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Experience Report

How an adolescent with nephrotic syndrome sees their illness: a case report

Como um adolescente com síndrome nefrótica compreende sua própria doença: um relato de caso

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Abstract

Introduction: Coping with a chronic illness causes changes in an adolescent's life and requires new meanings. The approach to the adolescent by the multiprofessional team requires a careful look at their childlike perspective, aiming at their engagement and empowerment in the care process. **Objective:** To understand how an adolescent, diagnosed with nephrotic syndrome, understands their health condition and their care. **Method:** An exploratory-descriptive qualitative methodology was used, with an interpretative approach to the phenomena based on the meanings obtained from a semi-structured interview. The empirical universe consisted of an adolescent diagnosed with nephrotic syndrome, followed at a university hospital. **Results:** The following categories emerged from the patient's speech: 1) *"Learning about their health condition"*, which evidenced curiosity and the desire to learn more about the disease and the confidence gained to engage in treatment; 2) *"The discomforts associated with the disease"*, which point to the need for painful procedures, daily tests, and the modification of self-image secondary to the treatment; and 3) *"Insecurity regarding the severity of the disease"*, which refers to the fear of dying and of staying at home when decompensation of the disease occurs. **Conclusion:** In a singular way, adolescents develop, in their own way, their conception of the disease and its treatment. The occupational therapist must explore and intervene for the acquisition of autonomy by the adolescent, their active participation, pain management, adjustments in daily activities, especially physical activity, and the redefinition of losses.

Keywords: Child, Chronic Disease, Adolescent Health, Patient-Centered Care, Occupational Therapy.

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Resumo

Introdução: O enfrentamento de uma doença crônica ocasiona mudanças na vida do adolescente e requer ressignificações. A abordagem do adolescente pela equipe multiprofissional requer um olhar atento à sua perspectiva infantil, visando seu engajamento e empoderamento no processo de cuidado. **Objetivo:** Conhecer como um adolescente, com diagnóstico de síndrome nefrótica, entende sua condição de saúde e seu cuidado. **Método:** Utilizou-se da metodologia qualitativa exploratório-descritiva, com abordagem interpretativa dos fenômenos a partir dos significados obtidos de uma entrevista semiestruturada. O universo empírico consistiu em um adolescente com diagnóstico de síndrome nefrótica, acompanhado em um hospital universitário. **Resultados:** Emergiram da fala do paciente as categorias: 1) "*Aprendizado sobre sua condição de saúde*" que evidenciou a curiosidade e desejo de aprender mais sobre a doença e a confiança adquirida para engajar-se no tratamento; 2) "*Os desconfortos associados a doença*", que apontam a necessidade da realização de procedimentos dolorosos, exames diários e a modificação da autoimagem secundária ao tratamento; e, 3) "*A insegurança em relação à gravidade da doença*", que se refere ao medo de morrer e de ficar em casa quando ocorre a descompensação da doença. **Conclusão:** De forma singular, o adolescente elabora, do seu modo, sua concepção da doença e seu tratamento. O terapeuta ocupacional deve explorar e intervir para a aquisição de autonomia do adolescente, sua participação ativa, o manejo da dor, os reajustes nas atividades do cotidiano, em especial na atividade física e na ressignificação das perdas.

Palavras-chave: Criança, Doença Crônica, Saúde do Adolescente, Assistência Centrada no Paciente, Terapia Ocupacional.

Introduction

Children and adolescents are subjects of rights, and this is ensured by the Convention on the Rights of the Child (CRC), of 1989 (United Nations International Children's Emergency Fund, 1989). The word "patient" derives from the Latin *patiens*, which denotes suffering. Thus, the patient is the one who suffers in a singular way (Albuquerque & Paranhos, 2017). In the case of children and adolescents as patients, it is essential to validate and legitimize their suffering, a fundamental condition for the realization of patient-centered care. In this sense, qualified listening to what the adolescent patient brings to the healthcare encounter is essential, as is the recognition that their active participation, as the protagonist of their care, is a right.

Health care is based on relationships among patients, family members, caregivers, and professionals, with empathetic, respectful, and effective communication being essential to all these interactions. In this context, communication with children and adolescents represents a challenge, given the limited dialogue with them as patients. It is urgent to transform this reality, recognizing and validating their experiences and anguish (Eler et al., 2022; Albuquerque, 2023b). Patient-centered care should be strengthened in Pediatrics, with the involvement of the family and the multiprofessional team. Therefore, redesigning work processes and improving health education and communication in the daily practice of pediatric care are imperative, considering the gap between current practice and the ideal (Valete et al., 2022).

The prevalence of chronic diseases in the population has been increasing over the years. Nóbrega et al. (2017) report that 11% of Brazilian adolescents aged 14 to 19 have some chronic illness. These diseases negatively impact the quality of life of children and adolescents. The process of chronic illness implies changes in the adolescent's daily life and adjustments in various areas, with long treatments and the need for reinterpretation (Lino et al., 2021). Indeed, the adolescent's healthcare experience can and should be improved. Herríman et al. (2025) showed that, even today, barriers persist that hinder adolescents' access to health information, resulting in hesitation to seek care for conditions that concern them. The authors also emphasize that the care experience can be improved by engaging the adolescent in a collaborative manner, including in decision-making. In this context, the occupational therapist plays a crucial role, promoting adjustments in these patients' lives, aiming at the realization of their autonomy and shared responsibility. However, weak communication and limited adolescent involvement in their care are barriers that must be addressed (Gardener et al., 2024). Furthermore, the effective inclusion of this professional in pediatric inpatient units, with an approach directed at adolescents, is still below expectations, representing a practical barrier and a significant gap to be filled. Recently, Hand et al. (2022) analyzed gaps in occupational therapy research and highlighted the low access of adolescents with autism spectrum disorder to occupational therapy care in North America, revealing that this difficulty in access transcends the continent’s borders.

Among the chronic diseases that affect adolescents, nephrotic syndrome (NS) is characterized by edema secondary to severe proteinuria, with periods of decompensation and hospitalization, significantly impacting physical and mental well-being, as well as impairing performance in occupations typical of this stage of life and progress in the engagement of future occupational roles. The uncertainty regarding the disease’s progression contributes to the challenges faced by patients with this condition (Gipson et al., 2011). Thus, patients with NS need appropriate support and communication to understand the disease and treatment and to exercise self-care (Beanlands et al., 2017). This support should be prioritized by the multiprofessional team, with emphasis on the role of the occupational therapist. Understanding the perspective of these patients, sharing emotions, and seeking support for the issues they raise qualify this care in an empathetic manner (Albuquerque, 2023a). Lino et al. (2021) had already emphasized the importance of understanding the experience of adolescents living with chronic illness, the impacts on their lives, and their care needs, which provide input for the care offered by the occupational therapist. Specifically regarding NS, there is a noticeable lack of qualitative studies exploring the perspectives of these patients with the aim of guiding their care.

Recognizing the relevance of the adolescent’s participation and perceptions in their care, as well as the contribution of these elements to a more comprehensive and assertive practice by the occupational therapist and the multiprofessional team, this study aimed to present the self-description of an adolescent diagnosed with nephrotic syndrome regarding their health condition and care following a health education intervention.

Method

This research is a case study, exploratory, descriptive, and reflective in nature, with a qualitative approach, through the narratives and accounts told by the subject himself based on his experience (Freitas & Jabbour, 2011). The case study investigates a contemporary phenomenon within a given real-life context, especially when the boundaries between the phenomenon and the context are not clearly defined (Melo Júnior & Morais, 2018).

The research setting was the pediatric ward of a public university hospital located in the state of São Paulo. This study was approved by the institution's Research Ethics Committee (CAAE 69730023.1.0000.5504), and both the Free and Informed Consent Form and the Free and Informed Assent Form were obtained. The writing of this article followed the CARE guideline for case report studies (Riley et al., 2017).

The adolescent studied is followed by the pediatrics department and had been approached by the multiprofessional team in an educational manner, so that he could actively participate in his care. The selection of this participant was by convenience. This patient was chosen because the team had identified failure in his home treatment, with frequent hospitalizations due to disease decompensation. After this, the multiprofessional team, especially the occupational therapist, intervened so that the adolescent could make the necessary adjustments, according to his understanding, to ensure greater adherence to his treatment. A reduction in the number of hospitalizations was observed after the interventions, which led the team to seek to understand his perceptions about his health condition and treatment.

Data collection was carried out through a single semi-structured interview, conducted in September 2023, previously scheduled, in a reserved space within the hospital, with the presence of the patient, his mother, and the researchers, using trigger questions. The interview consisted of two parts: the first concerned the adolescent's epidemiological and social information, which was stored in the REDCap (Research Electronic Data Capture) form, with restricted access via login and password; the second part included questions about his health condition and treatment, this part being recorded and saved in an encrypted file. The patient was invited to speak freely and without haste from the proposed questions, without conditioning the answers. After each question, the adolescent would speak freely and, only when he finished his response, was the next question asked. The questions proposed in the interview were: 1) "Do you know what you are being treated for here at the hospital, what condition you have? Do you recognize the symptoms when you need to be hospitalized? Can you explain to me?" 2) "Do you know the doctors who treat you? Do you know their names?" 3) "Do you think you know everything you would like to know about your health?" 4) "Do you ask the doctors and nurses when you have any doubts?" 5) "Do you think they manage to explain your doubts in a way you can understand?" 6) "Do you think they value your participation in your treatment?" 7) "When you need to be hospitalized, what would you say is good and what is not good?" 8) "Does your health problem bring any feelings to you? Please explain." 9) "Do you know which medications you need to take and at what time? Do you think it's important to know? Why?" 10) "Does someone help you with your medications when you have a doubt? Please explain." 11) "Would you like to participate more in your treatment? How can we help you participate more in your treatment?" 12) "Is there anything you would change in your treatment? Please explain." 13) "Would you like to say anything to the professionals, doctors, nurses, and everyone who takes care of you?"

The interview was recorded and then transcribed with the help of Clipto.AI (clipto.com), with the audio and text double-checked independently. After transcription, the recording was discarded. For the analysis, an exploratory-descriptive methodology was used, with an interpretative approach to the phenomena based on the meanings people assign to them, valuing the adolescent's speech (Denzin & Lincoln, 2006). The analysis of the written interview followed Bardin's proposal in three stages (Bardin, 2015). The first was the organization of the analysis, with an initial reading, exploration of the obtained material, and treatment of the results. The second stage was inductive coding, also called 'content processing', at which point the raw research data were systematically transformed and grouped into units, allowing an accurate description of the content's characteristics. In this stage, the software Iramuteq (www.iramuteq.org) was used to analyze co-occurrences and word connections, assisting in identifying the structure of the textual corpus. The third and final stage, categorization, is a facilitating instrument for inference, for the discovery of hidden or implicit information, and for the controlled analysis of the content.

The categories emerged from the construction of an analysis matrix, with recording and context units extracted from elements present in the patient's speech that were relevant to the study. At the end of this process, three categories were identified (Table 1). All stages were discussed among the researchers and contributed to the organization of the content and the extraction of information and results.

Table 1. Categories identified in the analysis process.

1. Learning about your health condition
2. Discomfort associated with disease decompensation and treatment
3. Insecurity regarding the severity of the disease

Results and Discussion

The 11-year-old male adolescent had been diagnosed with NS since he was three. He reported having three siblings, with his mother as his primary caregiver, and a family income equivalent to one minimum wage. In 2022, he had been hospitalized six times for decompensated disease, and twice in 2023. At the time of the interview, he reported taking five medications continuously. The excerpts from the adolescent's speech were organized into categories, described below.

The similarity analysis demonstrates the characteristics of the content obtained in the interview, revealing the importance of knowledge about his treatment. The three emerging categories were as follows.

Category 1: Learning about one's health condition

The analysis of the adolescent's speech revealed his desire to obtain more information about the disease and his ability to identify the onset of a decompensation episode, recognizing the initial symptoms and signs. In fact, he perceived the bodily changes resulting from the disease, which indicated a possible decompensation. The curiosity expressed by the adolescent highlights the urgency of broader dialogue and effective communication. Therapeutic health education is defined by WHO (World Health Organization) as "[…] a structured learning process centered on the person that supports individuals in managing their own health by using their own resources, supported by their caregivers and families" (World Health Organization, 2021). Thus, understanding the disease, the treatment, and coping strategies allows him to collaborate and take responsibility in the pursuit of a better quality of life, respecting his progressive development of skills. It is a challenge for us professionals to allow the adolescent patient to become the subject and agent of his health, but this needs to change (Tubiana-Rufi, 2009). The adolescent learns about his condition:

> *Swollen. When I'm not well, my slipper doesn't fit my foot. It's when it pulls the eye, like this, more or less. I feel pain in my belly. The first change is in the eye.*
>
> *I wanted to know more about the disease. I know it's Nephrotic Syndrome. I can understand what they tell me, what's happening.*

Literature proposes various educational strategies, such as interdisciplinary consultations, educational weeks, and patient associations. It is also recommended to use other resources adapted to the child's or adolescent's age and developmental level (Tubiana-Rufi, 2009). In Brazil, partnerships with institutions that produce graphic materials for the child population have resulted in explanatory pamphlets for some diseases, such as the Duchenne Muscular Dystrophy and Down Syndrome pamphlets, produced with characters from the "Turma da Mônica" (Eler et al., 2022). Regardless of the educational strategy used, it must be carried out to stimulate the autonomy of the participating individuals, transforming existing knowledge according to individual specificities and encouraging self-care. Thematic analysis of interviews with primary care nurses revealed that this education still falls short of what is desired, emphasizing the importance of investment in this practice (Costa et al., 2020b).

Still on health education, it was evident in the adolescent's speech that he is knowledgeable about his treatment, demonstrates confidence, and contributes to the necessary arrangements for the treatment to be followed:

> *I know the medication I need to take. It is dipyrone, I mean, it is prednisone, cyclosporine, vitamins, atensina and clonidine. Oh, and calcium. I know the exact times for the medications. I think it is important to know that.*
>
> *When it is time to take medication, my mom prepares it and puts it in the pill organizer, so I already know what day of the week it is. There is a night box and a day box. I set an alarm. It has happened that I took the medication outside the scheduled time.*

Children and adolescents living with chronic illness are capable of understanding their disease and making decisions regarding their care (Gomes et al., 2013; Silva et al., 2017), and health professionals need to understand this. Each encounter between professionals, children with chronic illness, and their families can become a therapeutic moment of care, encouraging the protagonism of those involved in the process. It is necessary to create opportunities for those with similar experiences to meet, so that they can exchange and build knowledge among themselves, as occurs in support groups (Gomes et al., 2013).

Lino et al. (2021) highlighted in the qualitative analysis of the story of an adolescent with chronic illness that one of the emerging subcategories was autonomy and protagonism in their own care. Indeed, adolescent protagonism has been emphasized in several areas of knowledge, including social and health sciences, forming part of the construction of public policies and transdisciplinary and cross-sectoral networks (Tasca et al., 2020). However, in healthcare practice, this protagonism needs to be implemented, and for that, health education is essential, because an individual can only be the protagonist of their care, participate, give opinions, share decisions, if they understand their condition. The child wants to effectively participate in decision-making that concerns them, wants their autonomy to be recognized, and wants an objective assessment of their competence for this (Valete et al., 2022). In this context, the occupational therapist holds the knowledge and necessary skills to work on the child's autonomy and active participation in their own care, reframing the illness process and increasing the adolescent's involvement in managing their own health. Adolescents aged between 15 and 18 years are capable of managing the control of another chronic illness, type 1 diabetes mellitus (Gardener et al., 2024).

Category 2: The discomfort associated with disease decompensation and treatment

Among the repercussions of the need for hospitalization, discomfort related to procedures for disease control emerged, although the adolescent understood their necessity:

> *When I'm hospitalized, it bothers me to keep drawing blood. It's something that has to be done, but it's bad. I understand that they have to keep collecting tests all the time. It's to see if my kidney is good or not.*

The need for painful procedures, such as blood draws, appears as a source of discomfort. However, these procedures must be performed using pain management strategies (Yu et al., 2023). The procedure itself, although necessary for maintaining and restoring health, provides the child with a painful and stressful experience, and even though the adolescent understands its necessity, which helps him cope, it is not enough to minimize the reported discomfort (Gomes, 2018). Children and adolescents report that the hospital is a place for performing painful procedures, which causes sadness and anxiety (Costa & Morais, 2017). Psychological preparation aims, among other goals, to reduce fear, anticipatory anxiety and/or stress, promote cooperation and behavioral adjustment during and after procedures, and assist in reducing and managing the pain experienced by the child or adolescent (Doca & Costa Junior, 2011; Dessen & Costa Junior, 2005). Among the distraction tools described in the literature are: relaxation exercises, breathing and imagery visualization, and expressive techniques (Sant'Anna & Mendes, 2019). Training healthcare professionals to identify developmental indicators in children and adolescents and communication behaviors between the patient and the healthcare team is an important factor in psychological preparation for procedures (Dessen & Costa Junior, 2005). Health professionals must foster positive experiences and minimize the negative impacts of this condition, creating spaces for qualified listening (Silva et al., 2021). The role of the occupational therapist in pain management must be emphasized in these situations and can contribute independently and interdisciplinarily so that the adolescent can face these situations (American Occupational Therapy Association, 2021).

Furthermore, the patient notices the bodily changes caused by corticosteroid use, and these changes bother him to some extent:

> *What I would change in my treatment is to remove the medications. Prednisone. Because it, like, makes me a bit chubbier. It's mainly the prednisone.*

This statement made it clear that the patient associated prednisone with weight gain. This perception may hinder treatment adherence and should be addressed, as this medication is fundamental in the treatment of NS. In this context, the occupational therapist should address healthy lifestyle habits and, in particular, the possibility of adjustments to physical activity to promote the well-being of these patients (Persch et al., 2015). Beanlands et al. (2017) investigated the experience of adult patients and relatives of children with NS and highlighted the importance of patient-centered communication in managing these patients. At times, in existing literature, the child's relative is considered the patient and their perspective is validated as such (Ehwerhemuepha et al., 2018). We reinforce that the child has their own perspective as a person, builds their own experience as a patient, and this can influence their treatment. More than that, the child is the holder of human rights as a person and of patient rights as a consequence (Eler & Albuquerque, 2019). Despite this, most studies assess the experience of parents, caregivers, and professionals, disregarding the child's perceptions.

A clinically based project implemented in Scotland gave voice to children, listening to what matters to them, with involvement from the clinical team and managers. The use of diaries called "About Me", where the child records, in their own way, everything they experience in healthcare, and the story wall (storyboard), where they write freely about their experiences, were fundamental for communication with the patients to occur. Among the records, it is worth noting that children believe that "[...] the team should listen to their preferences and accommodate them when possible", "[...] they would like to be treated as individuals and have their concerns considered" (Magowan et al., 2017). It is clear that the requests made by these patients can and should be addressed but require a change in behavior and approach from the entire team.

Low treatment adherence in cases of NS has already been reported in the literature, reaching up to 50% of cases (Wang et al., 2017). The change in body image reported in the present study may, in some way, interfere with identification with peers and hinder treatment adherence, and these perceptions should be individualized. This concern with weight gain is legitimate, and it is known that these patients experience negative impacts on their self-image and low self-esteem. This is particularly important in adolescence and must be addressed (Marciano et al., 2010; Sociedade Brasileira de

Pediatria, 2020). The complexity of patients with NS makes the patient-centered care model more intriguing (Hladunewich et al., 2017).

Category 3: Insecurity about the severity of the disease

Finally, the adolescent's speech revealed fear of death and insecurity about staying home when the disease decompensates. The hospital environment provided a sense of security in these cases:

> *It's good to stay here so I'm not at home. Sometimes something happens there and there's no time to get help. I feel safer in the hospital. I've been afraid my kidney would stop and I'd die. I thought that would happen. It was last year.*
>
> *I talked to my mom. I think it was good to talk about it. After I got here, when they started the treatment, started doing the tests, I felt safer and I felt better. That fear passed, but sometimes it still comes back.*

It was observed that the adolescent had formed the idea that the disease was serious, with the possibility of death if the kidneys stopped working. It is important to note that the possibility of death had not been considered by the care team up to that point, showing a disconnect between the patient's thoughts and the team's perspective, once again highlighting the importance of listening to the patient. Understanding the origin and depth of this perception, especially the symbolism and suffering associated with it, is fundamental. Thus, this statement was welcomed and passed on to the outpatient care team so that the topic could be further explored later.

Chronic illness can generate different perceptions in adolescents, including feelings of isolation, loneliness, and uncertainty about the future. It is important that health professionals address these issues and provide the necessary support, as these feelings can compromise the mental health of these patients (Suwary et al., 2024). However, to even begin to approach these issues, adolescents with chronic illness must be heard. We need to understand what they have to say, welcome their words, considering that they make the effort to make sense of what is happening to them, then to be understood, and, finally, to understand themselves, which is not easy (Costa et al., 2020a).

Understanding how children conceptualize death and the emotions involved is a significant gap in the literature. There is a scarcity of studies on how adolescents process their own death. The experience of grief after the death of a friend, for an adolescent diagnosed with cancer, triggers emotions, reflections on death, and fear of forming new relationships, making it essential that they receive support in dealing with such situations (Mackland & Wright, 2022). Death is still a taboo, often representing a space of silence. However, it was brought up in this conversation, even if briefly, and referred to his own death, so this statement must be valued. Losing control of the disease produces both objective and subjective effects, with associated suffering. Furthermore, children associate the concept of death with components such as irreversibility, non-functionality, and universality. We believe that the patient's statement was grounded in the concept of non-functionality, since if the kidney stopped working, his life would end (Sousa & Oliveira, 2018). In this context, the occupational therapist plays a unique role, contributing to the re-signification of loss and life, considering the biopsychosocial model, although literature points to a lack of structure in clinical practices related to grief (Saciloti & Bombarda, 2022).

Final Considerations

This adolescent's story contributes to health professionals' understanding of how he interprets and experiences the process of chronic illness, with impacts on his daily life, his self-image, and the feelings attributed to disease exacerbation, which carry the idea of the possibility of death. The multidisciplinary team must be prepared to understand the adolescent's perspective so that care can be provided in an empathetic and individualized manner. In this scenario, the occupational therapist's approach should explore and intervene to promote the adolescent's autonomy, active participation, pain management, adjustments in daily activities, especially physical activity, and the re-signification of losses.

One limitation of this study is that, as a case study, it refers to a single patient and therefore does not allow for the generalization of results. However, its findings allow professionals to gain a broader understanding of the impact of chronic illness on adolescents' lives and, thus, to plan their clinical approach accordingly.

Sharing this patient's experience contributes to the practice of occupational therapists and other health professionals. There is an urgent need to redesign the healthcare currently offered to adolescents living with chronic illness, giving them a voice and, in doing so, seeing and understanding their perspective.

References

Albuquerque, A., & Paranhos, D. G. A. M. (2017). Direitos humanos dos pacientes e vulnerabilidade: o paciente idoso à luz da jurisprudência da corte europeia de Direitos Humanos. *Revista Quaestio Iuris*, *10*(4), 2844-2862.

Albuquerque, A. (2023a). Empathic care as a command of a new clinical bioethics. *Nursing and Care Open Access Journal*, *9*(2), 95-100. http://doi.org/10.15406/ncoaj.2023.09.00266.

Albuquerque, A. (2023b). *Empatia nos cuidados em saúde.* Santana de Parnaíba: Manole.

American Occupational Therapy Association – AOTA. (2021). Role of occupational therapy in pain management. *The American Journal of Occupational Therapy*, *75*(3, Supl. 3), 7513410010.

Bardin, L. (2015). *Análise de conteúdo.* São Paulo: Edições 70.

Beanlands, H., Maione, M., Poulton, C., Herreshoff, E., Hladunewich, M. A., Hailperin, M., Modes, M. M., An, L., Nunes, J. W., Trachtman, H., Nachman, P., & Gipson, D. S. (2017). Learning to live with nephrotic syndrome: experiences of adult patients and parents of children with nephrotic syndrome. *Nephrology, Dialysis, Transplantation*, *32*(1, Supl.1), 98-105. http://doi.org/10.1093/ndt/gfw344.

Costa, C. L., Passeggi, M. C., & Rocha, S. M. (2020a). Por uma escuta sensível de crianças com doenças crônicas. *Educação*, *45*(1), 1-24. http://doi.org/10.5902/1984644440240.

Costa, T. R. L., Marcheti, M. A., Teston, E. F., Solon, S., Marques, F. B., Knoch, M., & Bezerra, A. M. (2020b). Educação em saúde e adolescência: desafios para estratégia de saúde da família. *Ciência, Cuidado e Saúde*, *19*, 1-7.

Costa, T. S., & Morais, A. C. (2017). A hospitalização infantil: vivência de crianças a partir de representações gráficas. *Revista de Enfermagem UFPE*, *11*(Supl. 1), 358-367.

Denzin, N., & Lincoln, Y. (2006). *O planejamento da pesquisa qualitativa: teorias e abordagens.* Porto Alegre: Artmed.

Dessen, M. A., & Costa Junior, A. L. (2005). *A ciência do desenvolvimento humano: tendências atuais e perspectivas futuras.* Porto Alegre: Artmed.

Doca, F. N. P., & Costa Junior, A. L. (2011). Preparação psicológica nos serviços de psicologia pediátrica dos hospitais universitários públicos federais. *Estudos de Psicologia*, *28*(1), 79-87. http://doi.org/10.1590/S0103-166X2011000100008.

Ehwerhemuepha, L., Schultz, S., & Feaster, W. (2018). Clinical and psychosocial factors associated with patient experience in pediatrics. *Clinical Pediatrics*, *57*(8), 937-944. http://doi.org/10.1177/0009922817737078.

Eler, K., & Albuquerque, A. (2019). Direitos humanos da paciente criança. *Cadernos Ibero-americanos de Direito Sanitário*, *8*(1), 36-52. http://doi.org/10.17566/ciads.v8i1.509.

Eler, K., Valete, C. O. S., Albuquerque, A., Dalcin, T. C., Lopes, C. R. C., & Ferreira, E. A. L. (2022). Direito de participação da criança e do adolescente na qualidade e na segurança do seu cuidado: estratégias para sua implementação. *Residência Pediátrica*, *12*(3), 1-11.

Freitas, W. R. S., & Jabbour, C. J. C. (2011). Utilizando estudo de caso(s) como estratégia de pesquisa qualitativa: boas práticas e sugestões. *Estudo & Debate*, *18*(2), 7-22.

Gardener, L., Bourke-Taylor, H., Desha, L., Gardener, M., & Turpin, M. (2024). Developing self-management in type 1 diabetes at secondary schools: who is responsible? A qualitative study. *The American Journal of Occupational Therapy*, *78*(5), 7805205110. http://doi.org/10.5014/ajot.2024.050662.

Gipson, D. S., Trachtman, H., Kaskel, F. J., Radeva, M. K., Gassman, J., Greene, T. H., Moxey-Mims, M. M., Hogg, R. J., Watkins, S. L., Fine, R. N., Middleton, J. P., Vehaskari, V. M., Hogan, S. L., Vento, S., Flynn, P. A., Powell, L. M., McMahan, J. L., Siegel, N., & Friedman, A. L. (2011). Clinical trials treating focal segmental glomerulosclerosis should measure patient quality of life. *Kidney International*, *79*(6), 678-685. http://doi.org/10.1038/ki.2010.485.

Gomes, A. M. (2018). *Boa enfermeira e bom enfermeiro: visão de crianças e adolescentes hospitalizados* (Dissertação de mestrado). Universidade de São Paulo, Ribeirão Preto.

Gomes, I. P., Lima, K. A., Rodrigues, L. V., Lima, R. A. G., & Collet, N. (2013). From diagnosis to survival of pediatric cancer: children's perspective. *Texto & Contexto Enfermagem*, *22*(3), 671-679. http://doi.org/10.1590/S0104-07072013000300013.

Hand, B. N., Li, C.-Y., & Mroz, T. M. (2022). Health services research and occupational therapy: ensuring quality and cost-effectiveness. *The American Journal of Occupational Therapy*, *76*(1), 1-4. http://doi.org/10.5014/ajot.2022.761001.

Herríman, Z., Tchen, H., & Cafferty, P. W. (2025). Could be better: adolescent access to health information and care. *European Journal of Pediatrics*, *184*(7), 7.

Hladunewich, M. A., Beanlands, H., Herreshoff, E., Troost, J. P., Maione, M., Trachtman, H., Poulton, C., Nachman, P., Modes, M. M., Hailperin, M., Pitter, R., & Gipson, D. S. (2017). Provider perspectives on treatment decision-making in nephrotic syndrome. *Nephrology, Dialysis, Transplantation*, *32*(Supl. 1), 106-114. http://doi.org/10.1093/ndt/gfw309.

Lino, T. B., Jacob, L. R., & Galheigo, S. M. (2021). O adoecimento crônico e o tratamento pelo olhar do adolescente: considerações com base em uma história de vida. *Cadernos Brasileiros de Terapia Ocupacional*, *29*, e2813. http://doi.org/10.1590/2526-8910.ctoao2128.

Mackland, A. E., & Wright, L. (2022). Remembering friends: exploring the bereavement support needs of teenagers and young adults experiencing the death of a friend in the cancer setting. *Journal of Adolescent and Young Adult Oncology*, *11*(2), 234-239. http://doi.org/10.1089/jayao.2020.0128.

Magowan, R., Chalmers, A., Millin, T., & Smith, C. (2017). *Person-centred paediatric care: capturing the experience and collaborating for the future.* London: FoNS. Recuperado em 5 de janeiro de 2025, de https://www.fons.org/resources/project-reports/person-centred-paediatric-care-capturing-the-experience-and-collaborating-for-the-future/

Marciano, R. C., Soares, C. M. B., Diniz, J. S. S., Lima, E. M., Silva, J. M. P., Canhestro, M. R., Oliveira, A. G., Melo, C. D., Dias, C. S., Correa, H., & Oliveira, E. A. (2010). Transtornos mentais e qualidade de vida em crianças e adolescentes com doença renal crônica e em seus cuidadores. *Jornal Brasileiro de Nefrologia: Orgao Oficial de Sociedades Brasileira e Latino-Americana de Nefrologia*, *32*(3), 316-322. http://doi.org/10.1590/S0101-28002010000300014.

Melo Júnior, A. L., & Morais, R. (2018). Estudo de caso como estratégia de investigação qualitativa em educação. *Ensaios Pedagógicos*, *2*(1), 26-33. http://doi.org/10.14244/enp.v2i1.59.

Nóbrega, V. M., Silva, M. E. A., Fernandes, L. T. B., Viera, C. S., Reichert, A. P. S., & Collet, N. (2017). Doença crônica na infância e adolescência: continuidade do cuidado na Rede de Atenção à Saúde. *Revista da Escola de Enfermagem da USP*, *51*, 1-8.

Persch, A. C., Lamb, A. J., Metzler, C. A., & Fristad, M. A. (2015). Healthy habits for children: leveraging existing evidence to demonstrate value. *The American Journal of Occupational Therapy*, *69*(4), 1-5. http://doi.org/10.5014/ajot.2015.694001.

Riley, D. S., Barber, M. S., Kienle, G. S., Aronson, J. K., von Schoen-Angerer, T., Tugwell, P., Kiene, H., Helfand, M., Altman, D. G., Sox, H., Werthmann, P. G., Moher, D., Rison, R. A., Shamseer, L., Koch, C. A., Sun, G. H., Hanaway, P., Sudak, N., Kaszkin-Bettag, M., Carpenter, J. E., & Gagnier, J. J. (2017). CARE guidelines for case-reports: explanation and elaboration document. *Journal of Clinical Epidemiology*, *89*, 218-235. http://doi.org/10.1016/j.jclinepi.2017.04.026.

Saciloti, I. P., & Bombarda, T. B. (2022). Abordagem ao luto: aspectos exploratórios sobre a assistência de terapeutas ocupacionais. *Cadernos Brasileiros de Terapia Ocupacional*, *30*, e3264. http://doi.org/10.1590/2526-8910.ctoao249532642.

Sant'Anna, J. L., & Mendes, D. M. L. F. (2019). Enfrentamento do câncer infantil e intervenções psicológicas: uma revisão da literatura. *Psicologia: Teoria e Pesquisa*, *35*, e35435. http://dx.doi.org/10.1590/0102.3772e35435.

Silva, M. E. A., Moura, F. M., Albuquerque, T. M., Reichert, A. P. S., & Collet, N. (2017). Rede e apoio social na doença crônica infantil: compreendendo a percepção a criança. *Texto & Contexto Enfermagem*, *26*(1), 1-10.

Silva, J. I. F., Oliveira, J. S. A., Macêdo, M. L. A. F., Dantas, A. K. C., Fernandes, S. M. B. A., & Melo, F. A. (2021). Histórias de crianças e adolescentes que (con)vivem com doença crônica. *Revista da Sociedade Brasileira de Enfermeiros Pediatras*, *21*(2), 65-71. http://doi.org/10.31508/1676-379320210000.

Sociedade Brasileira de Pediatria – SBP. (2020). *Adolescência: doença crônicas e ambulatórios de transição.* Rio de Janeiro. Recuperado em 5 de janeiro de 2025, de https://www.sbp.com.br/fileadmin/user_upload/22641c-ManOrient_-_Adoles-_doencas_cronicas_e_ambulat_de_transicao.pdf

Sousa, A. S., & Oliveira, J. H. A. (2018). A criança diante da morte: desafios. *Estudos Interdisciplinares em Psicologia*, *9*(1), 157-160.

Suwary, L., Frank, D., Oswyn, G., Rero, A., & Duke, T. (2024). Adolescent health care and perceptions in a provincial hospital in Papua New Guinea. *International Journal of Adolescent Medicine and Health*, *36*(1), 37-43. http://doi.org/10.1515/ijamh-2022-0110.

Tasca, B. G., Brandão, E. R., & Branco, V. M. C. (2020). Protagonismo juvenil: análise do projeto Rede de Adolescentes e Jovens Promotores da Saúde (RAP da Saúde) do município do Rio de Janeiro, na perspectiva de seus participantes. *Saúde e Sociedade*, *29*(4), 1-11. http://doi.org/10.1590/s0104-12902020200070.

Tubiana-Rufi, N. (2009). Éducation thérapeutique des enfants et adolescents atteints de maladie chronique. *Presse Medicale*, *38*(12), 1805-1813. http://doi.org/10.1016/j.lpm.2009.09.003.

United Nations International Children's Emergency Fund – UNICEF. (1989). *The United Nations Convention on the rights of the child: how legislation underpins implementation in England.* Recuperado em 5 de janeiro de 2025, de https://www.gov.uk/government/publications/united-nations-convention-on-the-rights-of-the-child-uncrc-how-legislation-underpins-implementation-in-england

Valete, C. O. S., Ferreira, E. A. L., & Bruno, C. H. (2022). O protagonismo da criança em cuidados paliativos para a efetivação da sua segurança. *Cadernos Ibero-Americanos de Direito Sanitário*, *11*(3), 52-69. http://doi.org/10.17566/ciads.v11i3.927.

Wang, C. S., Yan, J., Palmer, R., Bost, J., Wolf, M. F., & Greenbaum, L. A. (2017). Childhood Nephrotic syndrome management and outcome: a single center retrospective analysis. *International Journal of Nephrology*, *2017*, 1-7. http://doi.org/10.1155/2017/2029583.

World Health Organization – WHO. (2021). *Therapeutic patient education: an introductory guide.* Geneva: WHO. Recuperado em 5 de janeiro de 2025, de https://www.who.int/europe/publications/i/item/9789289060219

Yu, Z., Zhou, Y., Xu, X., Lin, L., Le, Q., & Gu, Y. (2023). Pharmacological and non-pharmacological interventions in management of peripheral venipuncture-related pain: a randomized clinical trial. *BMC Pediatrics*, *23*(58), 1-10. http://doi.org/10.1186/s12887-023-03855-z.

Author's Contributions
Cristina Ortiz Sobrinho Valete guided the development of the study, participated in the analysis, discussion, and interpretation of the data, and wrote and revised the article. Giovanna Bussi, Roseane Rigo, and Eduardo Guimarães Ratier de Arruda participated in the interview, analysis, discussion, and interpretation of the data, and drafted, drafted, and revised the article. Ludmilla Alexandra Araujo Lewinsohn and Daniel Ferreira Dahdah participated in the analysis, discussion, and interpretation of the data, and drafted, drafted, and revised the article. All authors approved the final version of the text.

Data Availability
The data supporting the results of this study are available from the corresponding author upon request.

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