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# Physical and mental exhaustion of the caregiver in pediatric patients with leukemia

Esgotamento físico e mental do cuidador de pacientes pediátricos com leucemia

Desgaste físico y mental del cuidador en pacientes pediátricos con leucemia

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It presents an exhaustive review of the literature to guide new studies on the problem addressed.

## ABSTRACT

**Introduction:** Pediatric patients with leukemia require direct care from the nursing staff in order to solve the health needs of the child, always taking care of their integrity and forming a therapeutic relationship of trust that allows dignified treatment and provides care timely manner with the support of the patient and their families. **Objective:** To analyze the nursing process to be used in the physical and mental exhaustion of the caregiver in pediatric patients with leukemia**.** **Methodology:** This research is qualitative with a descriptive design, which is characterized by a bibliographic review through articles, publications, reviews and documents from scientific societies. **Results:** In the review, 19 full-text articles were analyzed, finding that analgesia, emotional support and coverage of basic needs are the main requirements of the patient. **Conclusion:** The exhaustion of the caregivers of a child with leukemia manifests itself through physical and emotional exhaustion, which include various symptoms such as depression, anxiety, migraines, joint pain, sleep disorders, irritability, etc.

**Keywords:** Pediatric, leukemia, caregiver, nursing.

## RESUMO

**Introdução**: Pacientes pediátricos com leucemia requerem cuidados diretos da equipe de enfermagem a fim de solucionar as necessidades de saúde da criança, cuidando sempre de sua integridade e estabelecendo uma relação terapêutica de confiança que permita um tratamento digno e preste cuidados em tempo hábil com o apoio de o paciente e seus familiares. **Objetivo**: Analisar o processo de enfermagem a ser utilizado no esgotamento físico e mental do cuidador de pacientes pediátricos com leucemia. **Metodologia**: Esta pesquisa é qualitativa com desenho descritivo, que se caracteriza por uma revisão bibliográfica por meio de artigos, publicações, resenhas e documentos de sociedades científicas. **Resultados**: Na revisão, foram analisados 19 artigos em texto completo, constatando que a analgesia, o suporte emocional e a cobertura das necessidades básicas são as principais exigências do paciente. **Conclusão**: O esgotamento dos cuidadores de uma criança com leucemia manifesta-se através do esgotamento físico e emocional, que incluem vários sintomas como: depressão, ansiedade, enxaquecas, dores articulares, distúrbios do sono, irritabilidade, etc..

**Palavras-chave**: Pediátrico, leucemia, cuidador, enfermagem.

## RESUMEN

**Introducción:** Los pacientes pediátricos con leucemia requieren de cuidados directos del personal de enfermería con la finalidad de solventar la necesidad de salud del niño(a) cuidando siempre su integridad y formando una relación terapéutica de confianza que permita el trato digno y brindar los cuidados de manera oportuna con el apoyo del paciente y sus familiares. **Objetivo:** Analizar el proceso enfermero a emplear en el desgaste físico y mental del cuidador en pacientes pediátricos con leucemia. **Metodología:** La presente investigación es de tipo cualitativo con un diseño descriptivo, el cual se caracteriza por una revisión bibliográfica por medio de artículos, publicaciones, revisiones y documentos de sociedades científicas. **Resultados:** En la revisión se analizaron 19 artículos a texto completo encontrando que la analgesia, el apoyo emocional y la cobertura de las necesidades básicas son los principales requerimientos del paciente. **Conclusión:** El agotamiento de los cuidadores de un niño con leucemia se manifiesta a través de un desgaste físico y emocional, que incluyen varios síntomas tales como: depresión ansiedad, migrañas, dolores articulares, trastornos del sueño, irritabilidad, etc.

**Palabras clave:** Pediátrico, leucemia, cuidador, enfermería.

# INTRODUCTION

The term leukemia is used to refer to a group of malignant diseases that originate in the blood (Antunes et al., 2018). According to Fernández et al. (2019) leukemia is defined as a neoplastic process of hematopoietic tissue characterized by the uncontrolled and abnormal proliferation of leukocyte cells that have a generally tumour-like behaviours and frequently originate in the bone marrow. Leukemias constitute 4.0% of all neoplasms worldwide and are one of the main causes of death in patients under 40 years of age. In Ecuador, leukemia of the hematopoietic type, together with lymphatic leukemia, is the 14th leading cause of death. Childhood cancer is a rare disease that represents a rate of 0.5 to 4.6% of morbidity (Loja et al., 2019; Guerrero et al., 2019) Epidemiology shows that about 30% of leukemia cases are represented by acute leukemia, while about 70-80% are represented by acute lymphoblastic leukemia (Morales et al., 2017). In the pediatric population, the prevalence was observed in the age group between 2 and 5 years of age, predominantly in the male sex. This is a disease that affects hematopoietic tissue and bone marrow in a gradual and progressive manner and can lead to severe complications; however, if the appropriate therapeutic treatments are used early on, based on current protocols, more than 80% of cases can be reduced and cured (Recalde et al, 2022). In Ecuador, according to data reported in 2016 by the National Institute of Statistics and Census, a total of 3617 cases of leukemia were reported in the general population without age group discrimination, with the province of Guayas in first place with 858 cases reported that year (Brayley, 2019).

Pediatric patients with leukemia require direct care from the nursing staff to meet the health needs of the child, always taking care of their integrity and forming a therapeutic relationship of trust that allows for dignified treatment and timely care with the support of the patient and their families (Sánchez, 2022). Therefore, it is important that the nurse directs interventions according to the symptoms, needs and problems presented in children and adolescents with leukemia. The clinical manifestations can be very varied, ranging from a child who on assessment appears to be completely healthy to a child who has a high potential for infection (Li, 2021). This requires comprehensive assessment, as well as planning and evaluation of the achievements of the nursing care provided (Ardem & Kilikarslam, 2018; Arévalo et al., 2022)

The incidence of childhood cancer, especially leukemia, has remained stable, but there has been a considerable decrease in the mortality rate (Guimarães, C. et. al 2019). With scientific advances in cancer, it has now become a chronic degenerative disease with supportive care, in contrast to previous years when it was defined as a fatal disease. As a result of this change in the condition of cancer, a greater demand for interventions has arisen, influencing an increase in the number of formal and informal caregivers who are the ones who attend to all the needs of the patient, providing physical, practical and emotional support to the sick person and his or her relatives. Thus, it is increasingly recognized that "holistic" cancer care should not only focus on medical care but also on general wellbeing (Rosenberg, A. R, et.al, 2018).

According to Ríos, K. et.al (2018) informal caregivers, mainly the family, father or mother, often have the feeling that since they acquired the responsibility that the role of caring for a pediatric patient with leukemia demands, their health has gradually worsened, developing physical symptoms such as headaches or migraines, gastric problems, sleep disorders, stress, overload and, on a psychological level, commonly fear, worry, despair, frustration, anxiety and depressive symptoms. They suggest that being a caregiver is a difficult responsibility, coping with daily, work, social and caregiving activities can lead to limitations and major changes, evidenced by physical/psychological exhaustion under the stress of trying to support all areas (Cáceres Zurita L, et.al. 2022) With the overload that the caregiver manages, the caregiver syndrome develops, characterized by physical exhaustion and weariness manifested by changes in attitude, irritability, fatigue, psychological exhaustion that begins to affect the caregiver-society relationship, and emotional exhaustion with all those deep feelings that vary according to the situation (Cabada Ramos, E, 2019).

Another syndrome can also develop, known as the Burnt-out Caregiver Syndrome, which is well known for the number of symptoms it generates in the caregiver, the most prominent of which are: insomnia, lack of appetite, irritability, stress, anxiety, depression, feelings of guilt, social isolation, feelings of loneliness, they devote themselves solely to care, leaving aside family relationships and friendships. This syndrome may be caused by the lack of collaboration of other family members or by insufficient information about the pathology and the care that should be provided (Martínez S, 2020). The variables of caregiver overload and the relationship with quality of life are directly correlated with physical, psychological, spiritual well-being and social concerns, which interpersonally affect and generate a perception of low quality of life due to the multiple changes they must face (Arias, M.et. al, 2022).

Based on Borrescio, H. et. Al, (2022) The psychological and physical distress that remains between the pediatric patient with leukemia and their caregivers is significant during diagnosis, treatment and even post-traumatic stress. It is essential to highlight the importance of therapeutic support and appropriate psychosocial interventions provided by an extra staff, through support that seeks to enable the caregiver to face the challenges of the disease and to reduce the symptoms of overload, stress and anguish.

P, P. R. A. (2022) mentions that "the caregiver is really necessary for a favorable outcome in the treatment of the cancer patient and it is imperative to maintain the physical, emotional health and satisfaction of informal caregivers". For Carreño, S, et, al. (2019), the importance for health professionals to recognize the role of the caregiver and begin to offer health-friendly nursing interventions through coping strategies for stress, relaxation and resilience. The art therapy imparted in the process of emotional adaptation to the caregiver in the face of childhood cancer allows the exhibition, externalization or materialization of conflicts, feelings and emotions that are happening (Reyna, M. 2019).

Núñez K, et. Al (2020) & Cuevas, J (2018) highlight the importance of promoting strategies to parent cares focused on seeking harmony and relaxation through workshops where problems can be described, explaining emotional stress. Psychoeducation is a specific nursing intervention applied as a strategy to caregivers being a differential therapy since it is based on the reduction of psychological discomfort (stress, anxiety) structured in three educational phases, hierarchization of problems, deficits or needs with an educational, preventive and psychological approach that significantly helps the caregiver.

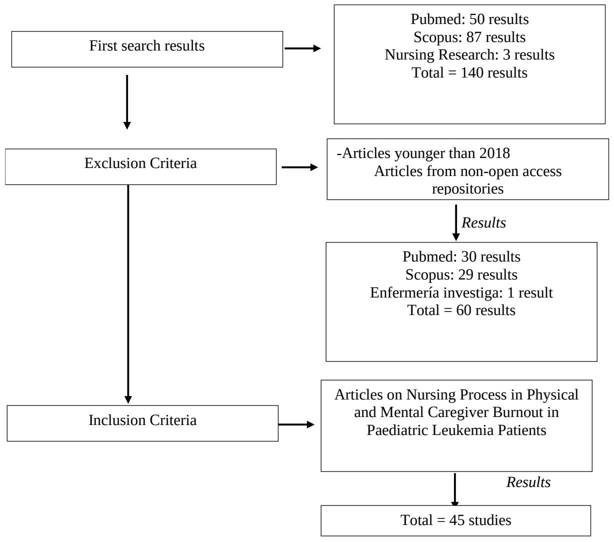
According to the results of the previous research, the following intra-occupational variables or risk factors stand out: work exploitation and overload of responsibilities. Similarly, the non-occupational risk factors were marital status, having children, age 31 to 40 years, and psychological variables: emotional exhaustion or burnout, depression, compassion fatigue, post-traumatic stress disorder. On the other hand, the research identifies protective factors described as emotions of compassion and satisfaction, hobbies, vocation as a nurse, personal fulfilment, greater financial rewards and leadership (Grau, C., & Hawrylak, M, 2019).

The role of the nurse in relation to the caregiver is very important and ranges from early identification of caregivers' needs to interventions to improve the caregiver's quality of life to provide emotional and social support and, in turn, to train them to develop disease management skills. promote self-care and adherence to treatment, and thus contribute to a better quality of life. Méndez, J. & Botero, A (2020). Obtaining information from the caregiver's own perspective allows for a better understanding of the health impact that caregiving can have on the provision of pediatric palliative care, it does not prevent or end curative treatment, in fact, it is nowadays considered that the intervention should be collaborative so that the child can be cured, if their illness allows it, and have an acceptable quality of life. Pediatric palliative care is a complex of interventions carried out through the coordination of an interdisciplinary team, as it is necessary to cover the needs of the child and his or her family in all areas, from the physical to the spiritual and from the medical to the psychological. (Castaño R. & Guevara R., 2019). From another point of view, it is essential to provide the respective care to the person who is in charge of the care of the child or caregiver, as they can suffer from a distress syndrome related to the burden and responsibility of complete care, triggering physical, psychological and even social problems in the long term (Silva et al., 2022). For this reason, the aim of this literature review is to analyse the nursing process to be used in the physical and mental exhaustion of the caregiver in pediatric patients with leukemia, based on the palliative care line of research.

## METHODS

This is a qualitative research with a descriptive design, which is characterized by a literature review using articles, publications, reviews and documents from scientific societies. The data search was carried out through databases such as Pubmed, Scielo, Elsiever, Scopus, Latindex, Enfermería Investiga, among other highly prestigious sources registered in different languages such as Spanish, English and Portuguese; using descriptors such as: pediatric, leukemia, caregiver, nursing.

**Figure 1** Study selection



Source: authors 2023

## RESULTS AND DISCUSSION

This study included research related to palliative care and pain management in patients with stomach cancer. These studies evaluated strategies and methods to improve the treatment and quality of life of these patients. These are described in table 1.

**Table 1**. Main studies

| **Nro.** | **THEME** | **AUTHOR** | **YEAR** | **METHODOLOGY** | **RESULTS** |
|---|---|---|---|---|---|
| **1** | The Psychosocial Burden of Families with Childhood Blood Cancer. | Borrescio-Higa, F., & Valdés, N. | 2022 | Qualitative Study | "The widespread impact on families of children with cancer after diagnosis, in a country where this topic has not been previously studied. Most families reported a negative impact upon diagnosis, which was related to ruptures in family dynamics, depressive symptoms in the patient, poor relationship between the patient's siblings and their parents, deterioration in the caregiver's spouse/partner relationship, as well as a worsening of the primary caregiver's economic condition." |
| **2** | Repercusiones del diagnóstico juvenil de leucemia en pacientes y sus familias. | Silva, C., Macedo, E., Aparecida, A. & Lima, U. | 2022 | Integrative Review | "...nursing interventions should be adopted according to the symptoms presented by children and adolescents, aiming at singular care and providing a link between all those involved in the treatment, providing security to parents and patients; the most effective and least painful assistance for both parties." |
| **3** | Calidad de vida en pacientes pediátricos tratados con quimioterapia por diagnóstico de leucemia linfoblástica aguda. | Recalde, M., García, C. & Criollo, A. | 2022 | Observational, cross-sectional, descriptive, descriptive research, with a quantitative approach. | "The elements of quality of life most affected were the presence of pain, difficulties with eating, communication, existence of anxiety and stress due to concern about the possible ineffectiveness of treatment." |
| **4** | Cancer-related psychosocial challenges | Wang, Y., & Feng, W. | 2022 | Descriptive and exploratory study, with qualitative approach | "...the burdens of care provision and the impact on the health of caregivers of cancer patients are highlighted. Improving doctor-patient communication and overcoming burnout are two major challenges facing health professionals in oncology." |
| **5** | Impacts of Caring for Persons with Cancer on the Caregiver and Family Dynamics | Lopes do Carmo, De Mendonça M, Toledo E, De Oliveira D, Do Carmo P, Andrade, J & Rodrigues A. | 2021 | Descriptive and exploratory study, with qualitative approach | "Family caregivers showed alterations in basic human needs related to the domains: psychobiological, psychosocial and psychospiritual. Such aspects guide the actions of health professionals and validate the importance of holistic and humane care for the caregiver, who also needs care." |
| **6** | SOBRECARGA Y CALIDAD DE VIDA EN CUIDADORES DE NIÑOS CON CÁNCER. | Carrillo, V., Reyes, C., & Chávez, D. | 2021 | Systematic Review | "Primary caregivers of pediatric oncology patients face different stressors and challenges than other caregiver populations due to the particularities of malignant blood malignancies that mainly affect children, which can result in stress, depression, anxiety, overload and consequent decrease in quality of life. The involvement of the primary caregiver in the management of any pediatric cancer patient is extremely important, yet many primary caregivers receive little preparation, information or support to help them better fulfil their role as caregivers." |
| **7** | The aplication value of information-based extended, nursing care, of disacharged, | Li, M., Jia, Y. & Zhing, L. | 2021 | Observational, cross-sectional, descriptive, quantitative, cross-sectional study | "Extended nursing care based on computerisation can effectively promote the nursing skills of parents of children with acute leukemia, improve children's quality of life and reduce their adverse psychological moods, leading to improved nursing satisfaction and worthy of clinical study." |
| **8** | Sobrecarga y calidad de vida de cuidadores de personas con cáncer en cuidados paliativos. | Arias-Rojas, M., Carreño Moreno, S., Sepúlveda García, A., & Romero Ballesteros, I. | 2021 | Descriptive correlational study with | "With regard to the perception of caregiving overload, some research has shown that from the experience of these caregivers there is a burden focused on physical exhaustion, a mental burden related to feelings of loss of self-esteem, hopelessness, discouragement, sadness and loneliness, and a social burden related to the female role in caregiving and the alteration of family dynamics. In this same sense, caregivers report that their most frequent burdens correspond to the feeling that they are the only people on whom their relative depends, making them perceive a greater dissatisfaction with their role in palliative care." |
| **9** | Assistência de enfermagem à criança com câncer em cuidados paliativos: uma revisão integrativa | Penariol, T., Carmo, G., & Lima, V. | 2020 | cross-sectional | "The nurse is involved in all phases of palliative care, from early integration into the treatment, in building bonds, in supporting the child, the family and the nursing team, pain relief and management, up to the time of the child's death and during family bereavement." |
| **10** | Estrategias de intervención para el estrés en padres con hijos con enfermedades oncológicas. | Núñez K. | 2020 | Integrative Review | "The most important outcome is the validation of the workshops as a tool to improve stress and problems collateral to having a child with cancer." |
| **11** | Qualitative Assessment of Unmet Information Management Needs of Informal Cancer Caregivers: Four Themes to Inform Oncology Practice. | Crotty, B. H., Asan, O., Holt, J., Tyszka, J., Erickson, J., Stolley, M., Pezzin, L. E., & Nattinger, A. B | 2020 | Research is quasi-experimental, pretest - posttest; explanatory, descriptive | "...thirteen caregivers participated, the majority between 41 and 60 years old: 53.8%, were predominantly female; 76.9% were educated, 76.9% had graduated from college; and of modest means, 46.2% had family income < $35,000. Four themes emerged: (1) the paradox of information overload, where caregivers felt overloaded with information but had unmet information needs; (2) navigating volatility as a caregiver, with changing or unknown expectations; (3) caregivers as information brokers, which placed new burdens on caregivers to seek, share, and protect information; and (4) caregiver care, including unmet information needs related to self-care." |
| **12** | Concepto de sobrecarga del cuidador del niño† con cáncer: revisión integrativa. | Fonseca, M., Rojas, J., & Cubillos, P. | 2019 | Qualitative study | "...this review makes visible the particular characteristics of caregiver overload for the child with cancer and clarifies that it is a concept with negative meanings. As observed throughout the integration of findings derived from primary studies, overburden is typified as an overexertion at the physical, psychological, social, economic and spiritual levels." |
| 13 | Estudio de caso: atención arteterapéutica a cuidadora primaria, madre de un hijo con leucemia para favorecer su expresión emocional y afrontamiento. | Reyna-Martínez, M., González-Romo, R. A., & López, J. A. | 2019 | Qualitative Integrative Systematic Review | "The results show that during the art therapy process a creative process was favoured that led to the restructuring of emotional experiences derived from childhood cancer and the development of functional coping strategies." |
| 14 | Promoting Resilience among Parents and Caregivers of Children with Cancer. | Rosenberg, A. R., Baker, K. S., Syrjala, K. L., Back, A. L., & Wolfe, J. | 2018 | Case study | "The Institute of Medicine has recommended that cancer care include the provision of appropriate integrated services to optimise psychosocial outcomes. This "care of the whole patient'' should include the care of parents and family members, particularly in the context of pediatric cancer." |
| **15** | Percepción del cuidador primario sobre las intervenciones de enfermería al paciente en estado terminal. | Guerrero, A., Romero, G., & Martínez, M | 2018 | Systematic review | "...caregivers were 79.5 % female, 56.4 % daughters, age range 40- 60 years, 59 % married, 53.8 % dedicated to the household and 56.4 % lived in the same house as their patient; the best perceived dimension was communication with 51.3 %, the least favoured was behavior in the face of terminality; the overall perception was fair, with 87.2 %." |
| **16** | Dimensiones de la calidad del cuidado de enfermería y satisfacción del padre o tutor del paciente pediátrico hospitalizado. | Gonzáles, N., & Romero, M. | 2018 | Analytical cross-sectional study | "...the age of the parents ranged between 31 and 40 years in 41.6%; the level of schooling was high school in 39%; the age of the pediatric patients was 7 and 8 years in 24.7%. Parental satisfaction was good in 49%." |

Note: own elaboration with research data (2023)

Regarding leukemia Carillo et. al (2021) and Fonseca et. al (2019) mentioned that in hospitals, all types of cancer not only lead to physical, mental, spiritual and social wear and tear on the patient but also on their caregiver, which becomes a challenge for their caregivers who in most cases are the parents, thus affecting their quality of life where it causes a significant change in their environment, taking into account that in a child this type of disease is very complex because of all the therapies they must go through to cope with the pathology, Forugh et al (2018), agrees and adds that having a child with cancer causes uncertainty and worry in caregivers, mainly in the mother and father, as it provokes a reaction where parents sacrifice and commit themselves only to the care of their child, seeking balance and above all stability, bearing in mind that sometimes this disease causes conflicts in the home and separations, which makes the patient's environment difficult. Guerrero et. al (2018) and González et. al (2018), agree with the authors, but their criterion is based more on the hospital environment where they mention that the patient's condition consumes the life of the caregiver in a short period of time, in which it is evident that there is insufficient attention to the parents' basic needs, in this case emotional needs, on the part of the health professional. This causes the parents to continue in crisis and vulnerability witnessing the poor state of their child. In this case, the main basis for nursing is the humanized care where the family is included, addressing the understanding of the patients and their caregivers without leaving aside the perception they have of the medical care.

Gonzales and Romero (2019) focus on the quality of care provided by the nursing staff in order to meet the satisfaction of the pediatric patient's caregiver, taking into account that this quality will depend on the perception that the caregivers, in this case the parents, have of the interventions that the health staff performs on their hospitalized child. The main nursing intervention is to reduce or control the anxiety and pain of the parents in order to obtain a better response in the treatment of their child, on the other hand, Abrantes et. al (2019) does not share the same criteria as he mentions that the tension generated in the care by the illness of their child is high when the nursing professional does not show empathy and sensitivity when carrying out procedures and therapies on the patient. Therefore, "Quality" is a difficult challenge to achieve for professionals who lack ethics. Lopes et. al (2021) agrees with Abrantes' criteria, as the family, mainly the parents, suffer a major impact when observing poor care for their children, which leads the family to organize themselves to provide good care, including transferring their child to another hospital or to their home, leaving them to take care of themselves for the well-being of the patient, increasing not only the physical but also the mental wear and tear.

Salas et. al (2018) and Sánchez et. al (2018) They state that caregivers may or may not be family members, who take on the care of the pediatric patient with leukemia or any other type of cancer. Informal caregivers who may not necessarily be parents also feel the burden and responsibility of devoting all their time to caring for the sick child. Accordingly, Penariol et. al (2020) states that in order to reduce the stress on parents or other caregivers, health care personnel, in this case nurses, should direct their care to relieve the patient's pain, improve communication, strengthen the bond and support with the family and in other cases offer palliative care, thus providing a dignified death in accordance with the wishes of the caregiver and the patient.

Wang and Feng (2022) expresses that, as cancer increases worldwide, health professionals have an important role to play, which is to improve and provide comprehensive care to patients and their families, taking into account that in most cases of cancer survivors and their caregivers experience a serious alteration in body image and self-concept, and that the caregiver experiences problems in social and sexual relationships due to the emotional toll that he/she has suffered during the course of his/her child's illness.

Bradley et al (2020) agrees with the criteria of the aforementioned authors but adds that the caregiver not only experiences physical exhaustion, but also begins with depression and stress serious enough for the caregiver to have thoughts of suicide, as on several occasions there are single mothers in which the overload is more complex for them or there is an inadequate economy that does not cover the hospital expenses, which increases the caregiver's fear and therefore to make bad decisions in which they can put their life at risk as a way out of the situation in which they find themselves. Therefore, the nursing staff should be vigilant and help the caregiver to cope in a positive way with their child's illness and thus avoid self-harming attempts.

## CONCLUSIONS

The exhaustion of caregivers of a child with leukemia manifests itself through physical and emotional exhaustion, which includes various symptoms such as: depression, anxiety, migraines, joint pain, sleep disorders, irritability, etc. The symptoms appear due to the great burden of caring for this type of patient, as they require an enormous amount of care and generate uncertainty and fear within the caregivers related to the doubts that arise about the possible evolution of the clinical picture. Added to this is the economic impact of treatment, as many resources are required during the recovery process.

It is necessary to emphasize that to avoid or reduce the appearance and symptoms of burnt-out caregiver syndrome, timely and adequate support must be provided by the nursing staff. Among the interventions that should be applied are self-care strategies, relaxation techniques, implementation of assertive communication, management of family conflicts and decision-making strategies; together these strategies favor the quality of care provided to the child and the physical and mental health of the caregiver. Including the implementation of such interventions in the care plan by the nursing staff effectively mitigates the occurrence of adverse events in the caregivers' health.

The implementation of education programmes for caregivers is necessary because it provides them with access to information about the disease the child is experiencing and how to effectively and correctly provide the necessary care that the disease requires. By providing all the necessary knowledge, caregivers' levels of anxiety and uncertainty are reduced, which limits emotional exhaustion.

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