

**Vulnerabilities Experienced in the Schooling of Children and Adolescents  
with Chronic Diseases: Perspective of Education Professionals**

**Vulnerabilidades experienciadas na escolarização de crianças e adolescentes  
com doenças crônicas: perspectiva dos profissionais da educação**

**Vulnerabilidades experimentadas en la escuela de niños y adolescentes  
con enfermedades crónicas: perspectiva de profesionales de la educación**

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**Abstract:** Objective: To know the perspective of education professionals about the difficulties faced in the school education of children and adolescents with chronic diseases, considering the aspects of vulnerability. Method: Descriptive and exploratory study of a qualitative nature. Data collection was carried out in a city in southern Brazil. The participants were fifteen education professionals who, in their daily routine, assist children or adolescents with chronic diseases. Data was analyzed through thematic analysis and interpreted through the concept of vulnerability. Results: Three themes emerged: programmatic vulnerabilities experienced in schooling and caring for children and adolescents with chronic illness; individual vulnerabilities experienced in the relationship between the family and the school and its influence on the schooling process; and social vulnerability and the schooling process of children and adolescents with chronic diseases. Conclusion: There is an evident need for an accurate look at the dimensions of vulnerabilities experienced, involving the availability of human and material resources, to minimize adversities and limitations in schooling, aiming to address individual demands of students, their families, and educators.

**Keywords:** chronic disease; educational status; child; adolescent; nursing.

**Resumo:** Objetivo: Conhecer a perspectiva dos profissionais de educação acerca das dificuldades enfrentadas na educação escolar de crianças e adolescentes com doenças crônicas, tendo em vista os aspectos de vulnerabilidade. Método: Estudo descritivo e exploratório de natureza qualitativa. A coleta de dados foi realizada em uma cidade ao Sul do Brasil. Participaram quinze profissionais da educação que em seu cotidiano atendiam crianças ou adolescentes com doença crônica. Os dados foram analisados por meio da análise temática e interpretados por meio do conceito de vulnerabilidade. Resultados: Emergiram três temas: vulnerabilidades programáticas vivenciadas na escolarização e cuidado a crianças e adolescentes com doença crônica; vulnerabilidades individuais experienciadas na relação da família com a escola e sua influência sobre o processo de escolarização; e vulnerabilidade social e o processo de escolarização de crianças e adolescentes com doenças crônicas. Conclusão: Evidencia-se a necessidade de um olhar apurado para as dimensões de vulnerabilidades vivenciadas, envolvendo a disponibilização de recursos humanos e materiais, a fim de minimizar adversidades e limitações na escolarização, objetivando sanar demandas individuais dos alunos, suas famílias e dos educadores.

**Palavras-chave:** doença crônica; escolaridade; criança; adolescente; enfermagem.

**Resumen:** Objetivo: Conocer la perspectiva de los profesionales de la educación sobre las dificultades que enfrentan en la educación escolar de niños y adolescentes con enfermedades crónicas, considerando los aspectos de vulnerabilidad. Método: Estudio descriptivo y exploratorio de carácter cualitativo. La recolección de datos se llevó a cabo en una ciudad del sur de Brasil. Participaron 15 profesionales de la educación que, en su rutina diaria, asisten a niños o adolescentes con enfermedades crónicas. Los datos fueron analizados a través de análisis temáticos e interpretados a través del concepto de vulnerabilidad. Resultados: Surgieron tres temas: las vulnerabilidades programáticas experimentadas en la escolarización y atención de niños y adolescentes con enfermedades crónicas; las vulnerabilidades individuales experimentadas en la relación de la familia con la escuela y su influencia en el proceso de escolarización; y la vulnerabilidad social y el proceso de escolarización de niños y adolescentes con enfermedades crónicas. Conclusión: Es evidente la necesidad de una mirada precisa a las dimensiones de las vulnerabilidades experimentadas, que involucran la disponibilidad de recursos humanos y materiales, con el fin de minimizar las adversidades y limitaciones en la escolarización, con el objetivo de atender las demandas individuales de los estudiantes, sus familias y educadores.

**Palabras claves:** enfermedad crónica; escolaridad; niño; adolescente; enfermería.

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## Introduction

Schooling is a phase of changes and imposes an adaptation process on children and adolescents, their parents and teachers, encompassing issues such as a new environment, routine, eating habits and new bonds. <sup>(1)</sup> Experiences in this new world generate situations, habits and routines determined by the space in which people are inserted, putting them in socially determined places, this being a moment of major transformations, especially individual ones. <sup>(1)</sup> These adaptations gain potential when associated with the need to live with a chronic disease.

Chronic diseases are those resulting from various causes which, initially, are gradually manifested and last for extended or undetermined periods of time. They relate to adapting to changes that occur throughout life and to intensification periods, which make it difficult to carry out everyday activities. They demand clinical interventions and changes in life habits, <sup>(2)</sup> in addition to family rearrangements to reconcile the needs of the family member with the chronic disease, with repercussions in the social, economic, and physical spheres. <sup>(3)</sup>

It is understood that the school is a space in which the individuals' development tends to be fostered, to encourage their autonomy. In this context, there are countless challenges to which teachers, family members and students are exposed in education, especially in its inclusive modality. Lack of materials, infrastructure, human resources and of an effective support network in this context, <sup>(4)</sup> school abstinence, socioeconomic aspects, lack of information about the disease, lack of knowledge in the professionals to deal with the situation, and the need to take on roles for which they are not prepared, are only some examples. <sup>(5-7)</sup>

The ability to attend classes and attain good academic performance is associated with the person's health conditions. These conditions differ between the students with some health need and the others and can be minimized with the students' active presence in the school environment, which also undergoes changes due to the need to be absent from this space for health care, which can be for short or long periods of time. <sup>(6)</sup>

These students face a complex routine, especially in the face of a Special Educational Need (SEN). Three dimensions are considered for this, namely: the school educational context, encompassing the school institution and the pedagogical action; the student, considering development level and personal conditions; and the family, in view of the characteristics of the environment and family life. <sup>(8)</sup> It is understood that the issues listed are co-responsible in the student's learning and schooling process.

The bonds established between parents and teachers have a positive result about assisting in this schooling process, aiming at the well-being of the child or adolescent. In addition, the relationship with health professionals, as well as of the several spheres between each other, reflects on their daily experiences, given the importance of each person's actions on their life. <sup>(3)</sup> Despite this, the link between the health and education environments still suffers resistance in its development, even when both share the same objective with these students. <sup>(6)</sup>

In addition to that, this condition evidence situations of vulnerabilities capable of hindering the schooling process; considering that vulnerability is not defined solely as a state arising from and acceptable to human beings, but that it also involves individual and, especially, collective circumstances. <sup>(9)</sup>

Individual vulnerability refers to people's understanding of the problem, so that they can adopt protective and preventive measures from the management of this knowledge;

social vulnerability encompasses the aspects related to the ability to obtain information and access to services, involving gender, ethnic/racial and economic issues and religious beliefs, among others; and programmatic vulnerability, also called institutional vulnerability, involves public policies, behaviors taken to minimize or avoid health problems to which these individual may be exposed, including the access modalities that are offered to the population to benefit from these measures, facilitating or limiting it. <sup>(10)</sup>

Adversities and limitations facing the public, health and social policies are also considered, and they demand the effective implementation of preventive, protective and proactive measures, <sup>(11)</sup> in view of the daily challenges faced by children and adolescents with chronic diseases and, therefore, special health needs, together with the families and educational professionals, regarding the school context.

These situations of vulnerability are linked to practicalities and difficulties emerging from the health and disease process; therefore, it is essential to identify these situations of vulnerability, which assists in the way in which this reality can be discussed, and in the actions to be developed to minimize them. Given the above, the following research question was elaborated: Which is the education professionals' perception about the vulnerabilities experienced in the schooling process of children and adolescents with chronic diseases?

### **Objective**

To learn the perspective of education professionals about the difficulties faced in the schooling process of children and adolescents with chronic diseases in view of the vulnerability aspects.

### **Method**

This is a qualitative research study, based on the understanding perspective, using the conceptual framework of vulnerability according to Ayres. <sup>(12)</sup> This research is part of the multicenter study entitled "Vulnerabilities of children and adolescents with chronic diseases: Care in a health care network", which was carried out concurrently in other cities in the states of Rio Grande do Sul (RS) and Santa Catarina (SC), Brazil. The data herein presented refer to the collection process carried out in the city of Pelotas, RS. As it is a qualitative study, its elaboration sought to meet the recommendation checklist of the Consolidated Criteria for Reporting Qualitative Research (COREQ). <sup>(13)</sup>

The study participants were education professionals who assisted children or adolescents with chronic diseases in their daily routine. They were indicated by the families of children and adolescents who took part in the collection process carried out in the first research stage, which took place in the hospital environment and included children and adolescents with chronic diseases hospitalized in all the hospitals that offered pediatric hospitalization in the municipality of the study. Therefore, from the identification of these children and adolescents, contacts were made with the families and those who agreed to participate in the qualitative stage were included in the research, and, thus, with the information provided by these families, the education professionals indicated by them were contacted.

The first contact with these professionals was made via telephone calls, explaining the research objectives and dynamics, and inviting them to participate. After the participants accepted the invitation to participate, the interview was scheduled at the school setting, which took place in the second half of 2019, after reading and signing the Free and Informed

Consent Form. Seventeen education professionals were contacted to take part in the research, of which two were educators/caregivers of the same child. Of the 17 professionals contacted, 15 agreed to contribute to the research and two refused to do so. They belonged to ten different schools and were identified as follows: “EP” (Educational Professional) with a sequential number, in order to preserve their anonymity, for example, “EP1”. When two professionals oversee the same child, the identification added the letters “a” or “b”, together with the identification number, to differentiate their statements (e.g.: “EP8a” and “EP8b”).

The data were obtained through semi-structured interviews with audio recording on a cell phone and lasting a mean of 30 minutes; and, subsequently, a comprehensive (manual) transcription was carried out with double checking (verification of the transcript by another person). The interviews were carried out by two Nursing students with research initiation scholarships, who were previously trained for collection by two professors from the Federal University of Pelotas, who were also researchers and academic advisors and with scientific publications on the theme. Collection took place in a private room at each school where the participating teachers worked. The interviews contained questions referring to the participants’ profile, as well as two additional open questions, namely: Which practicalities and difficulties do you find regarding the health care provided in the school to children/adolescents with chronic diseases? Which support networks do school professionals need to monitor children/adolescents with chronic diseases in the school?

The audios and transcripts were stored in digital files, on a computer belonging to the supervisors and will be kept for a period of five years to solve any doubts regarding the content of the interviews.

Data analysis took place deductively, using directed content analysis,<sup>(14)</sup> which is guided by a structured process based on an existing theory or theoretical concept. From this conception, key concepts or variables are elaborated as initial coding categories; subsequently, operational definitions are prepared for each category according to the theory or conception adopted. The theoretical conception adopted to guide analysis of the results in this study was the vulnerability and human rights framework proposed by Ayres et al.,<sup>(12)</sup> which seeks to understand the individual and collective factors related to greater susceptibility to illness or health problems and uses resources for protection in its three axes: individual, social and programmatic.<sup>(10, 12)</sup>

The project was submitted to *Plataforma Brasil* and approved with CAEE 54517016.6.1001.5327, under opinion No. 1,523,198. In addition to that, the ethical precepts recommended in Resolution 466/12 of the National Health Council belonging to the Ministry of Health were respected, which address aspects of research involving human beings,<sup>(15)</sup> converging with the precepts of non-maleficence, beneficence, justice and equality set forth in the Declaration of Helsinki.

## Results

The fifteen education professionals that took part in the research belonged to the age group between 26 and 53 years old, with a mean of 46. In relation to their marital status, seven were single, five were married, one was divorced, and one was a widow; the rest did not report on this question. Working time varied between seven months and 17 years, with a mean of 4 years and six months.

The education professionals’ occupations included teachers, who are fully responsible for the class, developing contents; pedagogists, responsible for preschool; caregivers/supervisors, who work as assistants both inside and outside the classroom, with

no specific training in most cases, also described as assistant-teachers; educational advisors, working together with the school management and helping the teacher in the students' education; coordinators, who guide collective functioning, integrating the roles of the professionals responsible for education and assisting in certain specific activities; and psychopedagogists, encompassing actions aimed at care and at seeking understanding of the students' behavior and assisting in their development when any difficulty is identified.

Three main themes were listed from the diverse information collected from the participants, namely: programmatic vulnerabilities experienced in school life and the care provided to children and adolescents with chronic diseases; individual vulnerabilities experienced in the relationship of the family with the school and their influence on the schooling process; and social vulnerability and the schooling process of children and adolescents with chronic diseases.

### ***Programmatic vulnerabilities experienced in school life and the care provided to children and adolescents with chronic diseases***

Lack of human resources, materials, infrastructure and/or support in the school environment was highlighted as a factor capable of hindering the inclusion of children and adolescents with special health needs in the school setting, these vulnerabilities being defined as programmatic. The statements below show how this takes place in the institutions:

*There are times when he needs some support [...]. He was attending the support classes there with her (coordinator), but there were another two or three children with more disabilities [...] so it's not possible to work only with him. [...] there's a lack [...] in the mornings, I work alone as an assistant-teacher and there are many children who have problems, disabilities [...] I'm a caregiver, so I take care of the child's hygiene and I also work in the schoolyard. [...] access to the bathroom [...] only that it's a very high toilet for him [...] the material has to be controlled, so that he always has it [...] sometimes I bring it from home. (EP8b)*

This report evidence both the deficit in human and material resources and the inadequate infrastructure to meet the children's needs. In this sense, it is necessary that the children/adolescents are encouraged to develop autonomy in self-care:

*This year we're working to create some autonomy because next year he'll be in 5<sup>th</sup>, I work in the mornings, I have nobody in the afternoons, then he has to begin [...]. Then we're trying to train him so that he can manage alone. (EP13)*

In terms of difficulties experienced by the schools' professionals, there is little elucidation about measures to be adopted when the children/adolescents with chronic diseases present an exacerbation of the health problem in the school environment. In this aspect, the presence of the health professional proves to be necessary, also encompassing the absence of a support network between the education and health sectors.

*Without the issue of the health professional [...]. I make a more superficial assessment to be able to inform the moment I call the SAME (Mobile Emergency Care Service) [...]. And then this child is directly taken to medical care. [...] as for health, if there's a child in crisis, we currently don't have a Nursing professional in APAE and it is very necessary. (EP5)*

Based on this statement, it is observed that, as the educational institution has children and adolescents with special needs, the presence of professionals trained to provide assistance is essential, and that the presence of the health professional in the school environment is relevant. In addition to that, the absence of this professional imposes the need to activate the family to offer support in cases such as medications or complications:

*We're not used to medicating in the classroom, we ask that the parents come at that moment and bring the medication. So that there is no problem [...] that the parents come at that moment or that they try to organize the schedule so that it is not during school. (EP7)*

*There are several times that he (student) looks like he's going to choke, the father brings [...] the suction tube [...] in the education are [...] we're not very prepared to deal with that [...] because we don't have the training to deal with these events. (EP3)*

The feeling of impotence in the face of these situations taking place in the school environment, when they escape the routine, hinders educational assistance, as shown in the statements below:

*The only support we have is the goodwill of the teachers and the administration, which is to call the parents. And if the parents authorize some other referral. (EP14)*

*At first, we'll inform the family and then we'll call the SAMU, because we have no other means. (EP4)*

Given the above, it is possible to identify that there is certain failure in the relationship between the school and health networks; thus evidencing the importance of including the health professional in the school environment:

*I believe that it would be necessary [...] closer access to health [...] this network that the school needs to be inserted to exchange information, to know how to act with certain children, greater contact with the health professionals [...] this deeper knowledge [...] about what to do in certain situations. (EP1)*

*I think [...] that we should have more support from the Psychology area. I see a major gap [...] if we had a professional from this area available at some times, it would really facilitate our work. (EP10)*

*This whole network needs to get together. Only that the number of professionals is too low. It's not much because, for example, we don't have a psychiatrist, we can refer them to psychologists, sometimes it takes two, three years for an appointment. We need a speech therapist. (EP2)*

*Care [...] in the health area [...] Nursing to monitor the students' families, but the nutritional part is major axes [...] the health area is a distant area. (EP5)*

### ***Individual vulnerabilities experienced in the relationship of the family with the school and their influence on the schooling process***

The relationship between the family and the school is fundamental in the schooling process; however, it presents facilitating and hindering factors. In the meantime, the

participants understand that the lack of active participation by the family in the school is a complicating element.

*This year her mother is pretty absent from the school's activities, [...] that's one of the reasons why she (the student) is sadder, more irritated. [...] (EP1)*

*The difficulty here with him (the student) was that the family was absent many times. The family more engaged in the support offered. (EP12)*

In this context, effective communication between the school and the family proves to be an indispensable factor for the full development of the student's educational process:

*And it's not like that for lack of calling, asking "you have to update your data"; then there are people who go like "but I don't have a cell phone", but there has to be someone that you can ask for a phone number in case of an emergency, because we have to be able to contact the student's family. (EP2)*

The mothers are often the only caregivers of children and/or adolescents and their right to priority care for being responsible for children/adolescents with special health needs is not respected in several places, a fact that interferes with their routine and, possibly, in the active participation within the educational institution, hindering the education process. A fact that can be noticed in the following reports:

*There are single mothers, so they face big difficulties. They talk a lot about the bus issue [...] sometimes they need assistance in a basic health unit and can't get transportation, because there are few adapted buses. Another thing is [...] the issue of the forms. [...] the unit doesn't understand that it is only on such day and at such time that they'll have someone to stay with the child in the wheelchair at home [...]. And then sometimes they need a consultation and they have to expose themselves with that child on the road because they have no one to leave them with and they also need care. (EP5)*

In a complementary manner, showing the importance of the family participating, another aspect positively highlighted by the educators was the mothers' participation in the school:

*The mother is such a wonderful person, always concerned, we called them and she came. It's not even necessary to call her for her to talk with us [...]. Whenever she can't come, because she has some respiratory problem, she calls and tells us. (EP4)*

*The mother is very accessible [...] always very willing [...] she's very present. (EP1)*

In addition to that, there are other female figures in the family accompanying them to school:

*Her grandmother really takes care of her (the student) [...] she gets a lot of support from her grandmother. (EP6)*



In addition, the education professionals believe that the mother's presence in the school confers confidence, as can be observed in the following statement:

*Some mothers remain in the school as a result of the children's pathology [...] during the period they're being seeing by a professional. (EP5)*

### ***Social vulnerability and the schooling process of children and adolescents with chronic diseases***

This category encompasses issues that involve social vulnerability and the schooling process in the school context, covering the interruption or absence of school activities due to health conditions, the difficulty in learning as a reflection of the health conditions, the restrictions faced due to the chronic diseases, denial of the diagnoses, and the coexistence, bond and social insertion of the students with chronic diseases.

*This is a school that has a lot of students who come from lower social classes, from poor neighborhoods, so it's not always the same care that another child would have. I'm not even saying on the part of the school [...] the part that is done with the family member is no longer the same care, even for lack of (financial) conditions. (EP2)*

*She needs a lot of care. Unfortunately, because of his health, we can't have continuous work [...] his health is a little fragile, he has respiratory problems; this is something that makes it difficult. (EP3)*

*His time availability is reduced, [...] he stays until ten o'clock [...]. Sometimes he misses classes one or two days, others he comes back more agitated and has to take some medication. (EP8a)*

The difficulty maintaining the school routine is intensified when there is a need for hospitalization, with a prolonged absence of the student from school, interfering with learning, development, and social insertion.

*At some moments, when she has the transfusion, she doesn't come. (EP1)*

*Due to the respiratory problem she ends up missing classes a lot [...] missing contents; because of her intellectual deficit, I work with her individually, so she ends up missing this. (EP4)*

*It's really worrying because, at the end, he's spent a whole lot more time in the hospital than in the school lately. (EP12)*

*It's difficult because she misses classes a lot. [...] I believe that it would be more due to family issues. [...] she hardly comes twice a month. It's not even possible to evaluate her in the learning issues. (EP9)*

In this way, the absence or interruption of school activity, among other reasons, reflect negatively on the schooling process, such as the difficulty in learning, mentioned by the education professionals, since, among the students who participated in the study, the majority need specialized care.

*She feels that she can't (follow up). [...] I notice this year that she's angrier, more impatient, she no longer sees herself as available to learn. Learning seems to have*

*become something less pleasant, tedious, tiring, something that until the end of last year we hadn't noticed [...] her biggest problem is this non-retention of learning. (EP1)*

*It's very difficult [...] I explain some activity to her today, some content, and she already forgets it after ten minutes, then she doesn't retain what I teach her, then it's complicated. (EP4)*

*And he'll learn, of course; he seems to have regressed in some areas; he learns some things but there are others that it seems like he forgets, [...] before he was more affectionate, he didn't hit anyone, he learned the letters; now he learned to hit people, he became aggressive. (EP8a)*

Another relevant consequence of the chronic diseases seen by the education professionals is the restricted participation in certain activities or events experienced at this life phase due to the pathologies, and this occurs in different ways:

*For these children, especially those with diseases such as diabetes [...] it's a disease that ends up depriving [...] of many things, let's say, in between quotation marks, good, [...] like soda, French fries. [...] and so, it's not deprivation, it's not for a week, it's not a diet, it's not a month, it's a lifetime. (EP10)*

In addition to the restrictions that chronic diseases can cause in the children/adolescents' daily routine throughout life, there is a process in which they tend to deny the diseases, making the issue of care and limitations in the school environment even more complex:

*It would reduce his suffering by some 50 %, [...] if he had greater acceptance and then [...] the psychological aspect come in. [...] the difficulty I see [...] the issue of acceptance of the patients themselves, [...] they don't accept their own disease well. (EP10)*

*The family being aware and making the child aware of the care they should have with themselves. (EP11)*

Another aspect that can present itself both as a positive and a negative factor is sharing time and space with the class and the relationship side. In specific cases, certain distancing from the peers and difficulty in interaction can be observed, which becomes a negative element for adapting to school life, enhancing the difficulties faced by these children/adolescents.

*So it's limiting [...] he used to interact with the children there, but now he [...] stays on his own, but he has that schedule of his, then he starts to ask for his mother, to call his mother, grandmother. (EP8a)*

*He came from a small group, it took a while to have that acceptance, but everyone hugged, was together, played, called, brought him along. This group [...] is already farther from him. [...]. There are few who go there and interact in some way. (EP13)*

## Discussion

Based on the results, it is possible to identify situations of programmatic vulnerabilities in the schooling process. It is noted that the need for professional support in terms of both human resources and materials, whether basic or for pedagogical and recreational use, in addition to inadequacy of the infrastructure, stand out as obstacles to the schooling process.

According to a previous research study, maintenance of classroom and of the physical structure, the extracurricular activities/games and the environments/resources that promote learning are essential elements in the view of parents, students and teachers alike regarding the school and inclusion, <sup>(4)</sup> highlighting its potentiating role for adequate learning. The fact that there is a changing table of an inadequate size to perform the student's hygiene, an essential and routine task, for example, is configured as a programmatic vulnerability, <sup>(10)</sup> in which the infrastructure of the service provided by the school environment is not adequate.

The lack of resources reflects the lack of a playful approach, which is a tool to promote knowledge and development in children and adolescents, in a pleasant and appealing way. <sup>(16)</sup> The playful approach has the usual meaning of games and leisure activities and/or entertainment in general; however, although this term is designated in this manner, it is understood that not every activity visualized in this way can be considered as such, as it is strongly influenced by who is performing it. <sup>(17)</sup> Its lack hinders the schooling process and the students' permanence in school, especially for those who need special health care, interfering with the schooling process.

This fact is enhanced when the children or adolescents have an educational deficiency and needs special attention for their adaptation and development, with the absence of professionals available to assist in both shifts.

The statements highlighted the lack of access to health services and of a professional assisting in the classroom as situations that hinder the process; these vulnerabilities were also found in other research studies. <sup>(7, 10)</sup> In this aspect, noncompliance with public policies and structured programs aimed at protecting children and adolescents can be contributing to the difficulty in the children's development. <sup>(18)</sup>

The lack of human, material and physical support resources is characterized as social vulnerability, which encompasses aspects related to the ability to obtain diverse information and access to services, involving gender, ethnic/racial and economic issues and religious beliefs, among others, <sup>(10)</sup> with regard to materials for everyday use because, if the school does not have anything to offer and the parents or family members cannot afford to buy them, the students are left without them. The social aspects related to family income issues are also identified and are considered an important factor associated with low quality of life, which arises or is accentuated after the diagnosis of the chronic condition, especially due to the care needs. <sup>(19)</sup>

It is noted that this situation ends up preventing specialized assistance outside the school environment, given the financial problem. In addition to that, the interviewees highlight the feeling of powerlessness, resulting from lack of training. Empirical care is perceived in these cases, as there is no training and knowledge; however, some situations are handled with skills for which the professionals do not feel prepared. <sup>(5)</sup>

There is also individual vulnerability, which refers to the person's understanding of the problem, so that they can adopt protective and preventive measures from managing this knowledge. Certain feeling of unpreparedness is verified in the statements about the methods capable of minimizing the problems arising from the students' chronic conditions, especially

because it is not a topic arising from their training. It is difficult to maintain a cooperative bond on the part of the school and the professionals without their knowledge of the student's clinical condition. <sup>(7, 10)</sup>

The professionals look for ways to adapt to the student's needs, even without guidance from their studies, taking initiatives such as adhering to new methods capable of minimizing their weaknesses, demystifying some crystallized thoughts, and encouraging them, taking into account each student's learning times. <sup>(20, 21)</sup>

Another point listed in the statements was the absence of a health professional, such as a nurse, in the school environment, which reflects the various limitations in relation to the school's actions towards the students; situations such as worsening of the existing chronic diseases and use of medications were highlighted, issues for which the school professionals cannot be responsible and, therefore, there is a need to call the family for support.

The divergence between the students with some special health need and the others is especially reflected in the fact that their absences from this environment are more frequent. <sup>(6)</sup> If the school has the necessary health resources for the children to establish themselves, even if the parents do not have enough of them, it is possible that the students integrate this environment, <sup>(7)</sup> representing a programmatic vulnerability in this study.

There is concern in the parents in the face of the children's health needs. This fact can be mitigated from the presence of a nurse in the school environment, becoming a mediator between the school, the student and the family, favoring the promotion of a better quality of life and health in the children, preventing injuries and facilitating coexistence and the social aspects involved, thus becoming a fundamental element in this experience. <sup>(22)</sup>

When inserted in the school environment, nurses are able to carry out education in health, favoring the education professionals' preparation and training to deal with, manage or initially refer the complications, <sup>(22)</sup> generating autonomy and confidence, as well as promoting an association between education and health; in addition to viewing students in their entirety based on the vulnerability dimensions, aiming to adopt measures that actually promote assistance to them, given the context inserted. <sup>(11)</sup>

The relationship with the health professionals, as well as of all the spheres between each other, reflects on their daily experiences, given the importance of each person's actions on the student's life. <sup>(3)</sup> Despite this, the link between the health and school environments still suffers resistance in its development, even when both share the same objective with these students. <sup>(6)</sup> The integration of these sectors is very important; however, there is certain dissociation between them: although there are policies designed in this scenario, health and education, their effective implementation is not yet in force, due to the lack of priority in investments that consolidate them, exerting an influence on the child's development and on the failure to articulate the health context with the other contexts. <sup>(18)</sup>

On the one hand, the issues encompassing the school and family spheres refer to an essential factor in the schooling process. It is identified that, for this process to be fully developed, participation and inter-relationships between school and family are essential. Despite being divergent and, sometimes presenting different objectives, it is understood that both are essential in the education of children and adolescents, aiming at their integration into society. However, the relationship between these two sectors is commonly and exclusively around a problem rather than associated with the student's development and progress and the family-school relationship in a way that points out the positive aspects of development, which is still a challenge. <sup>(23)</sup>

It is important to emphasize that matrimonial, patrimonial, and consanguineous aspects are not the only determinants of family constitution. A previous study <sup>(24)</sup> verified

that the family is described not only in the traditional model, including father, mother and children, but also as the one built from coexistence or kinship, as in cases where grandparents or uncles are included, and there must be welcoming ties regardless of the family constitution, taking into account the family group members that are responsible for the child/adolescent.

Therefore, with the association between school and family, aiming at the best for the students, with dialog, planning and continuity at home, there is a facilitating factor for their development. <sup>(20)</sup> Despite this, this link refers to a construction that is difficult to be established, in certain cases, even knowing about its essentiality. It is important that the family has essential information for the care of the child/adolescent, such as, and despite the pathology, trusting the school and becoming partners. <sup>(7)</sup>

Non-exercise of school participation can come from several aspects; however, there needs to be a family support network for this participation to be active. This structured network does not exist in many cases, as is the case of single mothers who cannot count on the support of others. There is significant predominance of the female figure as the main responsible for the children. <sup>(25)</sup> This context encompasses the other care measures inherent to the caregiver, such as cleaning the house and being present at the appointments and in the school, and was portrayed in the statements when the professionals did not highlight the presence of the mothers, but of another female figures in the family. The social support network for single-parent families is represented, above all, through their own family group and friends, but it is also related to neighbors, institutions, work and studies, and the main challenges for these mothers involve their children's economic, emotional and education spheres. <sup>(26)</sup> Among the institutions, the school stands out, which associated with the family, represents an essential element in the children's and adolescents' lives. This reality involves social vulnerability aspects, in terms of economic resources and support network, and programmatic vulnerability when looking at the behaviors taken to avoid or minimize these difficulties. <sup>(10)</sup>

To facilitate the association between them, communication between the family members and the school's professionals is essential. However, there are barriers capable of hindering this process and rendering it ineffective, including physical obstacles, such as noise or the distance between the speech senders and receivers, personal obstacles such as each individual's limitations and emotions, and systematic obstacles, when symbols or even gestures have different meanings for each person. <sup>(27)</sup> In this sense, it is understood that an important aspect to be taken into account with regard to communication is the schooling of the students' parents/guardians, which is often precarious, requiring understanding and capacity for dialog to occur in a way that both understand, targeting individual aspects.

Individual vulnerability is also present due to the health condition, given the need for special care. <sup>(10)</sup> Children and adolescents with chronic diseases face a different routine than the others. Factors such as climate, decompensated illness, non-fulfillment of some basic needs in the school environment, exams and consultations are some examples. This distancing from the school environment to receive treatment and care is shown in a study <sup>(28)</sup> that sought to identify the main causes of hospitalization in two hospitals in the Brazilian Northeast region, and these causes were similar, with a significantly high number for non-communicable chronic diseases when compared to communicable diseases, mainly due to asthma. Such fact should point to the family members' and teachers' attention and care regarding schooling and development.

In this way, the possibility of attending the school environment and achieving good performance is different depending on whether there is a related health condition, as well as

the need to be absent from this space to receive health care, thus affecting development.<sup>(6)</sup> It can be perceived that this interruption interferes in the students' learning and social life, as the school is also a socialization place. Consequently, children/adolescents with chronic diseases tend to suffer this school distancing at several moments of their life, a factor which can have repercussions in the learning process.

Childhood and adolescence are life phases in which it is natural for self-knowledge discoveries and construction of new bonds and likes to occur. These stages become limited when the children and/or adolescents have chronic diseases which preclude them from experiencing those phases with intensity, thus restricting them. When this situation involves eating habits, even though there is a lot of advertising for fast-food products and soft drinks, it cannot be assumed that food limitation and restriction reflect negatively on the daily lives of these individuals, as these elements consider the culture and habits.

Despite this, food restriction is significantly listed in cases of children and adolescents with Diabetes. The restrictions due to the chronic diseases negatively affect not only the children/adolescents but also their social environment, because, when depriving themselves of a certain activity or food, they end up feeling embarrassed to hang out with friends and feel different from the others in everyday activities, in some cases becoming more isolated.<sup>(29)</sup> There is a constant search for balance in the Diabetes cases, as carbohydrates are important sources of glucose that is transformed into energy, and any imbalance between what is consumed and what is used can compromise academic performance and, in these cases, the cognitive aspects. Low academic performance in children and adolescents may come to result in a negative socioeconomic consequence in adulthood.<sup>(30)</sup>

These limitations affect this population segment in many ways, which can be related to physical, cognitive and nutrition aspects, among others. The limitations resulting from the disease, preventing an exacerbation, such as running, cycling and swimming, in the case of asthma, for example, take deeper measures influencing the school routine, such as physical activities and playing with the other classmates.<sup>(31)</sup>

The disease denial process was also highlighted. This situation can be understood by the defense mechanisms used by people; however, they generate extreme distress in the children/adolescents, who do not accept the disease nor the necessary treatment to maintain their health, contributing to physical problems and to negative emotional aspects.<sup>(29)</sup>

When the special needs of students with chronic diseases go beyond health aspects and have educational impacts, it is important to offer care capable of minimizing the difficulties experienced in everyday life. Individualized care is required for this to occur, and it is necessary to have more professionals responsible for assisting in the behavior with the other classmates and, sometimes, specifically with the CRIANES; however, there is also a need to deal with all of them simultaneously, in some cases.<sup>(7)</sup> Thus, it is necessary to adapt the way in which the goals will be set and achieved, so that the students can follow up, but without interruptions in the planning already stipulated for the class.<sup>(20)</sup>

Chronic diseases affect the children's and adolescents' physical, and a significant number of times, emotional aspects. They often perceive themselves with a body with marks, scars and limitations resulting from the chronic disease, which prevents them from performing the same roles and doing the same activities as their peers.<sup>(32)</sup> Among other factors, learning is linked to the student's self-esteem, which is a variable that suffers internal and external stimuli. When the students' self-esteem is impaired, this reflects on the way in which they perceive themselves, where professionals and family members play an important role as motivators.<sup>(18)</sup>

Aspects of individual vulnerability, caused by the chronic disease, especially due to learning difficulties and the need for specialized educational care, can be understood because it is something that reflects a particular condition of these students. Likewise, it is possible to identify cases in which there is certain difficulty concentrating and retaining content already covered during the activities with the student, precluding evolution in development and worsening when there is lack of resources to assist in this process, configuring not only an individual vulnerability but also a programmatic one. <sup>(10)</sup>

Families can exert a positive influence so that the children perceive and accept their restrictions, although without ceasing to see themselves as children, or adolescents in this case, not excluding their marking experiences and discoveries of this life phase from their routine. Family readaptation in order to encourage the students to adopt new life habits that enable improvement in their health conditions is seen as a positive enhancing factor. <sup>(31)</sup> These adjustments are inherent to the entire family and affect a number of issues in the social, economic and physical areas, modifying the family context. <sup>(3)</sup>

According to the participants, the feeling of welcoming by the class also facilitates this process, as they feel welcomed, understood and interacting with the others. In certain cases, the student's insertion in this environment is flawed and this generates harms in social interaction and feelings such as contempt and inability to learn can arise, especially at the same pace as other students, making them feel excluded from this environment. <sup>(18)</sup> However, when there is effective interaction and support by the family and classmates, these aspects are able to minimize the consequences arising from the individual vulnerability of the student with chronic diseases.

Students who suffer from chronic diseases report expectations regarding the classmates' support to face the limitations imposed by the diseases; however, at certain moments, the situation occurs in an unexpected way, leading to social isolation, exacerbating the difficulties already faced. <sup>(33)</sup> This fact evidence coexistence with the class as being both a positive and negative factor depending on those who are inserted in this environment. Thus, the importance of the role played by family members, teachers and the health network is unveiled with even more strength.

## Conclusion

The results identified the different faces the vulnerability situations in the schooling process of children and adolescents with chronic diseases, based on the education professionals' perspective. These range from individual, programmatic and social aspects arising from the needs of the students, families and professionals in the face of chronic diseases to potential, positive and negative factors in development and, therefore, challenges to be faced.

Lack of professionals, material resources and infrastructure for the schooling process, non-guidance by the professional educators regarding the students' diseases and the feeling of powerlessness reflect obstacles to the students' development and the ineffectiveness of the support network between the health and educational spheres, as well as the importance of this association. Concomitant to this, there is the absence of professional nurses in the school environment, who would be able to assist in health care maintenance during the school period and in the training of professionals in this environment.

The association between the school and the family proves to be essential for academic performance; however, it is not a reality foreseen in its entirety due to variable factors.

Linked to this, the influence of social vulnerability is observed, as the conditions in which these students are inserted are directly related to access to these services.

There is an evident need for an accurate analysis of the dimensions of the vulnerabilities involved in this process, understanding the need for human and material resources to minimize adversities and limitations in the schooling process, aiming to solve the students' individual demands.

For the health care of children and adolescents with chronic diseases to be innovative and decisive, it is indispensable to plan and establish support networks between the health and school spheres, especially with the insertion of health professionals in this environment, aiming at the promotion of the students' health, reflecting on their schooling process and development.

In the meantime, the current study has the potential to contribute as a support for reflection regarding the effective school support network and the need to train education professionals, as well as to plan proposals for improvements to assist in the education and inclusion process. Among the study limitations is the difficulty scheduling the times to interview the professionals, as they encounters take place in a professional environment, requiring other professionals to replace them during the interview period and, therefore, certain planning by the school and researchers to enable data collection.

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