Daily care of adolescents with special health care needs

Cotidiano de cuidado de adolescentes com necessidades especiais de atenção à saúde

Cotidianidad de los cuidados de adolescentes con necesidades especiales de atención en salud

Andressa da Silveira[1]
Eliane Tatsch Neves[1]

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Adolescent; Adolescent health; Chronic disease; Delivery of health care; Disabled persons

Descritores
Adolescente; Saúde do adolescente; Doença crônica; Assistência à saúde; Pessoas com deficiência

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Abstract
Objective: To understand the daily care of adolescents with special health care needs.
Method: Qualitative study, based on the critical and liberating pedagogy of Paulo Freire and conducted in the pediatric outpatient clinic of a teaching hospital, in the second semester of 2016. The study was based on analysis of medical records, semi-structured interviews and construction of genograms and ecomaps of 35 adolescents with some kind of health demand. After the double transcription, the interviews were submitted to Pecheux discourse analysis.
Results: The daily care of these adolescents occurs through personal hygiene, physical appearance, medication use, nutrition and modified habits. The discourse of the adolescents presented different levels of emancipation: sometimes care was developed by adaptation and alienation, revealed by habits and by the need to develop the care through a technical reproduction, which contributes to oppression; and at other times it is developed with the possibility of emancipation, based on reflection on their reality and on the action of positioning themselves.
Conclusion: The daily care of these adolescents is full of possibilities and abilities at different levels of emancipation. The absence of dialogue, exchange of knowledge and reflection can contribute to the process of oppression. Nursing professionals need to enable the exchange of knowledge and reflection, so that the adolescent can transitions from a naive to critical conscience.

Resumo
Objetivo: Compreender o cotidiano de cuidado de adolescentes com necessidades especiais de atenção à saúde.
Métodos: Pesquisa qualitativa, pautada no referencial crítico-libertador Freireano, realizada no ambulatório pediátrico de um hospital de ensino, no segundo semestre de 2016. Realizou-se a análise de prontuários, entrevista semiestruturada e a construção do genograma e ecomapa de 35 adolescentes com algum tipo de demanda de saúde. Após a dupla transcrição, as entrevistas foram submetidas à análise de discurso Pechetiana.
Resultados: O cotidiano de cuidado desses adolescentes é traduzido por meio da higiene pessoal, aparência física, uso de medicamentos, nutrição e habituais modificados. O discurso dos adolescentes apresentou diferentes níveis emancipatórios: em alguns momentos a partir da adaptação e alienação, pelo costume e necessidade de ter que desenvolver o cuidado por meio de uma reprodução técnica, o que contribui para a opressão; e em outros momentos pela possibilidade de emancipação, a partir da reflexão sobre sua realidade e posicionar-se sobre ela.
Conclusão: O cotidiano de cuidado do adolescente é permeado pelas possibilidades e habilidades em diferentes níveis emancipatórios. A ausência de dialogicidade, troca de saberes e reflexão podem contribuir para o processo de opressão. A Enfermagem necessita possibilitar a troca de saberes e a reflexão, para que o adolescente transite de uma consciência ingênua para crítica.

Resumen
Objetivo: Comprender la cotidianidad de los cuidados de adolescentes con necesidades especiales de atención en salud.
Métodos: Investigación cualitativa, de acuerdo con el referencial crítico liberador de Paulo Freire, realizada en los consultorios externos de pediatría de un hospital universitario, en el segundo semestre de 2016. Se realizó un análisis de historia clínica, una entrevista semiestructurada y la construcción del genograma y ecomapa de 35 adolescentes con algún tipo de demanda en salud. Después de una doble transcripción, las entrevistas fueron sometidas al análisis del discurso según Pêcheux.
Resultados: La cotidianidad del cuidado de estos adolescentes se traduce mediante la higiene personal, apariencia física, uso de medicamentos, nutrición y cuestiones habituales modificadas. El discurso de los adolescentes presentó diferentes niveles emancipatorios: en algunos momentos, a partir de la adaptación y enajenación, por costumbre y necesidad de tener que desarrollar el cuidado por medio de una reproducción técnica, lo que contribuye a la opresión; en otros momentos por la posibilidad de emancipación, a partir de la reflexión sobre su realidad y tomar una posición sobre esta.
Conclusión: La cotidianidad del cuidado del adolescente está impregnado de posibilidades y habilidades en diferentes niveles emancipatorios. La ausencia de dialogicidad, intercambio de conocimientos y reflexión pueden contribuir al proceso de opresión. La enfermería debe permitir el intercambio de conocimientos y la reflexión, para que el adolescente transite de una conciencia ingenua a una crítica.

Corresponding author
Andressa da Silveira
http://orcid.org/0000-0002-4182-4714
E-mail: andressadasilveira@gmail.com

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[1]Universidade Federal de Santa Maria, Palmeira das Missões, RS, Brazil.
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Introduction

Technological and scientific advances in child and adolescent health have contributed to improve the survival rates of those living with chronic conditions. Since 1998, these children have been called Children with Special Health Care Needs (CSHCN), which was culturally adapted to Brazilian Portuguese as *crianças e adolescentes com necessidades especiais de atenção à saúde* (CRIANES).[1,2]

Health care is regarded as an extended understanding of the health-disease process. It is organized and systematized based on preventive and corrective policies and actions, which are continuous, interdisciplinary and aimed at meeting the health demands of individuals and communities.[3]

CSHCN can be divided in six groups: Developmental demands (require psychomotor and social rehabilitation); Technological (need some kind of technology in their body); Pharmaceutical (drug-dependent children); Modified Habits (depend on adaptations to perform daily tasks); Mixed (require associated care); Medically complex care (combination of all previous groups with the addition of life support technologies).[1,2,4,5]

The CSHCN group comprises children and adolescents between 0 and 18 years old who have or are at increased risk for the development of chronic conditions, behavioral or emotional limitations, mild or severe disability, and who need long-term health care.[1,6-10]

In Brazil, it is not possible to find official rates regarding the population of adolescents who are CSHCN. In the United States, there are approximately 14.6 million CSHCN, of which 43.2% are between 12 and 17 years old. Among the health problems presented by CSHCN, we can highlight: Attention Deficit Hyperactivity Disorder (ADHD) (32.2%), Asthma (30.2%) and learning disabilities (27.2%).[11] A study conducted in Chile, with the objective of proposing a model of care for children and adolescents with special health needs, showed that 12.9% had some type of functional limitation or disability.[12]

Due to their different medical complexities, distinct health needs and use of multiple health services, the care demands of CSHCN can lead to family overload. Thus, nurses must be sensitive to receive these families with extended, continuous, proactive and determinative care.[13,14-16]

In this context, it is imperative to prove the existence of CSHCN in adolescence, to allow their voices to be heard, understanding the care process in their daily life, and based on this, to provide differentiated care to this population.

In view of the above, the question was: how is the daily care of adolescents with special health care needs?

The objective of this study is to understand the daily care of adolescents with special health care needs.

Methods

Descriptive-exploratory qualitative research based on the critical and liberating pedagogy of Paulo Freire, and on the concepts of adaptation, alienation, oppression and emancipation. Adaptation results from the accommodation of men to a situation, with no possibility of transforming their reality; alienation is related to the absence of reflection on their own reality; oppression comes from the sum of the processes of adaptation and alienation; and emancipation occurs through an action-reflection, a consciousness that leads to awareness.[17,18]

The participants were 35 adolescents with special health care needs, followed up at the pediatric outpatient clinic of a teaching hospital in the South of Brazil.

Data was collected between September and November 2016, with a previous reading of the medical records in order to identify if the participants corresponded to the care demands that characterize the CSHCN classifications.[19]

The adolescents were selected through intentional sampling[20] with the following inclusion criteria: being between 12 and 18 years old; knowing their own diagnosis and being able to verbalize.

The semi-structured interviews lasted an average of 20 minutes, were recorded in digital media and held in a room next to the outpatient clinic,

with questions about the daily care of adolescents. The participants could choose whether or not they wanted the presence of their relatives in the interview, and everyone chose their presence. Only the speeches of the adolescents were analyzed. The theoretical saturation criterion was used, stopping data collection when there were no new elements.

Based on the orientations from the adolescents, the genograms and ecomaps were constructed and elucidated daily care, revealing the health services that adolescents used, the existing bonds and their family constitution. The lines can be strong (continuous), weak (dotted), stressed (cut), and arrows show the ecomap flows.[21]

After the double transcription of the interviews, the empirical material was submitted to Pecheux Discourse Analysis (AD), which is based on a general reflection on the meaning of the texts produced, in order to understand the way of functioning, the principles of organization and the means of production of meaning.[22]

The study was approved by the Research Ethics Committee of the Federal University of Santa Maria under the number of CAAE 57774916.7.0000.5346, and opinion number 1,673,887. The informed consent term was used for family members, and a consent term was used for the adolescents. An alphanumeric code with the letter "A" followed by ordinal numbers in the sequence in which the interviews were conducted was used for identifying the adolescents.

Results

Characterization of adolescents and access to health services

A total of 35 adolescents attending the pediatric outpatient clinic participated in this study. Among the participants, 21 were female adolescents and 14 male adolescents. The age of the adolescents ranged from 12 to 17 years, with a predominance of 12 year-olds.

All the care demands of CSHCN were present, with emphasis on pharmaceutical care, modified habits and mixed care. Regarding the follow-up specialties, 15 adolescents consulted in endocrinology; two of the adolescents were followed up in more than one outpatient clinic.

Based on the Genogram and Ecomap represented in figure 1 it is possible to identify the professionals and the health services accessed by the female adolescent, the presence of a nurse who works in the city, as well as the regular school and the church. A15 also pointed out the existing family ties.

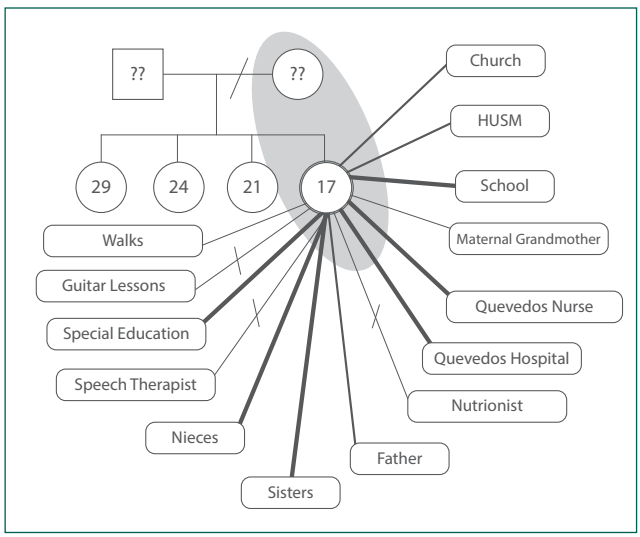

Figure 1. Genogram and Ecomap of A15

Figure 2 shows the heterogeneity of care required by a female adolescent and her access to different services and health professionals, reiterating the health care demands of CSHCN.

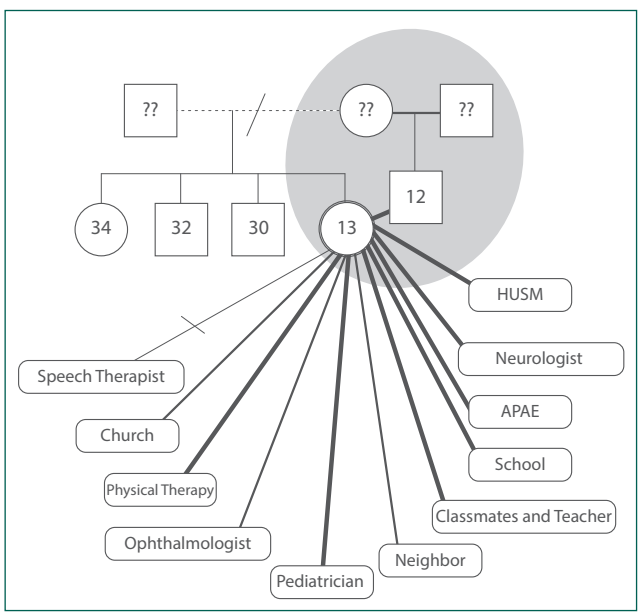

Figure 2. Genogram and Ecomap of A1

A total of 26 medical diagnoses were identified, some adolescents had more than one diagnosis and asthma was highlighted (9). In addition, two female adolescents with Down's Syndrome and one with Turner's Syndrome stand out. The time of diagnosis ranged from one to 17 years, and adolescents with genetic syndromes and malformations were previously diagnosed.

The daily care of adolescents

In their speeches, adolescents with special health care needs showed the possibility of developing their care by themselves. Polysemically, they emphasize daily care represented by personal hygiene, physical appearance, use of medication, nutrition and modifications of habits.

I go to the bathroom, brush my teeth and wash my face! [...] (A6).

[...] Yes, I brush my teeth, then I eat breakfast... [...] (A8).

Ah... I wake up, I take the insulin, I eat breakfast... (A10).

I wake up in the morning at 7 o'clock and I prepare my medication, and at night also at 7 o'clock! (A12).

I can do everything! [...] I do it by myself! [...] (A17).

[...] I take care of myself! (A18).

No, I do it all by myself! [...] I take the test and the insulin, and I go to class... (A29)

In their speeches, adolescents present possibilities to develop their care, signaling their movement towards emancipation. This process is present in the pharmaceutical care, based on a knowledge acquired by daily practice.

[...] I take (medication) alone! (A6).

I wake up, I take the insulin, I take 6 (units) before breakfast, // 12 (units) before lunch... that one is the NPH (insulin) and the regular one is 4 (units) only. // [...] (A10).

I take it (insulin), I take it by myself! In the morning I take 40 and at night when it is faster, I take 15 (A11).

I take Lantus® in the morning and then I take it at midday and midnight... (A25).

Insulin! Three times a day. I've learned it! [...] The nurses down there, from the PA (ambulatory care), in the PS Ped (pediatric ambulatory care), they taught me! (A26).

[...] In the morning I take my medication [...] I take Puran® T4 and Insulin... (A28).

Another care present in the daily life of these adolescents is diet control. The discourse fragments show the need to change habits and the awareness of the fact that the balanced diet has brought benefits to their health.

[...]] I eat a whole wheat cracker and / I drink a glass of milk... (A10).

[...] I only have ice cream once in a while!# (A21).

I drink more water! [...] (A23).

[...] I was very fat! I used to eat a lot! [...] It was hard to go on a diet... (A24).

The speeches of adolescents showed modified habits and use of technologies. Polysemically, they present behaviors that vary according to the symptoms they present, revealing a process of knowledge and skills for daily care.

[...] When there is dust like this, I close my nose so it does not get in! [...] I always have the inhaler (metered aerosol) with me, but I never had to use it... (A9).

[...] I have to stop (during apnea), then I sit down and drink some water first, then my shortness of breath decreases... [...] (A13).

I need the care, only the medications and the creams! [...] (A17).

[...] Every day sunscreen! [...] A straw hat... [...] Every time I come to an appointment, the day before they (doctors) ask for exams. [...] (A19).

And when I have allergy attacks, I put on some ointment... [...] When I go to school I take the inhaler (metered aerosol), I'm always prepared! (A31).

The adolescents studied present different levels of emancipation in their care. Some developed care by reproducing acquired knowledge, others incorporated care in their daily life by the habit of developing it without reflection.

Different levels of emancipation in adolescent care

The discourses show adaptive practices, when they reproduce the care because they are used to this routine. Replication and alienation can be seen in

the discourses "Oh, sometimes I don't take it", "Ah, sometimes I try", "I haven't done it a lot". These practices reinforce the alienation of the adolescent regarding the demands of care, meaning that there was no reflective process about their reality.

[...] I take them alone... I do not take it (the medication) at the right time... Oh, sometimes I don't take it! # (A3).

[...] Ah, sometimes I try, but I can't do it! [...] Ah, I see others eating and then I feel like eating... [...] (A5).

[...] It's not that it is uncontrollable (to follow the diet), but everybody drinks soda at home, then it is difficult! (A17).

[...] I haven't done it a lot... (blood glucose test) // But I do it! [...] Sometimes I almost never do it...# (A25).

These speeches demonstrate the interdiscourse with the different voices in the memory of these adolescents, the absence of dialogue with the health team and the family, and the lack of knowledge exchange and reflection on the care demands, which can contribute to oppression.

The contradiction between being an adolescent and being an adolescent with special health care needs is identified. The polysemy in the discourses reveals the difference between care in childhood and in adolescence.

[...] But now I can't make any effort... [...] I don't know how, but it interferes! Because I can't do anything, right?! [...] It bothers me, I get more agitated [...] (A3).

[...] It's just a bit difficult, but... /// Ah... I've already got used to it! (A10).

[...] It's not the same as when I was younger. Now I have to take care of myself a little more. Before, when I was younger, I didn't have to. It was a quiet life there... It's still quiet, but it's not that much! [...] (A19).

The discourses show the contradiction between care in childhood and in adolescence. Latent memory and recent memory indicate that living with special health care needs is a challenge. Care is part of the universe of these adolescents; however, it was possible to verify different levels of emancipation in relation to the process of developing care.

Discussion

The care of the adolescent with special health care needs is accomplished by alternating between "how" and "why" to develop this care. Some branches of care are in accordance with the critical and liberating pedagogy, in which adaptation is the accommodation of man to the situation, without possibility of transforming his reality. In alienation, man is deprived of reason, loses the control that belongs to him, does not reflect on his reality, and feels foreign in the world. Adaptation and alienation contribute to making man oppressed.[17]

The pedagogy of the oppressed has two stages: the first, in which the oppressed unveil the world of oppression and through the praxis commit themselves to its transformation; and the second, after the reality of oppression has been transformed, when this pedagogy ceases to belong to the oppressed and becomes a pedagogy of liberation. With action, reflection and awareness, it is possible for man to obtain his emancipation.[17,18]

CSHCN require care and interventions for their health conditions and risk factors. This population uses health care more than the general population.[23] The equivalence between being a teenager and being a teenager with special health care needs is perceived by the pursuit of personal identity. Acceptance is related to the need to deal with body image, since some changes are related to physiological factors that are not always controllable.[24]

For other adolescents, no change came from the discovery of their health condition. This finding is in accordance with a research carried out in São Paulo, with 52 adolescents with cystic fibrosis, who demonstrated a "everything is okay" attitude towards their health condition; however, this attitude is usually related to avoidance of reality.[24]

Traditional thinking is centered on diagnosis and disease. The chronic health conditions require care and functional skills; however, it is necessary to understand the context of individuals with chronic diseases, seeing them beyond their diagnosis and disease, from the perspective of their uniqueness.[25]

A study carried out with adolescents hospitalized in Rio de Janeiro revealed that, when faced with

a chronic illness and hospitalization, the daily lives of these adolescents are transformed, which makes them fragile and sensitive. Therefore, it essential for adolescents to participate in their care.[26]

The way that adolescents cope with their health situation is related to their emotional maturity, understanding and the support they receive from their social networks. The restrictions imposed by the chronic disease can affect the adolescent's adherence to treatment and their social insertion.[27]

A study carried out in Ceara with 25 adolescents, revealed the importance of hygiene and physical appearance, manifested through clothing. The adolescents reported, on the subject of body hygiene, the practice of the washing their hands and caring for their health, and considered clothing as a form of non-verbal language.[28]

Adolescents also believe in the importance of adherence to medication, and that regular and correct use reduces hospitalizations.[26] On the subject of nutrition, the difficulties in diet control are highlighted, since meals are related to collective interaction, sociability and socioeconomic conditions.[29]

A study conducted with adolescents with intellectual disabilities found high rates of obesity and hypertension, which is related to the risk of developing cardiovascular disease in the future.[30] As adolescents approach adulthood, they must assume greater responsibility for their health care. Adopting a proper diet may interfere with the ability to adhere to treatment and to control the disease, since they do not have fully developed emotional and cognitive maturity.[31]

Based on the analysis of the discourses of adolescents with health care needs, it was possible to perceive that they develop their care from two perspectives: sometimes by adaptation and alienation, revealed by habits and by the need to develop care through a technical reproduction, without reflecting on how it is done, and why it is done in this way, which contributes to oppression; and at other times, it is developed with the possibility of emancipation, based on reflection on their reality, on the practice of care and on the action of positioning themselves as subjects in the world.

One limitation of the study was the fact that it was developed in only one pediatric outpatient clinic. It would be necessary to expand it to other pediatric outpatient clinics in different regions of Brazil. This study's contributions for practice include allowing the exchange of knowledge and reflection, which can enable these adolescents to transition from a naive to a critical conscience. It is necessary to elaborate policies and specific programs for these adolescents, in order to increase the visibility of this group that requires singular and multidisciplinary health care and to favor a comprehensive care.

Conclusion

The demands of care of these adolescents are related to hygiene, physical appearance, use of medication, nutrition and modified habits. They rotate between adaptation and emancipation, possibly because of the difficulty of understanding the potential to develop their care. The daily care is full of possibilities and abilities at different levels of emancipation. The absence of dialogue, exchange of knowledge and reflection can contribute to the process of oppression.

Collaborations

Silveira A and Neves ET contributed to the project design, data collection, analysis and interpretation, article writing and final approval of the version to be published.

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