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ORIGINAL ARTICLE

HOLY POISON: MEANINGS ATTRIBUTED BY FAMILY CAREGIVERS TO PEDIATRIC CHEMOTHERAPY

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ABSTRACT

Objective: To understand the meanings that family caregivers of children and adolescents with cancer attribute to chemotherapy treatment. **Method:** A qualitative study, with a supplementary and expanded secondary analysis of two studies conducted in pediatric wards and outpatient clinics in São Paulo, Brazil. Data collection was carried out in 2017 and 2018, respectively. Data were collected through semi-structured interviews with 37 family caregivers and analyzed using inductive content analysis. **Results:** The sample was predominantly composed of mothers. Chemotherapy was perceived as a paradox between good and evil, described as a “holy poison” that triggers a range of emotions. Participants attributed to this treatment the meanings of a daily life filled with challenges, characterized by difficulties in dealing with the effects of therapy. **Final considerations:** Family caregivers perceive chemotherapy as a paradoxical “holy poison,” as a treatment that, despite temporarily weakening the child, is essential for managing the disease. This study enriches the body of scientific literature by expanding the discussion on the topic. Additionally, the results obtained provide valuable information for healthcare professionals and allow for a better understanding of the families' perspective during the complex process of pediatric chemotherapy.

Keywords: Neoplasms. Chemotherapy. Caregivers. Child; Adolescent.

INTRODUCTION

In Brazil, pediatric cancer represents 8% of deaths from diseases among children and adolescents(1). In our reality, for each year from 2023 to 2025, 7,930 new cases of cancer in children and adolescents are expected(2). Leukemias, followed by central nervous system tumors, and lymphomas are the most prevalent types worldwide(3). The primary treatment remains chemotherapy, which indiscriminately acts on the body's cells and causes a series of adverse effects(3-5). Currently, with advances in science and technology, the survival rate has increased by about 80%, thanks to early diagnosis and treatment. However, the disease is still considered a public health problem, being the leading cause of death from disease in individuals from 0 to 19 years old(6,7).

The diagnosis of pediatric cancer has significant physical, emotional, and psychosocial repercussions on the lives of children, adolescents, and their families(8). This disease transcends the individual condition of the child or adolescent, profoundly affecting the family environment and altering the daily functioning of all involved(8). In the context of treatment, chemotherapy can induce a series of symptoms and physical side effects, often severe, leaving family members in a situation of uncertainty and

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challenge in caring for young patients. Often, they find themselves in the position of making decisions and assuming responsibilities for which they may not be fully prepared(9,10).

On the emotional aspect, cancer often carries a stigma associated with the inevitability of death, causing suffering, stress, anxiety, and depression among family caregivers(11). Socially, the family may be forced to restrict their social interactions because of the immunosuppression caused by chemotherapy. Furthermore, evidence indicates a significant socioeconomic burden associated with pediatric cancer(12). Family caregivers, usually represented by the mother, play a crucial role in mitigating the suffering of children and adolescents, contributing to their physical, emotional, and social well-being(9,10,13). However, they are often not adequately considered in care plans but can benefit from targeted interventions since they also face a painful process and need help, support, and guidance(14).

Chemotherapy can cause various side effects in pediatric development, including hypothyroidism, scoliosis, pulmonary changes, and sensorineural hearing loss(15). In addition to physical impacts, studies link treatment to challenges in the social adjustment of children and adolescents, often associated with issues such as anxiety and uncertainty about the cure(16). With advances in cancer treatment, an increasing number of young people are becoming survivors of the disease. In this scenario, the importance of improving quality of life and intensifying evidence-based surveillance grows, especially considering new experiences related to chemotherapy, including the experiences of family members(17).

Thus, in the quest to strengthen this perspective, we sought to answer the following research question: “What meanings do family caregivers of children and adolescents with cancer attribute to chemotherapy treatment?” Considering the above, this study aimed to understand the meanings that family caregivers of children and adolescents with cancer attribute to chemotherapy treatment.

METHOD

A qualitative approach study with secondary data analysis(18) was conducted. This approach allowed for the understanding of subjective aspects of the phenomenon and the meanings present from the perspective of social actors. The adoption of secondary analysis is justified by the possibility of re-exploring pre-existing qualitative data from primary studies, aiming to answer a new research question and provide new insights into a specific phenomenon(19,20). This study was evaluated for rigor, methodological quality, and adequacy to the method(19), following the recommendations of the Consolidated Criteria for Reporting Qualitative Research (COREQ)(21).

Data from two primary studies conducted by the research team members were used. They were grouped as they shared identical objectives and were carried out with the same population, although in different locations and at different times due to operational issues. This strategy allowed for a more comprehensive understanding of the studied phenomenon, enhancing the richness of varied perspectives and expanding possibilities for data interpretation. The first study (A), conducted in 2017 in a chemotherapy outpatient clinic at a reference hospital for pediatric cancer treatment in São Paulo, Brazil, analyzed data using inductive content analysis. The second study (B), conducted in 2018 at a university hospital in Ribeirão Preto, São Paulo, Brazil, also of a qualitative nature, adopted symptom management theory as a reference for analysis(22). In total, 37 family caregivers of children and adolescents with cancer participated in the studies, selected by convenience, based on inclusion criteria: parents or caregivers, over 18 years old, whose children had undergone at least one complete cycle of chemotherapy. Family members of children undergoing another form of treatment simultaneously with chemotherapy or beyond curative therapeutic possibilities were excluded. Data collection was stopped when it was verified that the dataset obtained was sufficient to achieve the research objective(23).

Two undergraduate students and one doctoral student performed the interviews from both studies; and the research team’s supervisor, who has expertise in qualitative methods, previously trained them. The interviewers were not involved in tasks related to the care of children/adolescents and had no prior contact with the participants. Before the interviews, they reviewed the medical records of the children/adolescents to confirm diagnoses, disease stages, and treatment modalities used. When initially approaching potential participants, the interviewers introduced themselves, explained the study's purpose, and, if there was an interest in participating, they provided the informed consent form. This document was duly signed in duplicate, with one copy given to the participant and the other retained by the researcher.

Data from Study A were collected from June to August 2016, and from Study B, from December 2017 to December 2018, both through semi-structured interviews, with an average duration of 40 minutes, audio-recorded, and guided by a script previously developed by the researchers. The script consisted of an initial guiding question: “What do you perceive has changed in the routine of (Name of the child) since the beginning of chemotherapy?” Within this question, participants were also encouraged to share experiences in caring for their children during chemotherapy treatment. Throughout the development of both studies, the interviewers seized opportunities for interaction with participants to delve into questions considered important by participants that allowed for a better understanding of the investigated phenomenon. The first three interviews of each original study aimed to assess the relevance of the script, which proved to be suitable, and thus, subsequent interviews were continued. Only one meeting was held with each participant.

Secondary data analysis followed the procedures of inductive content analysis(24), involving the following steps: 1) exhaustive reading and rereading of transcripts; 2) coding of data with the assistance of the MAXQDA® program(25); 3) organization and grouping of codes by content affinity; 4) construction of initial themes; and 5) naming, refinement of theme wording, and adaptation to the dataset.

All ethical principles were respected, as stipulated by Resolution 466/12 of the National Health Council. The primary studies obtained ethical approval from the research ethics committees of their respective institutions, and this study was also approved by the Research Ethics Committee of the Ribeirão Preto School of Nursing, University of São Paulo, under the opinion 0243/2021 and Protocol CAAE: 47360321.5.0000.5393. To ensure participant anonymity, fictitious names were used, presented at the end of the interview excerpts.

RESULTS

The group of 37 caregivers was predominantly composed of women (97.3%), mothers (89.2%), aged between 30 and 40 years (37.8%), with completed high school education (51.1%), having children between 11 and 15 years old (35.1%) and mostly male (62.2%). Caregivers came from the states of São Paulo, Minas Gerais, Bahia, Rio Grande do Norte, Rio Grande do Sul, Pernambuco, and Alagoas. Regarding oncological diagnoses of children and adolescents, leukemias predominated (37%), followed by osteosarcoma (21.6%).

The caregivers' perspectives on the phenomenon were systematically grouped and analyzed, leading to the construction of two categories representing the phenomenon under study: 1) Meaning of chemotherapy: “a good poison”; 2) Daily challenges: experiences with the adverse effects of chemotherapy.

Meaning of chemotherapy: “a good poison”

Chemotherapy provides multiple experiences. Among children and adolescents, from the caregivers' perspective, it generates a paradox that oscillates between good and evil. While it appears to worsen the child's state of illness, it acts in favor of their recovery. Therefore, it is interpreted as a “good poison” and a necessary evil:

> It destroys everything good and bad, it's a good poison because it ends everything good, but it's treating the bad things, it destroys the child, but it's necessary, that's the cure, there's no other way. (Maria)

> At first, I thought it was doing more harm than good; it's a medicine that weakens a lot, abuses a lot, but it's the best thing they invented. (Júlia)

Although it causes intense changes by acting too powerfully, caregivers weighed the potential risks and benefits of chemotherapy against the available therapeutic options.

> So, I think when it enters, it's an overwhelming force that takes over everything, you know, and leaves her strong. (Lúcia)

> At first, I was terrified; I thought it was a very bad thing. Now I realize it's a necessary evil. I imagine it entering and destroying everything, everything good and bad too, that's what I think, and then we recover everything good that it destroyed. (Laís)

In this logic, chemotherapy destroys everything, kills both bad and healthy cells, leading caregivers to experience a synesthesia of feelings: uncertainty about the cure and the desire that, after all this suffering, everything returns to normal. Thus, faced with the paradox between good and evil, they resign themselves and accept the administration of the good poison as the only alternative to combat the disease, understanding that positivity is the best strategy to face the treatment's adversities.

> From what I hope and what I see, it's resolving, it's improving and healing. He (child) no longer has pain, there's nothing more we can do, there are bad things and good things, but I just want to imagine good things. (Joana)

> Chemotherapy acts directly on the cells and kills the bad cells and the good ones too, otherwise, they wouldn't be so bad afterward; immunity drops, affecting both, but it's the risk and benefit. If you don't do it, then it will grow (tumor), and there's no chance of curing. (Amanda)

The so-called “holy remedy” seems to meet caregivers' expectations, who even consider it divine care, crediting miracles to chemotherapy, especially in times of great uncertainty about the cure. For them, it is a treatment of ambiguous nature: it causes harm but also brings crucial benefits for health recovery, evident in signs of improvement after treatment.

> After my son started taking it, he transformed, from how he arrived at the hospital to now... Wow, he changed. It's a miracle; I thank this holy remedy that seems to do so much harm but does good. (Júlia)

> I tell God that chemo is the medicine he prepared for her. He guides the right medicines in her blood. (Eduarda)

Daily Challenges: Experiences with the Adverse Effects of Chemotherapy

Metaphorically, the holy remedy also poisons. Between the beginning and the end of treatment, caregivers experience this paradox. Reports were obtained about the child's lack of appetite at the beginning of treatment and the consequent weight loss, causing concern for the respondents. Caregivers constantly seek to provide nutritionally beneficial foods, capable of helping control symptoms. However, they often opt for foods more easily accepted by the child, even if they are not the most nutritious. For most of them, faced with adverse effects, it is preferable for their children to choose their preferred foods, even if they are processed, rather than not eating.

> I try to give less fatty foods, foods that don't loosen the bowels too much. I pay more attention to this; I give a lot of oats to balance it out. (Laura)

> I try to give him a lot of things to eat; he likes to eat tapioca [a preparation of cassava root starch often used as a pancake], so I make tapioca, he eats tomatoes. The things he likes, I force him to eat, but at least he eats junk food. If he didn't eat it, it would be worse. (Márcia)

> Such experiences endorse that chemotherapy causes severe adverse effects in children and adolescents, and this experience for family caregivers translates into daily challenges. Many classify it as aggressive because the child quickly shows physical signs of its action, such as hair loss or physical weakness:

> It's like when the hair started to fall. Wow, it was a hassle! He was discouraged. I said, 'He's going to get depressed because of his hair.' Then the psychologist talked, talked. (Laura)

[Chemotherapy] It really messes with him [the child]; he stops eating, gets very nauseous, with a lot of pain, strong headaches, in the eyes… (Ana)

A mother reported that the most constant and frequent adverse effect, in her daughter's case, was diarrhea. For another caregiver, not only diarrhea but also constipation was uncomfortable for her son, even affecting mood changes:

> She got sick, discouraged because she had a lot of diarrhea, which was the worst effect. (Laura)

> [Intestinal changes] weaken the person, mess a lot

> with his mood, he becomes very aggressive, answering back. He doesn't take it out on people but on me, a complicated process. (Melissa)

As chemotherapy presents itself as a necessary evil, dealing with its adversities is a daily struggle. Motivated by this kind of mantra, caregivers mentioned preparing homemade solutions, such as a concentrate made with “aranto” (a type of plant), soursop juice, or other natural juices, such as carrot or beet juice:

> So, we also started giving him aranto. But then you gave him aranto, and he vomited, so we stopped for that reason. He didn't accept it. (Eduarda)

> I gave juices for immunity. Natural juices: soursop, carrot, beetroot, kale, and others. (Esther)

In the articulation of the presented categories, the initial highlight is the paradox between good and evil, between the malefic and beneficial action of the holy remedy. Additionally, it is noted that the holy remedy manifests itself as a poison because the benefits and hope for a cure require daily coexistence with the severe adverse effects of treatment, with implications for children and adolescents, as well as for their family caregivers. The integration between the constructed categories has, as a point of confluence, the antagonism of the holy and beneficial treatment and the destruction by the deleterious effects of a poison that, in summary, can be called “holy poison.”

DISCUSSION

The caregivers' reports of children and adolescents with cancer reveal the perception of chemotherapy as a “holy poison,” essential for a cure despite its adverse physical effects. It was observed that family members adopt coping strategies, such as offering more appealing and nutritious foods, to deal with these effects.

Similar to the findings of this study, the literature indicates that chemotherapy for cancer is frightening for children, adolescents, and their families who need to adapt to new routines and cope with adverse symptoms of an unfamiliar treatment(26-28). Families often feel a lack of control and insecurity, as seen in other cultures(26,28). Parental fear and anxiety are amplified by a lack of knowledge about the disease and treatment(26), and the meanings attributed to chemotherapy by caregivers directly influence how they deal with the treatment and its effects(27).

The parents and caregivers in this study reported seeing chemotherapy as a hope for saving their children, believing it is the only possible remedy to combat the disease. In this sense, they placed their hopes for a cure in this treatment, even if it came with “necessary evils,” in this case, the adverse effects. Scientific literature emphasizes this perception as particularly positive because a lack of trust in treatment can trigger negative emotions such as fear, anxiety, depression, stress, and guilt(26,28).

The healthcare team must convey information to families from the beginning of treatment, appropriately and simply, to facilitate understanding. This care reduces uncertainty and helps parents regain a sense of control over their child's illness, contributing to better coping and generating a positive psychosocial response(26). Parents' knowledge about the disease, treatment, and related aspects can alleviate negative and threatening feelings and, consequently, make them more confident and cooperative(26).

The literature has shown that chemotherapy is a traumatic experience for some patients during the cancer treatment period(28). When looking at the caregivers' experience with the adverse effects on their children, there is a diversity of related symptoms, such as weight loss, alopecia, headaches, gastrointestinal changes, and immune system decline. The adverse effects mentioned by caregivers in this study are in line with scientific literature, highlighting the negative effects on the mood and quality of life of children and their parents, as well as disturbances in family roles and functions(28).

Studies also report that in parents' perception, pain, alopecia, fatigue, dyspnea, and anorexia are the most problematic experiences during the treatment period(28). Therefore, understanding these adverse effects and how they affect the lives of these children and families is extremely important for implementing appropriate interventions as early as possible. This way, it is possible to strengthen the confidence of these family members so that they can handle the overall care of their children by valuing their own perspectives on these treatment repercussions, as they are the ones who live with these adversities the most(27,28).

The predominance of women (97.3%) among the participants in this research highlights the burden associated with the role of women in caring for chronically ill children. This reality often implies sacrificing one's own employment, in addition to facing both emotional challenges and barriers to self-care(28-30). The importance of paternal involvement in the care of hospitalized children with cancer is emphasized, as well as the need for future research on the experiences of parents in pediatric oncological treatment, which is still underexplored. Studies that assess the perspective of other family caregivers, such as aunts and grandmothers, are equally relevant.

The limitations found in this study add to others already identified in the primary studies: the children and adolescents were at different stages of treatment, leading to a diversity of experiences for caregivers regarding chemotherapy; the caregiver's experience in two months of the child's chemotherapy cycle, compared to those who have experienced this for two years, may change how they perceive, feel, and cope with the treatment. Additionally, there was variability in the occurrence and intensity of symptoms throughout the entire treatment, which may have influenced the caregivers' reports.

FINAL CONSIDERATIONS

Based on the study's results, family caregivers perceive chemotherapy as a “holy poison,” necessary to combat the disease despite its devastating effects on the child and their family. To manage these effects, caregivers focus on improving nutrition, making it healthier and more nutritious, and resorting to pharmacological methods.

This study contributes to the field of scientific literature by expanding the understanding of the meanings attributed to chemotherapy by caregivers of children and adolescents with cancer. Recognizing and valuing the family's perspective is crucial for developing and implementing evidence-based care practices, integrating the study's findings into the realities experienced by this population. Highlighting these findings and their implications for nursing care can enrich and guide clinical interventions, ensuring a more comprehensive and family-centered approach to the needs of the child and their family.

SANTO VENENO: SENTIDOS ATRIBUÍDOS POR CUIDADORES FAMILIARES À QUIMIOTERAPIA PEDIÁTRICA

RESUMO

Objetivo: compreender os sentidos atribuídos por cuidadores familiares de crianças e adolescentes com câncer ao tratamento quimioterápico. **Método:** estudo qualitativo, com análise secundária suplementar e ampliada de dois estudos desenvolvidos em enfermarias e ambulatório pediátricos, localizados no estado de São Paulo, Brasil. A coleta de dados foi conduzida nos anos de 2017 e 2018, respectivamente. Os dados foram coletados por meio de entrevistas semiestruturadas com 37 cuidadores familiares e analisados conforme análise de conteúdo indutiva. **Resultados:** a amostra foi composta majoritariamente por mães. A quimioterapia foi percebida como um paradoxo entre o bem e o mal, descrita como um “veneno bom”, que desencadeia uma gama de sentimentos. Os participantes atribuíram a este tratamento os sentidos de um cotidiano repleto de desafios, caracterizados pelas dificuldades em lidar com os efeitos da terapia. **Considerações finais:** A quimioterapia é percebida pelos cuidadores familiares como um paradoxal "santo veneno", como um tratamento que, apesar de debilitar temporariamente a criança, é essencial para o manejo da doença. Este estudo enriquece o corpo da literatura científica, pois amplia a discussão sobre o tema. Adicionalmente, os resultados obtidos oferecem informações valiosas para os profissionais de saúde e permitem melhor compreensão da perspectiva das famílias durante o complexo processo de quimioterapia pediátrica.

Palavras-chave: Neoplasias. Quimioterapia. Cuidadores. Criança. Adolescente.

SANTO VENENO: SENTIDOS ATRIBUIDOS POR CUIDADORES FAMILIARES A LA QUIMIOTERAPIA PEDIÁTRICA

RESUMEN

Objetivo: comprender los sentidos atribuidos por cuidadores familiares de niños y adolescentes con cáncer al tratamiento quimioterápico. **Método**: estudio cualitativo, con análisis secundario suplementario y ampliado de dos estudios desarrollados en enfermerías y ambulatorio pediátricos, ubicados en el estado de São Paulo, Brasil. La recolección de datos se realizó en los años 2017 y 2018, respectivamente. Los datos fueron recogidos a través de entrevistas semiestructuradas con 37 cuidadores familiares y analizados conforme análisis de contenido inductivo. **Resultados**: la muestra fue compuesta mayoritariamente por madres. La quimioterapia fue percibida como una paradoja entre el bien y el mal, descrita como un "veneno bueno", que desencadena una gama de sentimientos. Los participantes atribuyeron a este tratamiento los sentidos de un cotidiano lleno de desafíos, caracterizados por las dificultades en lidiar con los efectos de la terapia. **Consideraciones finales**: la quimioterapia es percibida por los cuidadores familiares como un paradojal "santo veneno", como un tratamiento que, a pesar de debilitar temporalmente al niño, es esencial para el manejo de la enfermedad. Este estudio enriquece el cuerpo de la literatura científica, pues amplía la discusión sobre el tema. Además, los resultados obtenidos ofrecen informaciones valiosas para los profesionales de la salud y permiten una mejor comprensión de la perspectiva de las familias durante el complejo proceso de quimioterapia pediátrica

Palabras clave: Neoplasias. Quimioterapia. Cuidadores. Niño. Adolescente.

REFERENCES

1. Ministério da saúde. Instituto Nacional de Câncer José Alencar Gomes da Silva (INCA) ABC do câncer: abordagens básicas para o controle do câncer. 6a edição revista e atualizada [Internet]. 2020. [Citado Out 22]. Disponível em: https://www.inca.gov.br/sites/ufu.sti.inca.local/files//media/document/livro_abc_6ed_0.pdf.

2. Ministério da Saúde. Instituto Nacional de Câncer José Alencar Gomes da Silva (INCA) Estimativa 2020: incidência de câncer no Brasil [Internet]. INCA - Instituto Nacional de Câncer. 2019. [Citado Out 22]. Disponível em: https://www.inca.gov.br/publicacoes/livros/estimativa-2020-incidencia-de-cancer-no-brasil.

3. Urtasun Erburu A, Herrero Cervera MJ, Cañete Nieto A. Cáncer en los primeros 18 meses de vida. Anal de Pediatr. 2020;93(6):358–66. DOI: https://doi.org/10.1016/j.anpedi.2020.02.015

4. Giagnuolo G, Buffardi S, Rossi F, Petruzziello F, Tortora C, Buffardi I et al. Single center experience on efficacy and safety of Aprepitant for preventing chemotherapy-induced nausea and vomiting (CINV) in pediatric Hodgkin Lymphoma. Benjamin RS, editor. PLOS ONE. 2019;12;14(4). DOI: 10.1371/journal.pone.0215295. eCollection 2019.

5. Guimarães LA, Almeida KC de, Amâncio NFG. Os efeitos da música como terapia complementar na rotina de crianças sob tratamento oncológico. Brazilian Journal of Health Review. 2021;4(2):4964–80. DOI: https://doi.org/10.34119/bjhrv4n2-078

6. Mota ÍBB, Medrado AP. Percepção de pacientes oncológicos infanto-juvenis, profissionais de saúde e familiares sobre o adoecimento - revisão sistemática. J. Public Health Dent. 2020 Jun 2;11(1):33–43. DOI: 10.17267/2596-3368dentistry.v11v1.2806.

7. Renesto HMF, De Santana JB, Bushatsky M, Barros MBSC, De Morais VLL. Fique Atento Pode ser Câncer Infantojuvenil. 1a. Ed. Belo Horizonte: Poisson; 2020.

8. Neugebauer C, Mastergeorge AM. The family stress model in the context of pediatric cancer: A systematic review. J Child Fam Stud. 2021; 30, 1099-1122. DOI: https://doi.org/10.1007/s10826-021-01928-0

9. Ministério da Saúde. Instituto Nacional de Câncer José Alencar Gomes da Silva (INCA). Câncer infantojuvenil. [Internet]. 2021 [Citado Out 22]. Disponível em: https://www.inca.gov.br/tipos-de-cancer/cancer-infantojuvenil.

10. Paula DPS, Silva GRC, Andrade JMO, Paraiso AF. Câncer infantojuvenil do âmbito familiar: percepções e experiências frente ao diagnóstico. Cuid Arte enferm. 2019; 10(1): 1-12. DOI: https://doi.org/10.15649/cuidarte.v10i1.570

11. Young K, Bowers A, Bradford N. Families' experiences of child and adolescent brain tumor: a systematic review and synthesis of qualitative research. Psycho-Oncol. 2021; 30(10), 1643-1662. Doi:10.1002/pon.5745

12. Roser K, Erdmann F, Michel G, Winther JF, Mader L. The impact of childhood cancer on parents' socio-economic situation—A systematic review. Psycho-Oncol. 2019; 28(6):1207–26. DOI: https://onlinelibrary.wiley.com/doi/10.1002/pon.5088

13. Santos BD, Maques-Carmago AR, Pan R, Reis SMG, Andrade RC, Neris RR et al. Family knowledge about the legal rights of children and adolescents with cancer. Rev Bras Enferm. 2021;74(6):e20200725. DOI: https://doi.org/10.1590/0034-7167-2020-0725

14. Liu Q, Petrini MA, Luo D, Yang BX, Yang J, Haase JE Parents' experiences of having a young child with acute lymphoblastic leukemia in China. J Pediatr Oncol Nurs. 2021; 38(2): 94-104. DOI: 10.1177/1043454220975463

15. Keikhaei B, Bahadoram M, Keikha A, Bahadoram S, Hassanzadeh S, Mahmoudian-Sani MR. Late side effects of cancer treatment in childhood cancer survivors. J Oncol Pharm Pract. 2023;29(4):885-892. DOI: 10.1177/10781552221087611.

16. Siqueira HCH, Bick MA, Sampaio AD, Medeiros AC, Bento AS, Severo DF. Repercussões do câncer infantil no ambiente familiar. Rev. min. enferm. 2019; 8(1): 20-29. Disponível em: https://www.periodicos.unimontes.br/index.php/renome/article/view/2250/2318.

17. Turcotte LM, Liu Q, Yasui Y, Henderson TO, Gibson TM, Leisenring W et al. Chemotherapy and Risk of Subsequent Malignant Neoplasms in the Childhood Cancer Survivor Study Cohort. J Clin Oncol. 2019; 37(34):3310-3319. DOI: 10.1200/JCO.19.00129.

18. Hughes K, Tarrant A. Qualitative Secondary Analysis. Sage, London. 2019.

19. Chatfield SL. Recommendations for secondary analysis of qualitative data. Qual. Rep. 2020; 25(3): 833-842. DOI: 10.46743/2160-3715/2020.4092

20. Vila-Henninger L, Dupuy C, Van Ingelgom V, Caprioli M, Teuber F, Pennetreau, D et al. (2022). Abductive coding: theory building and qualitative (re) analysis. Sociol Methods Res. 2022 DOI: https://doi.org/10.1177/00491241211067508

21. Souza VRDS, Marziale MHP, Silva GTR, Nascimento PL. Tradução e validação para a língua portuguesa e avaliação do guia COREQ. Acta Paul Enferm. 2021; 34: eAPE02631. DOI: http://dx.doi.org/10.37689/actaape/2021AO02631

22. Silva-Rodrigues FM, Lucca M, Leite ACAB, Alvarenga WA, Nunes MDR, Nascimento LC. Gerenciamento dos sintomas relacionados à quimioterapia em crianças e adolescentes: perspectivas de cuidadores familiares. Rev Esc Enferm USP. 2021; 55: e20200484. DOI: https://doi.org/10.1590/1980-220X-REEUSP-2021-0484

23. Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: A systematic review of empirical tests. Soc Sci Med. 2022; 292:114523. DOI: 10.1016/j.socscimed.2021.114523.

24. Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs. 2008; 62(1): 107-115. DOI: 10.1111/j.1365-2648.2007.04569.x

25. Kuckartz U, Rädiker S. Analyzing Qualitative Data with

MAXQDA [Internet]. Cham: Springer International Publishing. 2019. DOI: http://link.springer.com/10.1007/978-3-030-15671-8.

26. Bernier Carney KM, Stegenga K, Linder LA. Informing parents as caregivers with a symptom assessment app developed for children with cancer. J Pediatr Hematol Oncol Nurs. 2022; 39(4):264-272. DOI: 10.1177/27527530211073307

27. Silva-Rodrigues FM, Vulczak VL da S, Alencar CF, Santos LSC, Nascimento LC. Concepções dos pais acerca da doença oncológica e do tratamento quimioterápico de seus filhos. Rev Enferm UFSM. 2020;10:e33. DOI: https://doi.org/10.5902/2179769235898

28. Lewandowska A. Influence of a child's cancer on the functioning of their family. Children (Basel). 2021; 8(7):592. DOI: 10.3390/children8070592.

29. Carrillo MIO, Valdez LC, Gutiérrez MLE. Perfil psicosocial del cuidador primario informal del paciente oncohematológico: un estudio piloto. Rev Elec Psic Izt. 2020; 23(3); 895-911. Disponível em: https://www.medigraphic.com/pdfs/epsicologia/epi-2020/epi203b.pdf.

30. Menezes LFM, Amador DD, Marchetti MA, Soldera AGS, Mandetta MA, Marques FRB. Estratégias de enfrentamento utilizadas por crianças com câncer em tratamento quimioterápico. Cienc Cuid Saude. 2023; 22: e66116. DOI: https://10.4025/ciencuidsaude.v22i0.66116.

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