


RESEARCH ARTICLE (ORIGINAL) 

The multi-professional team delivering care to children and adolescents with special health needs: trajectory and bonding

Trajatória e vínculo da equipa multiprofissional no cuidado de crianças/adolescentes com necessidades especiais de saúde

Trayectoria y vinculación del equipo multiprofesional en el cuidado de niños/adolescentes con necesidades sanitarias especiales

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Abstract

Background: The trajectory of health and special education professionals delivering care and support to children with special health care needs (CSHCN) is challenging and requires specific training and bonding.

Objective: To understand the trajectory and bonding of a multi-professional team with CSHCN in an Association of Parents and Friends of Exceptional Children (APAE).

Methodology: This is a descriptive and qualitative study, with 19 professionals working in an APAE clinic and school, using semi-structured interviews submitted to thematic content analysis.

Results: The evidence shows the relevance of the bond formed with the multi-professional team for the children's and adolescents' development and how the shared care, experiences, search for knowledge, and affection exchanges strengthen the relationship between professionals and CSHCN.

Conclusion: The challenges of working with this population shape the professionals' trajectories. Over time, they bond with CSHCN and become emotionally attached to them and their work. Including the specificities of special needs-related care in these professionals' training is recommended.

Keywords: child health; adolescent health; disabled persons; health services accessibility

Resumo

Enquadramento: A trajetória dos profissionais de saúde e da educação especial que prestam cuidados e atendimento a crianças e adolescentes com necessidades especiais de saúde (CRIANES) é desafiadora, exigindo formação específica e a construção de vínculos.

Objetivo: Conhecer como é constituída a trajetória e o vínculo da equipa multiprofissional que atua com CRIANES numa associação de pais e amigos dos excepcionais (APAE).

Metodologia: Estudo descritivo e qualitativo, com 19 profissionais que atuam na clínica e na escola de uma APAE, por meio de entrevista semiestruturada, submetida à análise temática de conteúdo.

Resultados: Evidencia-se a importância do vínculo para o desenvolvimento de crianças e adolescentes, que o cuidado compartilhado, as vivências, a busca pelo conhecimento e as trocas afetivas fortalecem a relação entre usuários e a equipa multiprofissional.

Conclusão: A trajetória dos profissionais está alicerçada nos desafios de atuar com esta população. Ao longo do tempo formaram vínculo e sentiram afeto e sensibilidade para o desenvolvimento do seu trabalho. Sugere-se que o processo de formação contemple as singularidades de cuidados requeridos por CRIANES.

Palavras-chave: saúde da criança; saúde do adolescente; pessoas com deficiência; acesso aos serviços de saúde

Resumen

Marco contextual: La trayectoria de los profesionales sanitarios y de educación especial que prestan cuidados y asistencia a niños y adolescentes con necesidades sanitarias especiales (CRIANES) es un desafío, requiere una formación específica y la construcción de vínculos.

Objetivo: Conocer cómo está constituída la trayectoria y el vínculo del equipo multiprofesional que trabaja con CRIANES en una asociación de padres y amigos de excepcionales (APAE).

Metodología: Estudio descriptivo y cualitativo, con 19 profesionales que trabajan en la clínica y en la escuela de una APAE, mediante entrevistas semiestructuradas, sometidas a análisis temático de contenido.

Resultados: Se observa la importancia del vínculo para el desarrollo de los niños y adolescentes, que el cuidado compartido, las experiencias, la búsqueda de conocimiento y los intercambios afectivos fortalecen la relación entre los usuarios y el equipo multiprofesional.

Conclusión: La trayectoria de los profesionales se basa en los desafíos de trabajar con esta población. Con el tiempo, formaron vínculos y sintieron afecto y sensibilidad por el desarrollo de su trabajo. Se sugiere que el proceso formativo contemple las singularidades del cuidado requerido por los CRIANES.

Palabras clave: salud del niño; salud del adolescente; personas con discapacidad; accesibilidad a los servicios de salud

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Introduction

Technological and scientific advances and the evolution of knowledge have enabled the survival of children and adolescents whose health conditions were previously deemed incompatible with life. This population's survival created the need for the delivery by multi-professional teams of specialized health care, in addition to that required by other children and adolescents (Silveira & Neves, 2020). The literature highlights the emergence of the term "Children with Special Health Care Needs" (CSHCN) (McPherson et al., 1998) in 1998, later on, translated into Brazilian Portuguese as *Crianças e Adolescentes com Necessidades Especiais de Saúde* (CRIANES).

CSHCN have temporary or permanent care needs associated with limiting motor, functional, behavioral, emotional, and developmental conditions (Favaro et al., 2020). These demand specialized care involving health, social assistance, and special education segments and a multi-professional team dedicated to delivering care and support to these children and adolescents (Silveira et al., 2020). The Brazilian Child and Adolescent Rights Act (ECA) ensures that children and adolescents have universal and equal access to health promotion, protection, and recovery services (Brazil, 1990).

The United Nations (UN) estimates that approximately 150 million children globally have some impairment characterized by the loss or abnormality of psychological, physiological, or anatomical structure or function (Organização das Nações Unidas, 2021). Thus, it is relevant to understand that CSHCN have chronic health conditions, disabilities, and special needs that justify the demand for specialized health care (Silveira & Neves, 2017).

Among the services forming the support and care network for CSHCN's development, the literature highlights hospital services, primary health care, specialized clinics, and the APAE - Association of Parents and Friends of Exceptional Children (Silveira & Nicorena, 2020). Considering that the diversity of specialized care is essential for maintaining the life of CSHCN, the existence of a space for welcoming, giving attention, delivering multi-professional and specialized care, and implementing special education activities is crucial (Precece & Moraes, 2020). The APAE constitutes a support and care network, offering its users a specialized health care clinic and a special education school, among other services. The APAE's services offered by the multi-professional team aim to promote the delivery of comprehensive care to the person with disabilities, guarantee rights and social inclusion, and develop the bonding with its users (Silveira et al., 2020). Health and education professionals implement care and health education practices that favor children's and adolescents' learning and integration. The APAE is a reference in the health care and special education of CSHCN, fostering relationships based on trust, empathy, and affection and bonding with its users through the delivery of comprehensive care (Vaz, 2018).

Hence, considering that CSHCN require specialized care and that the APAE is a multi-professional reference service designed for this population, the present study

aims to understand the APAE's multi-professional team's trajectory and bonding with CSHCN.

Background

CSHCN are a care-dependent population, and caring for them requires differentiated skills and numerous sources of support that constitute the network of specialized health care. This population's care network must be organized between the different services and health professionals because these children and adolescents have unique care demands and require support for special education (Silveira & Nicorena, 2020).

The APAE emerges as a leading example in health, care, education, and social assistance for CSHCN and their families. It is a multi-professional welcoming institution that provides comprehensive care and promotes CSHCN's development. The activities promoted by the APAE include the possibility of collectively working toward each user's abilities. Thus, the care and special education offered by the APAE clinic and school provide the necessary support for the CSHCN to progress, develop and socialize (Bueno et al., 2021).

The work done by the APAE's multi-professional team directly impacts CSHCN's development. The activities aim to foster the children's and adolescents' healthy growth and development and promote their integration. The clinic and the school intend to stimulate each child and adolescent and nurture their abilities, promoting autonomy. Also, for the multi-professional team's work to be successful, bonding and communication are vital, as the clinic, the school, and families are essential cornerstones of CSHCN, with a direct impact on their health and learning (Silveira & Neves, 2020).

Over time, the professionals working in the APAE establish emotional bonds, embodying the multi-professional team's commitment to CSHCN's development (Silveira & Neves, 2020). However, beyond the bonds and affective ties established, health and special education activities require specialized care, specific training, resoluteness, and strategies that enhance these children's and adolescents' abilities. Therefore, the multi-professional team working with CSHCN in the APAE must have specific training to develop continuous, successful, and dedicated work tailored to each user's reality (Silveira et al., 2020).

Furthermore, these professionals must connect and complement different areas of knowledge by applying a comprehensive approach. This must consider the reality of the child or adolescent and their family, the previously acquired knowledge, the health and education needs, the social context, the cultural aspects, the values, and the organization of a support care network consisting of specialized health services and a multi-professional team (Silveira et al., 2020).

Research questions

How was the trajectory of the multi-professional team members working in the APAE built? How do these professionals understand the bond they developed with the CSHCN of the APAE?



Methodology

This descriptive and qualitative study was conducted with health and special education professionals working in a reference APAE in the northwest region of southern Brazil. For over forty years, the work done by this APAE has made it a reference for children, adolescents, and their families. At the time of data production, 27 professionals worked in the APAE's social assistance, health, education, administration, and general services. The APAE also relied on the support of volunteers from the undergraduate nursing, nutrition, and biological sciences degrees through the teaching and extension activities carried out in its facilities.

The inclusion criteria for the present study were to be part of the APAE's multi-professional team and to have a minimum work experience of three months in the institution. The professionals who were away from work and the volunteers were excluded. After these inclusion criteria were applied, 24 professionals were selected as possible study participants.

Due to the social distancing measures related to the COVID-19 pandemic, data production was done using the digital platform Google Meet®. The study's project was presented to the APAE's direction and administration, followed by a meeting with the 24 professionals to clarify the study's objectives and methodology.

After receiving the APAE's authorization, a semi-structured script consisting of 10 questions was elaborated and tested by conducting a pilot study validated in a research group. The script's questions were divided into two central axes: 1) professional trajectory; and 2) bonding. Axis 1 consisted of five questions about the professional's academic training, continuous education, specialties, work process, and the limits and possibilities of working with CSHCN. Axis 2 contained five more questions about the strategies for approaching CSHCN, the professional's relationship with CSHCN, the existence or not of a relationship with the families of CSHCN, how is working with CSHCN over time, and the presence or absence of emotional bonds.

The investigator prepared a virtual invitation addressed to the APAE's professionals. After the invitations were accepted, a data production timetable was drawn up. The data production occurred for eight weeks between June and July 2021.

The investigator responsible for the present study carried out the interviews, accompanied by two undergraduate nursing students, holders of scientific initiation scholarships. The principle of theoretical data saturation was used (Minayo, 2014). Thus, when no further information was gathered from the interviews, the data collection was completed, and the final corpus of the study was established with 19 participants.

The interviews via Google Meet® followed a short script. The investigator began the interviews by welcoming the participants, recalling the study's purpose, and reading the informed consent form. Next, the participants' characterization was performed. The interviews lasted an average of 40 minutes. The audio recordings were transcribed twice

using Microsoft Word® to avoid possible inconsistencies. The data were then submitted to thematic content analysis through the following stages: pre-analysis; material exploration; treatment, inference and interpretation of results. (Bardin, 2016).

A floating reading of all interviews was performed during the pre-analysis stage to systematize the initial data. The analytical description, selection, and classification of the most frequent records were performed during the material exploration, highlighting the most representative ones. For the treatment of results, inferences and interpretation, the data were synthesized and categorized for analysis, resulting in the inferential interpretations and critical analysis of the research (Bardin, 2016).

The present study complied with Resolution No. 466/2012 of the Brazilian National Health Council and was approved by the Federal University of Santa Maria Research Ethics Committee through Opinion No. 2,632,767. It also received the Certificate of Submission for Ethical Appreciation No. 86186518.5.0000.5346. The study participants were identified with the letter "P" followed by the ordinal number corresponding to the order in which their interviews were conducted (P1..., P2..., P3...) to guarantee confidentiality.

Results

The study was conducted with 19 multi-professional team members working at the APAE clinic and special education school. Regarding gender, the study's sample was predominantly female (16 women and only three men). The work experience length in the institution varied between 3 months and 31 years.

Two categories emerged from the research: "The professionals' trajectory in care delivery to CSHCN," in which the multi-professional team members present their experiences with CSHCN and their integration into the APAE, and "Bonding with CSHCN," in which the participants report on the emotional ties established with CSHCN while working with them. The statements included in these categories are described below.

The professionals' trajectory in care delivery to CSHCN

Many professionals in the present study began building their trajectory in the APAE because it was their first job opportunity.

"I left university, and it was the first job I got; I graduated, and when I realized it, I was already working here at the APAE!" (P1)

"I said, I want to work to achieve my purpose, and I started working! In the APAE, I have worked with the school classes, I worked with the adults in the EJA (Youth and Adult Education Program), and I am here until today . . ." (P4)

"It was very challenging because it is different from the cases we encounter during university; it is still challenging for me. I am really enjoying working here!" (P6)

"It has been an adventure; I am getting to know more about the people at the APAE, especially the students. I

confess that I was a little bit afraid because it was new; we are always afraid!" (P12)

One of the study participants reported that she became familiar with the APAE and started her trajectory when she needed to accompany her daughter, who has special health needs. The integration process into the APAE as a family member of a child with special health needs fostered her proximity.

"I found out about it through my daughter, I started to bring her here for health treatments, and I came along . . . The job opening came up, and I started working here!" (P3)

Other participants, even with previous professional experiences in other institutions, showed in their statements the desire to be part of the multi-professional team of the APAE and revealed that the change of workplace was productive.

At first, it was a shock! I thought, 'I don't think this is for me.' But then, I started thinking . . . We have a new experience; I'm going to like it because I will work with children's special education! I liked it from the first moment; I liked it and said I will take it! I think I will like it, and, in fact, I did! (P5) The APAE was the happiest place in my life! I found myself; I love working here! I always say that it was a period when I had been going through delicate moments in my personal life, and here I found myself; I get along very well with my colleagues and students, and I like it a lot! (P11)

I was in another school and didn't want to leave, but I would also like to work with special children and adolescents. And it was like that, fast! Here I felt well, and at home, it's what I like! I want to continue here because I like my work and feel well! (P13)

Some professionals learned to work with CSHCN from their experiences in the APAE and other workplaces or through their contact with CSHCN in the APAE.

"I worked for two years in a childcare institution, there were many special children, when I got here, I had a little bit of experience . . ." (P16)

"In the beginning, it is very different! We are learning . . . Every day there are new things, then you get the hang of it, get to know the students, get to know the families too, and I'm still here today!" (P17)

"In the beginning it was hard. But we learn from them. Children teach a lot, you know? Here, we learn from them!" (P19)

Although the beginning of the professional trajectory was marked by the desire to work with CSHCN, it was in everyday work that the multi-professional team became familiarized with different realities. The participants highlighted that they went through new experiences full of challenges and different feelings, which turned into learning and confirmed the importance of working in the APAE.

Bonding with CSHCN

The study participants' statements revealed that, as time passed, their work process with CSHCN in the APAE changed. The time spent with the children and adolescents aroused feelings of esteem and affection, strengthening the

bond between the multi-professional team and the users. "It was an area I hadn't even imagined, I never thought of working, but it's something you fall in love with, working in the APAE is something you fall in love with!" (P1)

"We live the APAE, sleep the APAE, eat the APAE . . . The APAE is part of our life, so there is no way to disconnect the feelings from the APAE; it would be very difficult." (P2)

"I feel very well, thank God! I like it very much and their receptivity to us, it's fantastic! Working here, it is an experience that will mark all my life!" (P5)

"I really love it! And that's what I like; I love working at the APAE!" (P7)

It is very good to work here . . . The people are very sweet, the children, there aren't enough words to describe them! We leave the APAE and feel we have done our duty; every day is a different learning experience. We also develop [ourselves]. (P8)

One of the study participants reported difficulty distancing himself from the work activities at the APAE, as he had formed a strong bond with the APAE's children and adolescents.

Since the '90s. Here is a bond of love with the students! I really like working here, I will feel it the day I leave here, but there will come a time when I have to leave when I retire! (P10)

The study participants also reported that working at the APAE is rewarding, showing in their statements the bond of trust, affection, and reciprocity between the children and adolescents and the team.

"But it's just the time of getting to know the APAE, and everything changes. It has been very rewarding! I get home and say that every day is a different joy!" (P12)

"The work at the clinic is different! Although I do clinical work at the APAE, it is a work that includes affection. And that also develops the professional, besides helping them." (P13)

"I was told, 'you have to have patience, love, and care to work.' And that's it! I have completed many [training] courses to work with them, but we feel the feelings here. (P15)

"I like it! With understanding, with a lot of affection, you succeed! And they need love. In fact, all of us!" (P18)

"We grow; we develop a lot here. It is a job that involves feelings, dedication, knowledge of health besides others. It's a lot of things together . . ." (P19)

The importance of creating a bond to welcome, care for, and work with CSHCN is underscored. In this sense, the professionals emphasize the need to develop the emotional skills that involve working with CSHCN, as they need attention, specific care, affection, and empathy.

Discussion

The breaking of paradigms initially marks the trajectory of professionals working in the APAE due to the challenge of working with CSHCN and facing the uniqueness of each diagnosis, life context, family, and cultural aspect. Also, the multi-professional team must meet the chal-

lenges of seeking specific knowledge that contributes to the clinical practice and special education that CSHCN require (Oliveira et al., 2021).

Some participants' professional experience is limited to the APAE, while others reveal the constant search for improvement in the face of users' demands, challenges, limitations, and possibilities. Professional training is the basis of these professionals' preparation for adverse situations in their everyday work in the APAE. Professionals must be prepared to work with children and adolescents, as their professional trajectory is built through affection exchange, sensitivity, understanding, and integration (Silva & Haas, 2019).

The present study's findings also reveal that the participants consider that there are other skills, in addition to knowledge, that develop professional trajectories and bonding. They report that, together with training and specialization, empathizing with this population is crucial. These findings align with the recommendation of the Brazilian National Federation of APAEs to expand the training strategies and practices of professionals specialized in the area of exceptionality (Bezerra & Furtado, 2020). The findings also reveal that some participants had few experiences with CSHCN before working in the APAE, where they had their first contact with this population. The absence of experience can cause fear and lack of confidence in everyday professional life. Thus, developing the teachers' abilities and potential during their training process is essential. For Silveira et al. (2020), training and experience with special education are vital for reflecting on inclusion, breaking paradigms, and student integration.

The professionals' trajectory is consolidated through their everyday experiences, with integration broadening the knowledge about the demands of CSHCN. The bond the professionals working in the APAE forge with the CSHCN, together with communication, affection, sensitivity, search for knowledge, and coexistence, enables them to achieve the proposed objectives, positively impacting their everyday lives (Borbolla et al., 2018).

The professionals' specialized training is crucial, as working with CSHCN requires preparation, knowledge, and management skills. In this sense, continuous education must be part of their everyday lives, promoting the study and sharing of knowledge and practices to qualify the care and support provided. Furthermore, professionals must understand their role in the work process and be able to offer care and support (Oliveira et al., 2021).

The activities with CSHCN are challenging, and in this process, professionals must mediate knowledge and consider the characteristics and abilities of each child and adolescent. Also, the planning of routine care and interpersonal communication is vital so that care delivery can be organized and designed for CSHCN's development (Mattson & Kuo, 2019).

In light of this, professionals who wish to work with CSHCN must be sensitive to this population's singularities and committed to acting toward the delivery of quality care. CSHCN are a population with complex characteristics due to their multiple care demands. Nevertheless,

exchanging affection and paying attention enable bonding. Based on their contact with CSHCN, the present study participants reveal the possibilities, challenges, and limitations of working with them. They also show how the APAE and the contact with the children and adolescents are part of their everyday life. Thus, bonding occurs by sharing experiences, living together, and feeling welcomed at the institution (Borbolla et al., 2018).

Some statements denote the bond formed during the care process between users and professionals. This study indicates that users perceive contact with professionals as satisfactory and positive, facilitating treatment adherence (Altman et al., 2018). Thus, the importance of bonding for CSHCN's development in the APAE is evident. Moreover, it is observed that shared care, experiences, the search for knowledge, and affection exchanges strengthen the relationship between users and professionals.

Conclusion

The present study focuses on professionals working in an APAE. It shows how their trajectory and bonding with CSHCN are developed, providing essential contributions for those who wish to work with children and adolescents with special health needs. The findings underscore the importance of training with an emphasis on special needs and the continuous search for knowledge to meet the demands of CSHCN and benefit their care, learning, and development. Also, bonding is associated with affection, sensitivity, sharing, and contact between professionals and users.

The present study is limited by the fact that all interviews were carried out with professionals from only one APAE, thus making it impossible to establish comparisons with other realities. The implications of this study for the nursing area point to the need to develop health education actions with multi-professional teams to train health and special education professionals who work with CSHCN. Further studies focused on professionals working with CSHCN are recommended to highlight the impact of the APAE's work on the development and care of these children and adolescents.

Author contributions

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