by the hospitalization. Instead, it goes beyond this goal, gaining therapeutic dimensions as it detaches the children from disease-related issues.

School intervention mainly represents a resource to recover pediatric patients' self-esteem through a socializing pedagogy that can acknowledge patients' human potential⁽⁸⁾.

Thus, hospital class practices should center on pedagogical-educational actions, but should nevertheless include play-educative activities to stimulate knowledge. They represent a locus of help to annual patients' inconformity, equipping them for a better quality of intellectual and socio-interactive life. These gains, in turn, can favor both the efficacy of medication treatments and help to face the stress of hospitalization⁽¹⁷⁾.

In this space, pedagogical activity demands greater flexibility from the teachers involved, as these clients are constantly changing in terms of quantity, age range and hospitalization time, as well as the fact that they are children and young people with different illnesses, demanding different interventions. Hence, there is no recipe, but a challenge to set out individualized routes⁽¹⁸⁾. Therefore, emancipatory pedagogical practice is needed, with principles, methods and assessments that distinguish it from traditional school.

Limitations the disease imposes on education

For hospitalized children, the meaning of being distanced from school goes much further than mere academic loss. The chronic illness alters the children's life rhythm, so that they are deprived of many activities characteristic of children's daily life. This limits their social participation and interferes in their self-esteem⁽⁸⁾.

Due to frequent hospitalizations, disease symptoms, treatment and physical and emotional limitations, the children need to miss school, causing delays and hampering their learning. The reports transcribed below confirm that inference:

a) Children's physical limitations for education imposed by the chronic illness:

I didn't let her go to school in fourth grade either because she couldn't catch sun, because she was itching all over, feeling that agony in her body, mainly after she got blood (E2).

When he got to class [in school], he immediately sat down, dropped down really and then, sometimes, his notebook fell on the floor. Then he just watched class actually! His tests were oral because he wasn't able to write [...] He took the pencil and was like that, then he couldn't go to school! (E6).

The diseases affecting these young people often represent significant physical implications. In this sense, it is important to reflect on the nature of the complexity that permeates these patients' education process. The discourse reveals actual physical limitations deriving from the disease, such as: difficulty to manipulate objects; upper limbs compromises, impeding writing; difficulties to talk and walk; asthenia.

Thus, during educative practices, depending on the children's disease and treatment, some special care may be necessary, such as longer rest periods, pauses in activities for medication, or even isolated attendance. However, except for these critical moments, there is no doubt that these children can and should be integrated in educational programs.

b) Children's emotional limitations for education imposed by the chronic illness:

He is easily irritated, when he doesn't manage to do something, he cries a lot, he says he's "stupid", he doesn't want to do the task anymore, he tears the sheet apart and says he doesn't want to do it anymore. He thinks he's not able to learn (E1).

He felt rejected! At the time he cried, he said he didn't want to go to school anymore. It was a struggle to take him, he said his colleagues would just mock him (E6).

He says he doesn't want to study anymore and that he doesn't want to do anything! That he knows he's going to die! That's all he says: that he's going to die! We are concerned too, that he puts that in his head! He didn't even want to come here anymore to get hospitalized! [...] He just lies down, he doesn't think he's able anymore (E8).

Among other aspects, the sick children's quality of school life is closely related with their physical and emotional wellbeing. These will exert positive or negative influence on their availability to go to school, altering their academic performance and motivation. Thus, it is common for sick children to express their anxiety to return to school. Therefore, it is important to encourage them to continue studying through strategies like hospital classes.

c) Limitations on education imposed by prolonged and frequent hospitalizations:

He should be in the fifth grade, but he was hospitalized several times, so he lost the year! (E3).

It's the second time he can't go to the next year! It was because he had to be hospitalized and wasn't able to follow anymore. What is more, it happened during exam periods and he wasn't able to reach the targets, the grades anymore (E6).

She's hospitalized each month, my daughter. She's been here since she was small. Then I didn't let her go to school anymore because she spends more time her. In fact, she hasn't studied anymore this year (E10).

The above testimonies indicate the families' unanimous idea about the extent to which recurrent hospitalizations

imply dropping out of school and repeating a year among children with chronic illness. In this sense, attendance through hospital classes helps to enhance the children's return to and reintegration in their class group, as it encourages them, together with the family, to seek mainstream education after discharge from hospital⁽⁷⁾.

d) Limitations on education imposed by the child's impaired self-image:

She was ashamed because of the belly! She only used wide blouses because they would hide it better. [...] When she went to school, she used to take the book and put it like this: on top of her belly! She was ashamed to walk on the street because of the people (E2).

He thinks he's a young man who's, I don't know... he has a complex about the disease, because he sees his classmates playing, doing activities and he doesn't (E6).

Families in this study revealed the young patients' concern with the self-image modified by the illness. The children and adolescents are not pleased with comments on their physical appearance and health problems, as they want to be seen as *normal people*, without the stigma of sickness. Being ill is negative and includes being harmful, unwanted and socially devalued. In this situation, usually, there is an urgent need for comparisons that provoke decreased self-esteem and discrimination⁽⁵⁾.

In view of the complex feelings and situations experienced in the daily reality of chronic illness, it is important for the multiprofessional team to know these difficulties and incorporate them into the care plan, with a view to a more effective and comprehensive intervention. Thus, the hospitalization period can be transformed into a time for learning and gaining new meanings, without simply being filled with the suffering and void of affective, psychic and social non-development.

The school's limitations to support the child with chronic illness

When released to attend mainstream education, after hospital discharge, children with chronic illness face the deficits that show how neglected the Brazilian educational system is. Most teachers and directors feel technical and emotionally unprepared to welcome these children. Families in this study perceive the repercussions of this problem, as clarified by the following statements:

a) Relation with the teachers and/or school board

If it depended on them, he was going to repeat the same year again, again... (E1).

We took the doctor's bill of health, but the teachers didn't believe it, they thought it was a lie and that he could write with his other hand! How could he write with his other hand, the left one? (E8).

In these testimonies, the families appointed that the teachers ignored the chronically ill child's needs, putting

them in a distinguished position, so that the school worked as a mechanism of social exclusion. Besides not helping the children, they hampered their academic situation.

In general, due to lack of information about the disease and treatment or because they do not know how to work with sick children and the rest of the class group, the teachers are confronted with personal and technical limitations that impede inclusive commitments. In this perspective, activities should involve not only the child, but the teachers also need help with their concerns regarding their student's illness⁽¹⁹⁾.

The teaching staff's lack of preparation and prejudiced attitudes make them distance the child from school, making their reintegration into mainstream education even more difficult.

When he came back from the hospital, where he used to study, they didn't give him room for help (E1).

When he loses the tests they do it afterwards. And the classes?... They're lost... they don't replace them! (E3).

They gave him a lot of tasks, without him having studied anything! (E8).

Another relevant aspect the families of children with chronic illnesses highlighted was the teachers' lack of availability regarding bureaucratic requirements, doing tests or handing in tasks, although the student did not actually have access to the topic. This strictness in teaching administration represents a bottleneck that hampers hospitalized children's reintegration process into the academic career.

It is important for the school to redirect activities, guaranteeing flexibility, as a means to prioritize educational performance over organizational routines. Both the medical and the education team play a peculiar role in care delivery to the students, systemizing a new form of care based on the relation between health and education⁽²⁰⁾.

Contact between the hospital team and the school before the sick children return to their academic activities is considered fundamental for their successful welcoming and inclusion in the classroom. Sending folders/leaflets to the schools, showing information videos, organizing didactical seminars for the school team and lectures with teachers and students are strategies that can contribute in this process.

b) Relation with classmates

It was in 4th grade that he had the chorea! [...] His classmates used to make fun of him in school! He couldn't manage to get the books and then he used to throw them and leave (E6).

Once she told me: *Mom, I'm not going to school anymore!* She takes the little pill with folic acid, the vitamin she takes every day. [...] Then she said she wasn't going to take the pill to school anymore because the boys there said she was taking medicine to avoid a family and they made fun of her. She already had quite a large belly, then they said she was pregnant. She wasn't even 11 at the time, she must have been about 9 years old (E7).

These testimonies reveal the situation of exclusion, moved by peers' prejudices and lack of solidarity in view of the disease, thus confirming the inference that the greatest bottleneck for post-hospitalization children's inclusion in mainstream education does not come from the disease's physical limitations, but from the disbelief of a society that is still quite conservative and uninformed.

The families also highlighted the lack of intersectorial and comprehensive actions to support the reinsertion of children with chronic illnesses into mainstream education. Thus, neither the hospital nor the school alone will manage to recover the contents lost, urgently demanding a partnership between health and education.

I used to send all of the medication, (...) then they [the teachers] did not want to, they were afraid, of giving him the medication, during lunch breaks (E1).

Nobody from school comes here to visit him. Nobody! (E8).

I think that the teachers [from school] already do the impossible, because there's no way to compensate for all of these class days. No way! It's like a night's sleep lost which you'll never find back! (E9).

The families in this study emphasize the need for urgent solutions to this situation, in the sense that all efforts need to focus on collective actions, involving the family, school, hospital and society in the construction of pedagogical-educational strategies that effectively preserve the rights of children and adolescents at this moment of weakness caused by the illness.

The history of Brazilian hospital education is being constructed with many obstacles and challenges. It needs to be known in order to be understood as an emerging social issues, so as to cover the rights of hospitalized children and adolescents as a whole, promoting their rights to life and health⁽¹⁶⁾.

This undertaking is based on the belief that patients-students, equipped with knowledge about themselves and reality, rediscover their role and can draw, with their own hands, their competencies and future possibilities. Hence, children with chronic illnesses can and should be in school, as their potential to grow and develop continues like any other child.

CONCLUSION

The researchers believe that pedagogical work in hospital minimizes the negative effects of hospitalization, equips the child for a better quality of life and contributes to the search for comprehensive health care.

Countless difficulties are faced, however, in education for children with chronic illness, including the school's lack of information about the disease, hospitals' indifference towards their patients' academic situation, lack of communication between school and hospital, school boards' negligence and lack of efforts to improve their sick students' integration, teachers' difficulties regarding how to work with students who are/were hospitalized, children's impotence to face so many obstacles, in short, managers' lack of commitment to the development and practice of effective public policies to guarantee the right to continue the education process of hospitalized children and adolescents.

Thinking about these children's educational follow-up is a challenge, as it involves direct collaboration between two extremely weakened sectors in Brazil: Health and Education. It becomes feasible, however, when professionals from different areas manage to turn intersectoriality into a daily work tool to see the children as a whole, and detect action possibilities for the stakeholders in this process, which are: public managers, hospitals, families and schools.

The researchers could infer the extent to which undergraduate health programs have ignored information on this practice. In this perspective, specialization programs in hospital classes are needed, as well as local forums on pedagogical attendance in hospitals, and studies to support the formulation of curricular guidelines and teaching-learning methods, for development together with hospitalized children and adolescents.

Today, a brilliant community service is developed at the Pediatric Clinic of the study hospital, concerned with the children and adolescents who are distanced from school. It lacks support, however, mainly from the Municipal or State Secretary of Education, to be able to actually establish itself as a hospital class.

In this sense, partnerships are needed to establish integrative actions to strengthen Hospital Pedagogy, such as the participation of Education Secretaries in the articulation between hospitals and mainstream schools, in hiring and training teachers and in funding and material resource supply to permit education in the hospital context. This measure would not only expand the activity area of the teachers and college students involved, but would also be extremely relevant for hospitalized children and youth.

In this paper, the researchers did not intend to exhaust the theme, but to stimulate discussion as a pretext to set up the education project for hospitalized children. Finally, the introductory nature of this theme is acknowledged, but the fact that this kind of dialogue is proposed is a sign that changes are approaching.

REFERENCES

1. Damião E, Angelo M. A experiência da família ao conviver com a doença crônica da criança. *Rev Esc Enferm USP*. 2001;35(1):66-71.
2. Lima RAG de, Azevedo EF, Nascimento LC, Rocha SMM. A arte do teatro Clown no cuidado às crianças hospitalizadas. *Rev Esc Enferm USP* [Internet]. 2009 [citado 2009 ago. 4];43(1):186-93. Disponível em: <http://www.scielo.br/pdf/reeusp/v43n1/24.pdf>
3. Brito DMS, Guedes TG, Victor JF, Medeiros AB. O cuidado de enfermagem em uma criança com Diabetes Mellitus tipo 1: um relato de experiência. *Rev RENE*. 2006;7(1):98-102.
4. Mattos RA. Os sentidos da integralidade: algumas reflexões acerca de valores que merecem ser defendidos. In: Pinheiro R, Mattos RA, organizadores. *Os sentidos da integralidade na atenção e no cuidado à saúde*. 6ª ed. Rio de Janeiro: IMS/UERJ/ABRASCO; 2006. p. 41-66.
5. Canguilhem G. O normal e o patológico. 5ª ed. Rio de Janeiro: Forense/Universitária; 2000.
6. Bortolote GS, Brêtas JRS. O ambiente estimulador ao desenvolvimento da criança hospitalizada. *Rev Esc Enferm USP* [Internet]. 2008 [citado 2009 ago. 6];42(3):422-9. Disponível em: <http://www.scielo.br/pdf/reeusp/v42n3/v42n3a01.pdf>
7. Ceccim RB. Classe hospitalar: encontros da educação e da saúde no ambiente hospitalar. *Pátio Rev Pedagógica*. 1999;3(10):41-4.
8. Vasconcelos SMF. Intervenção escolar em hospitais para crianças internadas: a formação alternativa re-socializadora. In: *Anais do 1º Congresso Internacional de Pedagogia Social*; 2006, São Paulo, BR [Internet]. [citado 2008 out. 26]. Disponível em: http://www.proceedings.scielo.br/scielo.php?script=sci_arttext&pid=MSC0000000092006000100048&lng=en&nrm=iso
9. Brasil. Lei Federal 8.069, de 13 de julho de 1990. Estatuto da Criança e do Adolescente. 2ª ed. atual. Brasília: Ministério da Saúde; 2003.
10. Brasil. Resolução n. 41, de 13 de outubro de 1995. Dispõe sobre os direitos da criança e do adolescente hospitalizados. Brasília: Imprensa Oficial; 1995.
11. Brasil. Ministério da Educação. Secretaria de Educação Especial. Política Nacional de Educação Especial. Brasília; 1994.
12. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 11ª ed. São Paulo: Hucitec; 2009.
13. Conselho Nacional de Saúde. Resolução n. 196, de 10 de outubro de 1996. Dispõe sobre diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. *Bioética*. 1996;4(2 Supl):15-25.
14. Brasil. Lei n. 9394, de 20 de dezembro de 1996. Estabelece as diretrizes e bases da Educação Nacional (LDB) [Internet]. Brasília; 1996 [citado 2008 out. 26]. Disponível em: <http://portal.mec.gov.br/seed/arquivos/pdf/tvescola/leis/lein9394.pdf>
15. Darel MS. Classe hospitalar e escola regular: tecendo encontros [dissertação]. Florianópolis: Universidade Federal de Santa Catarina; 2007.
16. Paula EMAT. O ensino fundamental na escola do hospital: espaço da diversidade e cidadania. *Educ Unisinos*. 2007;11(3):156-64.
17. Fonseca ES. Classe hospitalar: resposta sistemática na atenção às necessidades pedagógico-educacionais de crianças e adolescentes hospitalizados. *Temas Desenvolv*. 1999;8(44):32-7.
18. Amaral DP. Saber e prática docente em classes hospitalares: um estudo no município do Rio de Janeiro [dissertação]. Rio de Janeiro: Universidade Estácio de Sá; 2001.
19. Fontes RS. O desafio da educação no hospital. *Rev Presença Pedagógica*. 2005;11(64):21-9.
20. Ortiz LCM, Freitas SN. Considerações acerca da inclusão de crianças pós-hospitalizadas. *Cad Educ Especial* [Internet]. 2002 [citado 2007 jun. 29];(20). Disponível em: <http://www.diaadiaeducacao.pr.gov.br/portals/portal/educacao/hospitalar/pdf/consideracoes.pdf>