

**FAMILY CARE FOR ADOLESCENTS WITH SPECIAL HEALTH NEEDS IN THE HOME SPACE****CUIDADO FAMILIAR AOS ADOLESCENTES COM NECESSIDADES ESPECIAIS DE SAÚDE NO ESPAÇO DOMICILIAR****CUIDADO FAMILIAR A LOS ADOLESCENTES CON NECESIDADES ESPECIALES DE SALUD EN EL ESPACIO DOMICILIARIO**Andressa da Silveira<sup>1</sup>, Mariana Padilha Werle<sup>2</sup>, Alexa Pupiara Flores Coelho<sup>3</sup>

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**ABSTRACT**

**Objective:** to know how family care for adolescents with special health needs in the home is established. **Method:** qualitative, descriptive and exploratory research developed with family caregivers of adolescents, users of an Association of Parents and Friends of the Exceptional in the South of Brazil. The data were produced in the home space from the semi-structured interview. Saturation sampling was used. The statements were transcribed and submitted to content analysis. **Results:** assistance is centered on the basic needs of adolescents, mainly on the administration of medication and around personal hygiene. Home care is developed by women, especially mothers, rarely shared and restricted to the family nucleus. **Conclusions:** care is part of the daily life of family members, strongly exercised by the women of the family, who challenge themselves to develop it in order to meet the health needs of adolescents, often sacrificing their personal projects.

**Descriptors:** Caregivers, Family, Disabled persons, Adolescent health, Nursing.

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## RESUMO

**Objetivo:** conhecer como se estabelece o cuidado familiar aos adolescentes com necessidades especiais de saúde no espaço domiciliar. **Método:** pesquisa qualitativa, descritiva e exploratória, desenvolvida com cuidadores familiares de adolescentes, usuários de uma Associação de Pais e Amigos dos Excepcionais do Sul do Brasil. Os dados foram produzidos no espaço domiciliar a partir de entrevista semiestruturada. Utilizou-se amostragem por saturação. As enunciações foram transcritas e submetidas à análise de conteúdo. **Resultados:** a assistência está centrada nas necessidades básicas dos adolescentes, principalmente na administração de medicamentos e em torno da higiene pessoal. O cuidado domiciliar é desenvolvido pelas mulheres, sobretudo as mães, poucas vezes compartilhado e restrito ao núcleo familiar. **Conclusões:** o cuidado faz parte do cotidiano dos familiares, fortemente exercido pelas mulheres da família, que se desafiam a desenvolvê-lo com o intuito de atender as necessidades de saúde do adolescente, abnegando muitas vezes, seus projetos pessoais. **Descritores:** Cuidadores, Família, Pessoas com deficiência, Saúde do adolescente, Enfermagem.

## RESUMEN

**Objetivo:** conocer cómo se establece la atención familiar a los adolescentes con necesidades especiales de salud en el hogar. **Método:** investigación cualitativa, descriptiva y exploratoria desarrollada con cuidadores familiares de adolescentes, usuarios de una Asociación de Padres y Amigos de los Excepcionales en el Sur de Brasil. Los datos fueron producidos en el espacio domiciliario a partir de la entrevista semiestructurada. Se utilizó muestreo de saturación. Las declaraciones fueron transcritas y sometidas a análisis de contenido. **Resultados:** la atención se centra en las necesidades básicas de los adolescentes, principalmente en la administración de medicamentos y en torno a la higiene personal. El cuidado domiciliario es desarrollado por las mujeres, especialmente las madres, pocas veces compartido y restringido al núcleo familiar. **Conclusiones:** el cuidado forma parte del cotidiano de los familiares, fuertemente ejercido por las mujeres de la familia, que se desafían a desarrollarlo para atender las necesidades de salud del adolescente, muchas veces sacrificando sus proyectos personales. **Descriptor:** Cuidadores, Familia, Personas con discapacidad, Salud del adolescente, Enfermería.

## INTRODUCTION

Children and Adolescents with Special Health Needs (CRIANES) demand care in addition to other children and adolescents due to their health condition. In the international scientific scenario they are called Children With Special Health Care Needs (CSHCN). This denomination includes the population that is at increased risk for physical, developmental, behavioral or emotional conditions, as a result of some chronic health condition,

thus CSHCN need specialized attention, family care and multidisciplinary support.<sup>1</sup>

The term CRIANES covers a variety of clinical health conditions, which intersect with socioeconomic determinants, such as age, sex/gender, poverty, race/ethnicity and the impact of their unique characteristics on their daily activities.<sup>1</sup> With regard specifically to adolescents, in addition to the transformations of this stage of development, articulated with social

involvement and the re-dimensioning of their identity and new social roles. Thus, health care for CSHCN in adolescence is challenging given the repercussions of this stage of life, in which adolescents seek autonomy.<sup>2</sup>

Technological advances and numerous findings in the health area make it possible to survive in the face of serious and/or disabling diseases, through specific care to preserve life.<sup>3</sup> However, CSHCN face the prospect of an uncertain prognosis and have periods remission and symptomatic exacerbation, which is why they need continuous care.<sup>3-4</sup>

This context brings into play the role of family caregivers in the home, a scenario in which most of the daily care and coexistence of CRIANES takes place, in which the family member is fundamental. In addition, the health and quality of life of this population is related to the knowledge of their families, as well as access to health services, support network and bonding with the multidisciplinary team.<sup>4</sup> In addition, it is understood that it is in the home space that the daily care for CSHCN is carried out by the family caregiver.

The daily care of CSHCN during adolescence can be challenging for the family member, as there is overload and stress involved.<sup>5</sup> Families may also face difficulties in financial, personal and even

physical and mental health aspects, given the care demands presented by adolescents.

In this sense, it is important to understand how family care for CSHCN is established at home, and how this care is experienced by the caregiver family. The importance of this issue is reinforced by a longitudinal study carried out in the United States, which revealed that caring for CSHCN has an impact on family dynamics. The authors emphasize the need to work towards the promotion of care centered on these families, with a focus on social support, in order to improve the quality of life of these subjects.<sup>5</sup>

The care needs of CSHCN are complex, multifaceted and require attention and care from different health professionals.<sup>6</sup> Also, the important role of the family in the execution of care for the maintenance of life and the importance of clinical nursing practice in the daily assistance provided to CSHCN and their families.

In view of the above, the question is: How is family care established for adolescents with special health needs in the home space? The research aims to know how family care is established for adolescents with special health needs in the home space.

## METHOD

Research with a qualitative, descriptive and exploratory approach, carried out with family caregivers of CSHCN in adolescence, who attended an Association of Parents and Friends of the Handicapped (APAE), in the northwest region of southern Brazil.

The following inclusion criteria were established: being family caregivers of adolescents (between 12 and 18 years old), APAE users; caregivers should be over 18 years old; residing in an urban area, in order to enable the research team's logistics for data collection; present cognitive conditions for the process of consent and participation in the research; and developing care for adolescents for at least six months, considering that from this time onwards, family members would have experience and experiences to form impressions and feelings about the studied phenomenon. Based on the established inclusion criteria, it was possible to reach 15 family caregivers.

Subsequently, a search was carried out in the medical records of adolescents attending the APAE school. In the records, it was possible to find their complete addresses and an indication of who their caregivers were and who played the role of primary caregiver. Then, a drawing was carried out to define the order in which the possible participants would be accessed,

through telephone contact, in order to present the research and invite them to participate. The interviews were scheduled and held at the adolescents' homes, at an agreed date and time according to the availability of the participants, there were no refusals and the data were saturated in the 12th interview.

Data production took place between November 2018 and February 2019, using the semi-structured interview technique. A semi-structured script was elaborated, consisting of the characterization of family members/caregivers and 11 questions which addressed CSHCN health care during adolescence. Regarding the theme of the questions, it is highlighted questions about the routine of health care; adolescent participation in daily care; facilities and difficulties for care practices; presence/absence of support networks for care; lessons learned throughout the practice of care; challenges for CSHCN home care in adolescence.

The saturation sampling criterion was used, a conceptual tool in research on qualitative approaches in the field of health, with the aim of closing the final size of a sample of participants<sup>7</sup>, totaling 12 interviews. The audios were recorded on digital media, later transcribed simultaneously with the collection, by a pair of research assistants, in order to avoid

inconsistencies and proceed with the analysis.

The transcripts were submitted to content analysis in three stages: 1) pre-analysis; 2) exploration of the material; and 3) treatment of results, inferences and interpretation. Thus, the analysis, coding, categorization and treatment of results were organized through inferences.<sup>8</sup>

In the pre-analysis stage, a skimming reading of all interviews was carried out in order to systematize the initial ideas. In the exploration of the material, the analytical description was carried out, the process of marking the most frequent speeches and categorization, where the most representative enunciations were highlighted. In the treatment of results, inferences and interpretation stage, information was condensed and highlighted for analysis, culminating in inferential interpretations and reflective critical analysis of the research.<sup>8</sup>

In order to maintain secrecy about the identity of the participants, the letters CF (referring to family caregiver) were used to present the results, with a numerical sequence that represents the order of the interviews. The study was developed in accordance with the ethical precepts established by Resolution 466/2012 and was approved by the Research Ethics Committee under Opinion

nº 2,632,767 and CAAE 86186518.5.0000.5346.

## RESULTS

Twelve family caregivers of CSHCN participated in the study. Women predominated (n=11), 10 mothers and one grandmother, aged between 28 and 69 years. A father reported being the main caregiver of the teenager. Regarding marital status, there was a predominance of single family caregivers (n=7), with primary education (n=10), who performed domestic activities at home (n=7). The issue of low education has repercussions on the participants' lack of paid employment. Regarding the age group of CSHCN in adolescence, it is highlighted that they were between 12 and 17 years old.

Qualitative data were organized into two thematic categories: "Family care in the daily life of adolescents with special health needs" and "Family selflessness in favor of caring for adolescents with special health needs".

### **Family care in the daily life of adolescents with special health needs**

As for the CRANES care demands in adolescence, family members mentioned the presence of medication, usual, modified and mixed care, as can be seen in the statements below.

*Just the medicine! (FC2)*

*The medicine, she knows when I prepare to offer the medicine at noon. (CF6)*

*Yes, he always needs help... (CF8)*

Taking care of adolescents' hygiene requires a lot of attention, as these CSHCN often need help or a command to perform this care properly.

*Take a bath he goes alone, eat too. But he needs help in the bath and with the clothes... (CF2)*

*I have to be together, I need to help... (CF4)*

*To brush your teeth, you have to help... (FC7)*

*Bathing and brushing my teeth, then I have to help... (FC8)*

The routine of family care for CSHCN is presented through daily actions that involve waking up, helping with dressing, helping with eating and personal hygiene.

*She gets up, goes to the bathroom, I take off her pajamas and put clothes on her, sometimes she goes back to bed, sometimes she stays here in the living room, she drinks coffee, sometimes not... (FC 6)*

*He leaves the bathroom and his plate is already served, he has lunch, then I go to make sure he is going to brush his teeth well, then I tell him to put on the deodorant! (CF 7)*

When living with CSHCN in adolescence, one can visualize the daily care routine. The use of diminutive expressions in the context of utterances reveals a relationship of dependency

between family caregiver and CSHCN through protective care.

### **Family abnegation in favor of the care of adolescents with special health needs**

CSHCN caregivers verbalized the sharing of care with other members of the family nucleus. However, they recognized that this care was sometimes lonely. In some cases, care was centered on mothers and sometimes they received support from the family nucleus.

*Me and my aunt... (FC 2)*

*Me and her father... (FC 3)*

*Grandma and I... (FC 4)*

*Now because his father works outside, sometimes I, sometimes my mother. (CF 5)*

*Stepfather helps! (FC 9)*

*On a daily basis, I am the one who takes care of him, my father and mother... (FC 10)*

These caregivers report that skills in caring for adolescents were sometimes acquired with the help of the internet and health professionals. At other times, they state that these abilities arose intuitively. However, there are those who develop their skills in the context of a solitary challenge, faced with an unexpected demand.

*I was learning by myself. (CF 2)*

*Myself! There was nothing to do, I had to learn the hard way... (FC 4)*

*Because I think that when she was born, I already brought the practice with me, you know? (FC 6)*

*I learned to take care of myself... (FC 7)*

*I learned over time... (FC 8)*

*I learned kind of scared... (CF 9)*

*After talking to a psychologist, pedagogue, neurologist, doctors and asking for guidance, I went looking on the internet, I ended up learning what the disease is and how to treat it. I ended up putting it into practice! (CF 10)*

The practice of caring for CSHCN brought experience to these family members, who sought alternatives to improve their daily care practice. In addition, the process of self-denial and work activities, as well as the difficulties of insertion, access and accessibility.

*I need to take care, and there is no place to stay, to leave someone special. It is difficult! (CF 4)*

*I tried to go back to work, but it didn't work. I tried to leave her at home, but I couldn't. (FC 6)*

*I don't go out because I have to take care of him... And taking him is difficult, with someone special, access is always more difficult! (CF 7)*

*I stopped working to take care of him, there is no place he can stay! (FC10)*

From the statements of the deponents, it is evident the care restricted to the family nucleus, sometimes lonely, in addition to the difficulties of social inclusion, access and accessibility found in the daily life of CSHCN in adolescence.

## DISCUSSION

CSHCN family caregivers had a care routine in order to establish attention to their basic and daily health needs. Part of this care turned to drug treatment. It is known that this care must be continuous and observed, as studies show that CSHCN continuous drug therapy is frequent and they usually receive five times more drugs than children in general.<sup>9</sup>

There must be care with the administration of the medication, especially when the adolescent does not have the physical and/or cognitive conditions for its autonomous use. The risk of self-medication is highlighted, including the use of leftover drugs or even the acquisition of medication without a prescription. The irrational use of medication in children and adolescents is still a real and frequent practice.<sup>10</sup> This reinforces the need for supervision in the administration of medication to CSHCN, in order to avoid the risk of overdose, which corroborates the importance of family supervision.<sup>11</sup>

Family members also highlighted, regarding modified routine care, care that goes beyond that offered to a healthy child or adolescent, such as the use of diapers in children over three years of age, use of devices to aid in locomotion, orthoses and prostheses and any other care that differs from the care offered to a healthy child.<sup>12</sup>

The modified usual care described by the participants was aid for bathing and other intimate and personal hygiene actions.

These modified routine care are still integrated with other health demands, appearing associated with other special health needs such as development demands, technology dependence, among others, reinforcing that CSHCN in adolescence requires mixed care.<sup>13</sup> In addition to dealing with the issue of technology, the family needs to adapt to this new way of carrying out their routine care, such as hygiene, food, among others.

The data showed dependency relationships between the CSHCN and their family caregivers. It is known that the presence of adolescents with health problems changes the home environment and impacts the family. Added to the care routine is the daily tension in their homes, due to living with the suffering of the other, excessive concern, the need to provide assistance to the minor in everyday life and the supervision of behaviors considered problematic by CRIANES.<sup>14</sup> Therefore, establishing a daily care plan can be a challenge for these family members.

The care exercised in the home space is predominantly practiced by family members, especially by mothers. The results did not show the presence of care provided by professionals hired by the

family. Perhaps this is explained by the economic conditions of these family members, who mostly had incomplete primary education and did not have formal paid employment. But the full dedication of these people – most of them women – to caring for adolescents can also be related to the strong presence of the family itself in the daily routine of home care.

The results of this study also revealed how learning about the care to be offered to CSHCN by their family caregivers took place at home. In some cases, care is learned/with the help of health professionals, which is a positive result, considering that the support of these professionals is directly related to the relief of the burden of family caregivers.<sup>14</sup>

The evidence indicates that the learning of care sometimes happens, in a solitary way, due to the immediate need in the daily experience with the CSHCN. In this regard, it is known that family caregivers are included in the process of deinstitutionalization of patients with special health needs. This transition to the home space as the main care setting often happens without the family caregiver, who becomes the main actor in this care, receiving the necessary preparation to perform this function.<sup>14</sup>

This reinforces the need to discuss support aimed at family caregivers, because if, on the one hand, the home



space appears as the universe of choice for establishing relationships of coexistence and care for adolescents, on the other hand, one must rescue the needs of technical, financial and psychological support to caregiver families. The literature highlights the need to develop home care, which is incorporated by family members who need to reorganize themselves to reconcile work activity with care.<sup>15</sup>

Support for family caregivers of CSHCN also involves the issue of sharing care with other people. Despite the data showing the presence of other family members in the CSHCN's daily home care, it can be seen that the main care was exercised by women, with the mother being the main responsible for carrying out the care and managing the therapy.<sup>9</sup>

The daily life of CSHCN families is modified, with the mother's routine being the most altered due to the large amount of time assigned to the role of caregiver. Mothers sacrifice their personal, family and social life for care. Occasionally, some fathers help in the execution of care, but most of the time they are mentioned as the financial provider.<sup>16</sup>

The role of financial provision and protection of the family is mainly delegated to man. In relation to the woman, it is expected that she assumes the role of generating and promoting daily care

for the child, in addition to managing domestic activities. Most of the time, the mother assumes the role of main caregiver. It is expected that family arrangements will advance with regard to the sexual division of labor, establishing a process of collaboration between men and women in the functions of family provision and domestic activities and childcare.<sup>17</sup>

The testimonies point to the abnegation in favor of the care of these adolescents, with abandonment of the possibilities of insertion in public life and in the labor market. The literature points out that there is a growing responsibility in the performance of the role of caregiver of CSHCN, added to household chores and financial difficulties, which enhances social isolation, depressive symptoms and marital dissatisfaction, thus generating an overload for the main family caregiver.<sup>12</sup> Home care can generate overload on family caregivers, who often give up their jobs and personal fulfillment in favor of meeting the care demands of these adolescents.<sup>18</sup>

It is an arduous and constant quest for women, who dedicate a large part of their lives to taking care of their children. This task is challenging, since meeting their emotional and physical needs requires dedication, time and effort, in addition to bringing financial, social and emotional wear and tear.<sup>19</sup> It is also considered that

maternal burden may cause damage to their quality of life and the quality of care offered.<sup>11</sup>

The impact of the special health need is noticeable in families, they end up suffering changes in their routine, leisure and interaction between their members. In addition, some families seek better treatment for their children and end up undergoing many changes, causing damage to their personal well-being.<sup>16</sup>

One should reflect on the implications of these findings for nursing practice with families living with CSHCN. Nursing care should include the family as the nucleus directly related to the care system for these adolescents. This is in line with a systematic literature review, which showed the adjustment process of families to the needs of CSHCN; the burden experienced by family caregivers; challenges for nursing care; and the communication and organization of care centered on the family as an alternative to face these challenges.<sup>20</sup>

When considering the overload of family caregivers of CSHCN in the home space, support and support for them should be a concern for all health professionals involved in assisting these families. Nurses stand out and their potential to help the family during their adjustment process to the reality presented by CRIANES. The multidisciplinary team must be synergistic

in this care model, so that the adolescent and his family are effectively the center of the care they need.<sup>20</sup>

Family caregivers of CSHCN also face difficulties regarding inclusion and social life, in addition to the lack of services that facilitate the process of insertion in society. These factors are potentiated by the limitations of health services that do not offer support for home care, little resolution and the difficulty of access or limitation of health services.<sup>18</sup> Thus, for the process of inclusion of CSHCN in adolescence, it is necessary to break paradigms of that these are incapable; this reinforces the urgency of public inclusion policies and the role of care networks for this population and their families.

## CONCLUSIONS

Home care for CSHCN is configured in the attention to basic health needs, exemplified by medication care and daily personal hygiene actions. Family care is exercised mostly by the women of the family, with emphasis on maternal care, rarely shared. These women sacrifice their personal and professional lives for the sake of their children, which creates an overload.

This study presented as a limitation the simple narratives of the deponents, in part made up of people with little

education and little used to talking about their experiences and feelings. This may have limited obtaining more robust testimonies with regard to the richness of elements that characterized the study phenomenon. However, this limitation did not invalidate the results obtained, which met the challenge of responding to the research problem.

As contributions, the study presents elements that guide nursing care centered on the CSHCN caregiver family. Family empowerment is a necessary way to promote the quality of life of these adolescents and to obtain better health outcomes.

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