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ORIGINAL ARTICLE

PERCEPTION OF MOTHERS ABOUT THE SCHOOL INCLUSION OF CHILDREN WITH CHRONIC DISEASE

PERCEPÇÃO DE MÃES ACERCA DA INCLUSÃO ESCOLAR DE CRIANÇAS COM DOENÇA CRÔNICA

PERCEPCIÓN DE MADRES ACERCA DE LA INCLUSIÓN ESCOLAR DE NIÑOS CON ENFERMEDAD CRÓNICA

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ABSTRACT

Objective: to understand how mothers perceive the role of the school in the inclusion of children with chronic diseases. **Method:** an exploratory-descriptive study, with a qualitative approach, carried out with six mothers enrolled in family health units. The data were produced using semi-structured interviews and analyzed by the technique of Content Analysis in the Thematic Analysis modality. **Results:** Mothers understand that their children's illness imposes limitations and difficulties for their stay in school, which, in turn, does not yet provide the necessary conditions for their adaptation and inclusion. **Conclusion:** it becomes urgent to analyze the needs of children and adapt pedagogical projects compatible with the educational conditions of each one so that they have their right to guaranteed education and effective citizenship. **Descriptors:** Chronic Disease; School Inclusion; Pediatric Nursing.

RESUMO

Objetivo: compreender como as mães percebem o papel da escola na inclusão de crianças com doenças crônicas. **Método:** estudo exploratório-descritivo, de abordagem qualitativa, realizado com seis mães cadastradas em unidades de saúde da família. Os dados foram produzidos a partir de entrevistas semiestruturadas e analisados pela técnica de Análise de conteúdo na modalidade Análise Temática. **Resultados:** as mães compreendem que a doença dos filhos impõe limitações e dificuldades para a permanência na escola, que, por sua vez, ainda não oferece condições necessárias à adaptação e inclusão dos mesmos. **Conclusão:** torna-se premente analisar as necessidades das crianças e adaptar projetos pedagógicos compatíveis com as condições educacionais de cada uma a fim de que tenham o seu direito à educação garantido e efetivação da sua cidadania. **Descritores:** Doença Crônica; Inclusão Escolar; Enfermagem Pediátrica.

RESUMEN

Objetivo: comprender como as mães percebem o papel da escola na inclusão de crianças com doenças crônicas. **Método:** estudo exploratório-descritivo, de abordagem qualitativa, realizado com seis mães cadastradas em unidades de saúde da família. Os dados foram produzidos por a partir de entrevistas semiestruturadas e analisadas pela técnica de Análise de conteúdo na modalidade Análise Temática. **Resultados:** as mães compreendem que a doença dos filhos impõe limitações e dificuldades para a permanência na escola, que, por sua vez, ainda não oferece condições necessárias à adaptação e inclusão das mesmas. **Conclusão:** torna-se premente analisar as necessidades das crianças e adaptar projetos pedagógicos compatíveis com as condições educacionais de cada uma, a fim de que tenham o seu direito a educação garantido e efetivação da sua cidadania. **Descriptores:** Las Enfermedades Crónicas; La Inclusión Escolar; Enfermería Pediátrica.

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INTRODUCTION

The most common chronic diseases in childhood are asthma, allergic, digestive, central nervous system disorders and epilepsy. These conditions make the child fragile due to the needs of visits to the doctor, prolonged treatment, hospitalization and various restrictions. Besides the institutional health network (clinics, health centers and hospitals), this situation requires the existence of a network of social support, such as neighbors, services and school, to provide them with hospitality, trust and security, ensuring humanization and creation of links to favor more adaptation to the specificities of the disease, a less hostile daily life and a better quality of life.¹

The school has an ideal setting to provide the first experiences of socialization, as well as to expand them, contributing to the development of the child's potential.² Regardless of the limitations related to chronic diseases, it is necessary to include it socially within the school, especially those of school age. However, attending students with chronic diseases, in their most diverse special needs, has been a great challenge faced by schools. In this sense, these children have been less contemplated in the teaching-learning process in the others, besides not having their health specificities respected, such as the absence of school attendance due to clinical recurrences and/or repetitive hospitalizations. Vulnerabilities in peer relationships and school performance, given absenteeism imposed by health demands.⁴⁻⁵ Thus, the school and the health team must be prepared to plan and adapt the activities to the specifics of the children to contribute to their social and academic success. It is also estimated that by 2020, 80% of the burden of diseases in developing countries will come from chronic diseases, with an increase in the number of children affected.⁶

The identification of the needs of these children is among the difficulties experienced in the school, since they may be more susceptible to learning, social and emotional difficulties.⁷ Therefore, they will demand knowledge and skill of the professionals and offer appropriate conditions so that they can develop their skills and play roles in the family, school and social context. A study carried out with teachers shows that they feel unprepared to deal with students with special needs since they have not had the orientation to play their part, generating them despair, anguish and a feeling of impotence.⁸

The integration and inclusion in environments such as the school require preparation for the child and professional educators as there is special care that cannot be neglected such as food, physical activities, sometimes medication and the processes of reception and interactive with other children. Thus, the lack of a pedagogical project designed based on teamwork and the collaboration of each member of this group for the development of activities adapted to the singularities reflexes of the child can easily make the school a scenario of academic failure with negative social.⁴

This study is justified the importance of collaborating in raising awareness of schools and educators to host all children, regardless of their special needs, as guaranteed by Brazilian law, with a commitment to find ways to educate and contribute to these come to perform their activities successfully⁸ from the perspective of socialization and the development of their potential. In this context, the question is: how mothers of children with chronic diseases perceive the role of schools in providing the conditions for the inclusion of these children in the school? Thus, to answer the objective is:

- To understand how mothers perceive the school's role in the inclusion of children with chronic diseases.

METHOD

This is an exploratory-descriptive study with a qualitative approach was carried out in a city of Paraíba, Brazil, in the period between June and July 2013. Mothers of children with chronic diseases identified from a previous consultation to the families' records were enrolled in the Family Health Units, and who met the following inclusion criteria: being a mother of a child with a confirmed diagnosis of chronic disease, and who is duly enrolled in a school institution.

The data were collected through a recorded interview, guided by a semi-structured script, containing the following guiding question: What is the role of the school in providing conditions for the inclusion of its children? The interviews were carried out in the mothers' homes, after the signing of the Informed Consent Form and clarification about the research and the implications regarding their participation. The criterion for closing the data collection was the saturation.

The interviews were transcribed in full and submitted to content analysis, categorical thematic modality⁹, following the operational steps: 1) floating, intuitive, or partially

oriented text reading; 2) definition of hypotheses; 3) determination of the registration units (UR); 4) definition of units of meaning (US) or themes and 5) categorical analysis.⁹

The research project obtained a favorable opinion from the Ethics and Research Committee of the University Hospital Alcides Carneiro, under protocol nº: 12151613.7.0000.5182.

RESULTS AND DISCUSSION

The study included 06 mothers aged 25 to 42 years old, whose family income was less than one and a half minimum wage in force in Brazil (R\$ 618.00 at the time of collection). The children were between 6 and 9 years old, with only one female. The diagnoses of the children were: Brain Neoplasia, Hyperactivity, Mental Retardation, Cerebral Palsy and Autism, defined according to the International Statistical Classification of Diseases and Related Health Problems - ICD - 10.

Based on the mothers' statements, three thematic categories were constructed: 1) School: a favorable element for the inclusion of children with chronic illness; 2) The teacher: facilitator element of the process of inclusion of the child with chronic illness in school and 3) Inclusion x integration: path to be trod.

♦ School: a favorable element for the inclusion of children with chronic illness

Living with human diversity, valuing the particularities and differences of individuals and respecting the equality of rights, is essential for the full psychosocial development of every human being. Based on this principle, the school is characterized as a foundation tool for building a social practice, implemented based on the recognition of the talents of individuals¹⁰, and amplified by resources that stimulate the development of psychomotor skills and abilities of the children.

The mothers participating in this study reveal that not all schools have the necessary conditions to promote the learning of children with a special condition, although the availability of resources represents an inclusion strategy since it stimulates the performance of the child's neuro-psychomotor functions. Interaction in the social context.

In my opinion, there are municipal schools with more resources, so he [the child] adapts better. (E1)

The school collaborates with its room, the resource room, which is very important and is a very large advance for him [the child]. Because of there [in the resource room], he

is learning, he trains the motor coordination. (E6)

The school should not only treat a special child well. On the other hand, in my point of view as a mother, the school should prepare children who are "normal," in quotation marks, to be clear, to accept a classmate who is not in quotation marks, normal. Because it is like I told you before, prejudice is sometimes the parents who pass to their children. (E5)

The understanding that the school must provide much more than physical resources is evidenced in the E5 speech, emphasizing the need to value the individuality of children without denying their limitations, since they are real. Mothers explain the importance of fostering in the school discussion about a society that adapts to meet the special needs of its citizens.

Although this is fundamental, a study reveals that many teachers have not yet been properly trained to act in these circumstances, which may be a hindrance to the implementation of certain resources to aid in the process of teaching and learning of the child, making communication and interaction difficult Between these and other children.¹⁰

Faced with the possible difficulties and special needs that a child with a chronic condition presents in the classroom, it is necessary for educators to be properly qualified and have essential tools to attend to their particularities, such as specialized guidance and appropriate materials that enable them to offer conditions for the learning of these children.

Changes are necessary for the organization of schools with the inclusion of specialized, attitudinal, pedagogical and communication activities that enable the entrance of special children into the teaching space regardless of their condition to guarantee access and regular stay of these students in school.¹¹

At school, there are several factors that contribute to a successful school performance, whether related to the institution (physical, pedagogical, and teacher qualification factors), to the family (parents level of education, parental presence, and parents' interaction with school and duties) and the student (time to perform tasks, cognitive ability, learning). Thus, by articulating the partnership between family and school, this scenario favors the inclusion of children with chronic illness. Therefore, parents and teachers need to be interconnected to discuss existing needs and, together, appropriate for the construction of alternatives that favor the insertion of the

child, the bonding, and socialization with their peers, strengthening the incentive to remain in the school context.²

♦ The teacher: facilitator element of the process of inclusion of the child with chronic illness in school

Being a teacher of children with special needs requires unique skills such as patience, availability, and sensitivity to attend to demands with care, without lowering it about others. These professionals are essential aggregators since they can provide the total and unconditional insertion of children.

The mothers' statements show that they recognize the teacher as a facilitator in the process of inclusion of the child with chronic illness in school.

Thus, at school, the teacher gives her much attention. (E1)

They arranged a teacher to stay with him. Because he does not talk, many things he still put into his mouth, and he has to have someone not to let it do that. (E4)

The teacher and the assistant help, and he [the child] is in the morning in the resource room and the afternoon in the normal classroom. (E2)

The duty that is equal to that of the others she [the teacher] reduces to him, already for him to do. He does not equal others, but he tries. The teacher is very attentive to him. (E3)

These results are consistent with the literature⁵, given that the educator must be prepared to deal with adverse situations, and be able to devise coping strategies, as well as exercises that stimulate both coordination and communication to promote interaction with others inserted in the context, always with an attitude of respect for the individualities and limitations of each student.

Contrary to the positive results of this investigation, the study pointed out that some hyperactive children, due to difficulties of concentration, are classified by the educators as a negative example for the other colleagues, which contributes to low self-esteem. Therefore, it is necessary to raise awareness among managers to carry out training and qualification courses directed to teachers to improve their competencies for an efficient performance and to rescue in these students' performance favorable to the feeling that they are capable and productive individuals.¹⁰

Research on the teachers' attitudes towards the aspects of school inclusion of children with special educational needs (NEE) showed that teachers with special education training, regardless of the position assumed in

the school (administrative or teaching), were the most supportive of the inclusion of children with intellectual, visual, hearing, speech and language impairments. However, neither teacher training nor the professional role assumed at school made a significant difference to support the inclusion of children with physical disabilities, autism spectrum disorder (ASD), attention deficit/hyperactivity disorder (ADHD), specific learning, and the gifted.¹¹

There is an urgent need to train teachers to deal with special children, but also to raise awareness of the inclusion of all children, regardless of their needs, considering this essential factor to promote inclusion. Thus, the inclusion of children with special needs may be favored by the formation of a structured environment with an adequate classroom, compared to another environment that, even playful, does not offer the physical and human resources necessary for pedagogic and recreational activities, limiting opportunities.¹²⁻³

♦ Inclusion x integration: path to be trod

The inclusion of special children in school involves the processes of inclusion and integration, both aiming to insert the student or a group of students in regular education. However, these terms present differences regarding the time of occurrence of the action, being considered integration, the entrance of those students previously excluded, and entry from the beginning of school life as inclusion.¹⁰

Thus, it is the responsibility of the school and the teachers to act in the perspective of the socialization of students with special needs and, they must be adequately qualified to work on the insertion of the child, not exclusion, but inclusion and integration are not always practiced in the school, as evidenced by the mothers' statements:

The afternoon class is especially for this (for the inclusion), the morning to the normal. (E3)

It is just him; he has no other. Then, when there are the other boys who are also special, who also speak, the school accepts that there are three in the same room. (E4)

In my opinion, some municipal schools have more resources; there are people who adapt better there. The school he studies is private school, in this case of inclusion, I do not see much of anything (E1)

This separation by the school, using adapted environments, between normal children and those with special needs is evidenced by mothers as normal. In no testimony, there was any mention of

improving the conditions to receive their child, either on the adaptations of the environment or with requirements made by the school so that their children could attend it.

The creation of specialized environments, exclusive for the participation of children with special needs, favors the partial and conditional insertion of them since the changes aim at the same ones. On the other hand, inclusion requires changes that benefit every person, not making sense of who makes the most, because everyone tends to win. Such transformations are profound in nature; society adapts to meet the needs of people with disabilities, becoming more attentive to the needs of all.¹³

The inexistence of this understanding raises the need for discussion and reflection by the managers about these situations that indicate unpreparedness, lack of qualification and even prejudice by the educators. It can imply in more suffering and traumas for the children, in front of the necessities of special health care and limitations for learning in regular school. The study states that overcoming this situation implies focusing on enhancing student participation with special educational needs (NEE) in different school contexts and activities, facilitating their performance and stimulating their independence and autonomy.¹⁴

The equality of conditions of access and permanence in the school is guaranteed by Brazilian legislation of the Federal Constitution, the Statute of the Child and Adolescent, the National Education Guidelines, and Bases Law (Law 9394/96), National Curricular Parameters, National Plan of Education and through Decree nº 6.094 / 2007. This legislation reaffirms the guarantee of access to regular public education, the permanence in it and the attendance to the special educational needs of the students. This process goes beyond the simple act of placing a student with special needs in the regular school, and this action implies a collective commitment to the school and the agents involved, an adequate political-pedagogical project and the planning of the continuing education for the education professionals.¹⁵

The chronic condition imposes difficulties and special needs on children but does not exclude them from the right to education, and socialization in school life with other children. Thus, it is up to the school to plan inclusion strategies for these and their families to establish links and interactions with the

school to help these children to be potentially productive.

CONCLUSION

The role of the school is to provide conditions to include the child in educational activities and establish favorable conditions for their inclusion in society, seeing and understanding their difficulties as a basis for designing and planning strategies that promote the inclusion of this student. In this sense, the results of this study demonstrate the absence of favorable conditions in the school that provides the inclusion of children with chronic diseases, including the lack of trained educators and basic infrastructure to deal with their demands, causing significant harm to children and their families.

Although it is a condition that affects all ages when in childhood, chronic disease determines stress and risks to the child. For the scholar who begins to be identified among his peers, any situation that exposes him as different, can generate feelings of inferiority in relation to the group, becoming a challenge for social inclusion, which needs and must be faced towards overcoming and achievement of that child.

The reality of children with a chronic health condition at school revealed by the mothers participating in this study, raising questions about the way schools are facing this reality and if they are really prepared to develop an inclusive education, as well as how families perceive their participation in this process.

As a sociocultural fundamental environment to the constitution of the subjects, the school should promote an environment conducive to the development of the potential of the child and inclusion among his peers, in view of the existing social diversity, which favors the sharing of experiences, interaction, respect and cooperation between them. In this way, it is up to the school to make feasible the possibilities of socializing experiences.

Thus, it becomes urgent to analyze the needs of the children and adapt pedagogical projects compatible with the educational conditions of each one of them to have their education guaranteed, a condition that favors the effectiveness of their citizenship.

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