

ADOLESCENTS WITH SPECIAL HEALTH CARE NEEDS: CHALLENGES OF SCHOOL INCLUSION ACCORDING TO FAMILY MEMBERS/CAREGIVERS' VIEWPOINT

Adolescentes com necessidades especiais de saúde: desafios da inclusão escolar no discurso de familiares/cuidadores

Adolescentes con necesidades especiales de salud: desafíos de la inclusión escolar en el discurso de la familia/cuidadores

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ABSTRACT

Objective: The study's main purpose has been to understand the challenges of school inclusion of adolescents with special health care needs according to family members/caregivers' viewpoint. **Methods:** It is a qualitative research that was performed at an ambulatory pediatric specialty care, which assists adolescents with special health care needs. There were carried out analysis of medical records and semi-structured interviews with 35 family members/caregivers of adolescents. The interviews were subjected to double transcription and the Michel Pêcheux's Discourse Analysis. **Results:** Family members/caregivers brought in their speeches the challenges faced for school integration and inclusion, professionals and people who contribute to the adolescent's social insertion process, as well as the skills and potential of Children and Youth with Special Health Care Needs (CYSHCN). **Conclusion:** Inclusive education must be articulated in an interdisciplinary manner, engaged by all spheres of management, politics, work, families and its users. Inclusion should be discussed by nursing while looking forward to implementing health promotion and social space for the adolescent community.

Descriptors: Adolescent health, Chronic disease, Disabled persons, Special needs education, Family.

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RESUMO

Objetivo: Conhecer os desafios da inclusão escolar de adolescentes com necessidades especiais de saúde a partir do discurso dos familiares/cuidadores.

Método: pesquisa qualitativa, realizada no ambulatório pediátrico de especialidades, que atende adolescentes com necessidades especiais de saúde. Realizou-se a análise de prontuários, entrevista semiestruturada com 35 familiares/cuidadores de adolescentes. As entrevistas foram submetidas a dupla transcrição e à análise de discurso Pecheutiana. **Resultados:** os familiares/cuidadores trouxeram em seus discursos os desafios enfrentados para a integração e inclusão escolar, os profissionais e as pessoas que contribuem no processo de inserção social do adolescente, as habilidades e potencialidades da CRIANES. **Conclusão:** a educação inclusiva deve ser articulada de forma interdisciplinar, engajada por todas as esferas de gestão, política, trabalho, famílias e usuários. A inclusão deve ser debatida pela enfermagem, em busca da promoção da saúde e de espaço social para o adolescente.

Descritores: Saúde do adolescente, Doença crônica, Pessoas com deficiência, Educação especial, Família.

RESUMEN

Objetivo: Conocer los desafíos de la inclusión escolar de adolescentes con necesidades especiales de salud desde el discurso de los familiares/cuidadores. **Método:** investigación cualitativa, realizada en la clínica de especialidad pediátrica, que asiste a adolescentes con necesidades especiales de salud. Se realizó el análisis de los registros médicos, una entrevista semiestruturada con 35 familiares/cuidadores de adolescentes. Las entrevistas fueron sometidas a doble transcripción y análisis del discurso pecheutiano. **Resultados:** los familiares/cuidadores presentaron en sus discursos los desafíos que enfrenta la integración e inclusión escolar, los profesionales y las personas que contribuyen al proceso de inserción social del adolescente, las habilidades y el potencial de CRIANES. **Conclusión:** la educación inclusiva debe articularse de manera interdisciplinaria, involucrada por todas las esferas de la gestión, la política, el trabajo, las familias y los usuarios. La inclusión debe ser discutida por la enfermería, en busca de la promoción de la salud y el espacio social para el adolescente.

Descriptorios: Salud del adolescente, Enfermedad crónica, Personas con discapacidad, Educación especial, Familia.

INTRODUCTION

The Children and Youth with Special Health Care Needs (CYSHCN) addresses children and adolescents between 0 to 18 years old (incomplete) who either have or are at greatest risk for developing a chronic condition, physical or developmental restriction, emotional or behavioral limitations, mild, moderate disability or severe.¹⁻⁵ CYSHCN requires specialized interdisciplinary, health, or educational care, capable of understanding CYSHCN and their families.⁶

The care demands presented by this clientele are classified into six groups, as follows: Developmental demands (they need psychomotor and social rehabilitation); Technological (they need some technological device in their body); Medicines (drug addicts); Modified Habits (adaptations to carry out daily activities); Mixed (association of two or more care demands); Clinically complex care (a combination of all of the above including life support technologies).^{1,5,7-9}

In the literature, it is possible to find several nomenclatures in an attempt to name a characteristic, without stigmatizing it, so Special Health Care Needs (SHCN) encompasses deficiencies that require different treatment, chronic, transitory, or definitive conditions. In education, there are specialized educational needs for children and adolescents that require differentiated educational support strategies, when regular education does not guarantee the integration and inclusion process, called Special Educational Needs (SEN).¹⁰⁻¹³

It is important to highlight the constitutional right that ensures equality and conditions of access, without any type of discrimination. In this respect, CYSHCN in adolescence must have its rights guaranteed,¹³ including attitudinal accessibility, to break patterns that stigmatize SHCN, starting with school inclusion.

So, it is necessary to offer CYSHCN learning conditions, so that they are able to develop skills. Social inclusion contemplates inserting them and making them participants in society with their rights ensured,¹⁴ emphasizing the potential and possibilities, demystifying taboos and prejudices.

The presence of CYSHCN in adolescence in the classroom does not guarantee its inclusion. Therefore, the debate on inclusion, which is still incipient in the health area, must permeate the various segments of society, be discussed in an interdisciplinary approach, including the attitudinal aspect, as the stigmas are not restricted to physical accessibility, but discriminatory attitudes.¹⁴

Herein, it is affirmed the role of Nursing and people's sensitivity when working with this particular theme, since the nurse is a link of informative/training support, which can articulate with other professional spheres,¹⁵ promoting a connection between health/education/adolescent/family.

Bearing the aforesaid in mind, this work meant to understand the challenges of school inclusion of adolescents with special health care needs according to family members/caregivers' viewpoint.

METHODS

This work is a section from the database linked to a Doctoral Thesis in Nursing Care named, The daily life of adolescents with special health care needs: implications for nursing (hidden reference for blinded reviewers' appraisal, will be attached later).

It is a descriptive research with a qualitative approach, which was performed at an ambulatory pediatric specialty care located in the central region of Southern Brazil. Such ambulatory is a referral center for health care of children and adolescents bearing special health care needs.

For the data production, there were implemented reading sections of medical records aiming to identify whether the adolescents met the criteria for the classification of CYSHCN.¹⁶ There were included family members/

caregivers of adolescents bearing special health care needs, able to verbalize and who were present during the ambulatory consultation. Family members who had never developed care for adolescents were excluded, then totaling 35 family members.

The characterization and interviews were carried out in an ambulatory room in order to respect the privacy of the participants. To verify the theoretical saturation and end the production of data, sampling was used in qualitative research.¹⁷ The audio of the interviews were recorded in digital media, double transcribed, subjected to Michel Pêcheux's Discourse Analysis, in order to promote a reflection general view on the meaning of the speeches produced and the ways of producing meaning.¹⁸

The research was approved by the Research Ethics Committee from the *Universidade Federal de Santa Maria*, under the *Certificado de Apresentação para Apreciação Ética (CAAE)* [Certificate of Presentation for Ethical Appraisal] No. 57774916.7.0000.5346, and Legal Opinion No. 3.940.550. The "F" code corresponding to the Family member was used, followed by a random ordinal number to maintain the participants' anonymity.

RESULTS AND DISCUSSION

The insertion of the adolescent in the school occurs through the efforts of his family, looking for strategies so that the adolescent has the opportunity to study, such as the *Associação de Pais e Amigos dos Excepcionais (APAE)* [Disabled People Parents and Friends Association], the presence of mediators, and the pedagogical complement.

[...] I wish she had gone to APAE before... But we couldn't get a place! It was through her teacher... otherwise she would be at the other school today! (F4)

Oh, she has been studying in the special class since she was eight years old! [...] I didn't get a place at the APAE; it was very important for her, but we couldn't... [...] (F14)

[...] She does follow-up with special education! (F15)

[...] I looked for a neurologist at that time. Cognitive testing was done with a psychologist, all proving for her to have special care! [...] With a special school educator in the afternoon, once a week... (F21)

Yes, it is once a week [tutoring for the adolescent]. [...] But she has a schoolteacher as well. (F22)

The discourse of family members/caregivers underlines the cognitive delay of some adolescents, reflecting on the regression towards literacy, reading and writing. Nonetheless, these CYSHCN with SEN are enrolled at school, and their learning is conditioned to special needs.

She counts a few numbers, and now she is getting [learning] the alphabet! (F4)

[...] They put her back in the special class, and the girl forgets things! She cannot write... Reading, she cannot do it! (F14)

Sometimes, families and adolescents get help from people close to them, such as teachers and even classmates, who are facilitators of this inclusion process.

I put her on the bus, and the teacher goes with her. [...] There are my niece and granddaughter, they are in the same room, they are her colleagues [...] (F15)

There are two teachers, one normal and the other special. [...] (F24)

The family members/caregivers accentuate that adolescents are often at school, but are not included in the proposed activities, with significant developmental limitations.

It is because, she is not an adolescent to be in 5th grade. She doesn't even know how to do simple math... It's so wrong! [...] I think they are putting her forward, without her knowing anything! (F1)

She is in the 7th grade, but you know... [...] It's just because she has to go forward! In her case, a 1st grade was good, but you have to move on... (F15)

[...] Yes, she is very late, but she has not yet developed! There is a difference between her colleagues and her... I see the others and the cleverness she doesn't have! (F22)

[...] She has an IQ [intelligence coefficient] with difficult reasoning, so, I don't know how she is in this advanced grade! (F27)

Further statements point to the School's lack of preparation when receiving adolescents with special health care needs, underestimating their capacity. Latent memory denotes the stigma and social taboo that such adolescents experience, since his skills and potential are not worked, making inclusion distant from the reality of these adolescents.

She gets a stomachache, dizziness, vomiting, if it's not one thing, it's another! Thus, I need this medical certificate that requests the presence of a mediator during classes... (F1)

Yes, at school I think it is much more difficult! [...] Look, she always said she liked to dance and then I put her in

a dance class, then she said she was hurting her head or foot, she doesn't adapt! (F5)

When she went to this school that she is nowadays, she was in the 4th grade, because the other school she was in before, she was advancing grades, you know? [...] We, as mothers, monitor and see! (F14)

In class, she does paintings mostly! She is in 7th grade... She just doesn't follow the class, you know? Before, she went to have classes and I stayed with her in the classroom... [...] (F15)

[...] She is in school and they call: Oh, the [name of the adolescent] was sick... [...] (F16)

I made the school aware of her health care! [...] (F21)

Due to their health demands, adolescents often miss classes and, as a result, they need to develop strategies to accompany the school class, adapting their routine to health care needs.

[...] She never asked for a medical certificate due to physical education, in fact, we don't send her to physical education classes because of her tiredness. [...] She still has many changes... (F16)

[...] So, at school when she gets out of herself, she stays with a washcloth all the time and her colleagues make fun of her... (F20)

To every school he would change I took both a medical report and a medical certificate with me! (F28)

He goes! At night! As he lost a little due to the illness, he had to do two years in one! (F30)

For some family members/caregivers, adolescents demonstrate a certain autonomy in school activities, this movement is highlighted by the adolescents' achievements and learning possibilities.

She writes... She writes poorly, but still does it! (F1)

She does everything! [...] She goes with transportation to APAE [...] (F4)

Normal, when she is not the first in the class, she is the second; if it is not her, it is her brother. [...] Yeah, she studies harder than he does! (F7)

The [name of the adolescent] is a poet too! [...] She makes a lot of poetry for our State [...] (F8)

He does very well at school! (F10)

[...] She writes down only her first name for now! (F14)

[...] The name... She can only read her name! (F15)

[...] So, only when he is not well, right? Otherwise, he does everything! [...] (F19)

Skills and potential for development are part of the relatives' discourses. Although some adolescents have difficulties, family members brought out the process of autonomy based on the adolescents' achievements.

The paradigms of school integration and inclusion are linked to social taboos and the stigma of disability related to adolescents with special health care needs. The scarcity of mediators, the need for help so that the adolescents remain in school, and the unpreparedness to welcome the adolescent permeated the discourse of the study participants.

Society defines standards of normality, where previously established standards are considered normal. The transgression of these standards characterizes the stigmatized, disadvantage and discredit. Stigma interposes, as an internalized social construct, among them, the perception of disability of the person with special and educational needs stands out.¹⁹

The inclusion of adolescents with special needs implies a reorganization of the educational system, in order to break with social paradigms that have roots in the segregation and exclusion of CYSHCN.^{19,20}

Given this framework, it is necessary that inclusion goes beyond the walls of the school and reaches society. Hence, inclusion is a social practice that applies in different social spheres, whether in work, in the structure of a city, in education, culture, and empathy with others. In the educational field, it is evident that working with diversities, differences and identity are fundamental, based on innovative methodologies.²⁰

The school plays a fundamental role for the adolescent and his family, in order to strengthen the adolescent's link in society. The school must accept, respect the limitations of the SHCN/SEN, making inclusive education real and not just a theoretical possibility.²¹ The school must prioritize mediating resources that enable the disability compensation process, through educational strategies that favor development and participation. The effectiveness of accessibility should break paradigms and prejudices about the possibilities of students with special needs.²²

The speeches of the family members/caregivers participating in this study reveal the significant role they play when seeking inclusion strategies and enabling better conditions for learning and development for the adolescent. The family is the determining link in the formation and

affective, cognitive, and social development of adolescents with SHCN.^{5,6}

Family routines are affected in the face of situations of change and stress, so it is essential to understand how these changes can be made to promote health.^{23,24} When identifying the presence of SHCN, families can end up restricting CYSHCN to certain activities, demonstrating overprotective behavior and judge daily activities as dangerous.¹⁴

Intending to understand the family dynamics of adolescents with SHCN, it is vital that nursing professionals assess the health conditions of CYSHCN and that they understand the inclusive policies, so that they can develop the care planning, implementation, and monitoring of this clientele.²⁵

Just as for health care demands, a wide institutional network is crucial, when it comes to the need for special education, it is essential to have specialists who enable the development of these adolescents.

The nursing professionals must propose educational strategies that envision health promotion and disease prevention, as well as education professionals must be trained to welcome, integrate, and include adolescents with special health care needs. Nurses must welcome and meet the care needs of these adolescents and their families in the community, in order to ensure continuity of care, in addition to contributing to the participation of children/adolescents with special health care needs in society.²⁵

Considering that the care network for people with disabilities is a policy that has been in existence for less than a decade, it is understood that its proposal for integration between the teams working in the different segments is not yet articulated. In this perspective, there is a lack of technological and structural investments, instrumentalization and interdisciplinary training, the involvement of public managers, professionals, and committed teams.²⁶

The network of people with special needs must guarantee comprehensive care, have actions and services articulated between health professionals, education, managers and users, so that health needs are effectively met, respecting the uniqueness of these people.²⁷

Conclusively, this research has as limitations the restriction of data collection in the ambulatory pediatric specialty care in a referral hospital, since if it were expanded to other scenarios it could expand the debate on the inclusion of adolescents. Moreover, the small male participation among family members/caregivers, as the discourses might have cultural roots such as the maternal protection bias.

CONCLUSIONS

Inclusive education has been gaining strength in the discourse of family members who look for including adolescents

at school and in society. In the statements, latent memory rescues the adolescent's social stigma, which sometimes appears only in the social space, but not embraced.

In this regard, both inclusion and integration underlined in this work, demonstrate that it is necessary to break paradigms that CYSHCN in adolescence is incapable of doing, furthermore, challenge them to work on their potential and skills in the school space, respecting their uniqueness.

Health professionals, particularly nursing professionals, need to internalize the discourse of inclusion and make it effective in their practice, working in an interdisciplinary way so that the network of adolescents with special health care needs guarantees their rights. Ultimately, the inclusion and integration of the adolescent must enable belonging to the group, where different spheres are engaged to guarantee the attitudinal accessibility of this adolescent, the breaking of taboos and prejudices, the guarantee of their rights, and their recognized autonomy.

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