

Family behavior in the face of childhood and adolescent cancer diagnosis

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Abstract

Patient's family plays a relevant role in coping with the disease, including treatment and hospitalizations. This study aimed to understand family's influence on the treatment and prognosis of pediatric cancer patients. An integrative review was conducted based on 15 articles selected from database searches. The results show that a cancer diagnosis causes a major emotional impact on families, involving feelings of fear, anguish, sadness, and anticipatory grief, as well as profound changes in family routines. Furthermore, religiosity/spirituality stands out as a coping strategy, alongside the deconstruction of projects and expectations regarding the child's future. It is concluded that family presence and support contribute significantly to the child's adaptation to treatment and recovery. Thus, the nursing team's sensitive and ethical performance in welcoming and supporting the family throughout the illness process is of utmost importance.

Keywords: Family. Child. Cancer. Neoplasms. Oncology nursing.

Resumo

Comportamento familiar diante de diagnóstico de câncer infantojuvenil

A família do paciente tem papel relevante no enfrentamento da doença, incluindo tratamento e hospitalizações. Objetivou-se compreender a influência da família no tratamento e no prognóstico do paciente pediátrico com câncer. Fez-se revisão integrativa com base em 15 artigos selecionados em busca em bases de dados. Os resultados evidenciam que o diagnóstico de câncer provoca grande impacto emocional na família, com sentimentos de medo, angústia, tristeza e luto antecipatório, além de profundas mudanças na rotina familiar. Destacam-se ainda a religiosidade/espiritualidade como estratégia de enfrentamento e a desconstrução de projetos e expectativas relacionados ao futuro da criança. Conclui-se que a presença e o apoio familiar contribuem significativamente para a adaptação da criança ao tratamento e para sua recuperação, sendo de extrema importância a atuação sensível e ética da equipe de enfermagem no acolhimento e no suporte à família durante todo o processo de adoecimento.

Palavras-chave: Família. Criança. Neoplasias. Enfermagem oncológica.

Resumen

Comportamiento familiar ante el diagnóstico de cáncer infantojuvenil

La familia del paciente desempeña un papel relevante en el enfrentamiento de la enfermedad, incluyendo el tratamiento y las hospitalizaciones. El objetivo fue comprender la influencia de la familia en el tratamiento y pronóstico del paciente pediátrico con cáncer. Se realizó una revisión integradora basada en 15 artículos seleccionados mediante búsqueda en bases de datos. Los resultados evidencian que el diagnóstico de cáncer provoca un gran impacto emocional en la familia, con sentimientos de miedo, angustia, tristeza y duelo anticipado, además de cambios profundos en la rutina familiar. Se destacan también la religiosidad/espiritualidad como estrategia de afrontamiento y la deconstrucción de proyectos y expectativas relacionados con el futuro del niño. Se concluye que la presencia y el apoyo familiar contribuyen significativamente a la adaptación del niño al tratamiento y a su recuperación, siendo de extrema importancia la actuación sensible y ética del equipo de enfermería en la acogida y el soporte a la familia durante todo el proceso de enfermedad.

Palabras clave: Familia. Niño. Cáncer. Neoplasias. Enfermería oncológica.

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Several chronic diseases occur with greater or lesser prevalence in the population aged 0 to 18, depending on the specific characteristics of each age group and geographic region. Among childhood chronic diseases, cancer stands out due to its high incidence and the repercussions it has on the lives of children and their families¹.

Cancer is unquestionably a public health problem, with high prevalence, incidence and mortality rates worldwide, especially in developing countries. It is estimated that 704,000 new cases of cancer occurred in Brazil in 2022–2023².

The incidence of the disease in individuals under 19 accounts for about 3% of cancer cases worldwide and is considered rare when compared with the number of cases in adults. In 2023, in Brazil, the mortality rate among patients with cancer in this age group accounted for 8% of total deaths³. In childhood, leukemias are the most common types of cancer (25% to 35%). Among adults, in turn, tumors of the central nervous system are the most common, followed by lymphomas and leukemia⁴.

Despite all advances in diagnosis and treatment, the stigma surrounding cancer remains very strong. Therefore, it is essential that families receive clear and accurate information from healthcare professionals at the time of diagnosis in order to ensure the success of treatment⁵.

The impact on family members is one of profound distress, as they devote themselves intensely to their loved one out of fear that the worst may happen. Learning about the illness and facing limitations and restrictions—unable to engage in physical activities, prevented from attending school, cut off from friends and normal life—generates distress and suffering in the child, but also in the mother and father, who provide care, protection and, above all, love around the clock⁶.

The family, defined as a more or less enduring and socially approved union between parents and their children, is a universal phenomenon present in every type of society⁷. It plays a relevant role in coping with the disease, including during treatment and hospitalization. Family members support the patient throughout the process of discovery and treatment of the neoplasm, helping them face the losses and limitations imposed by the illness⁸. Given the many concerns surrounding

the child, the following question arises: *What is the family's behavior in the face of a diagnosis of childhood and adolescent cancer?*

The inclusion of the family in the hospital setting to support the child or adolescent is provided in the Statute of the Child and Adolescent^{9,10}, which states in article 12 that the presence of a responsible person during hospitalization is guaranteed and that hospitals must provide conditions for the full-time presence of one parent or guardian during hospital admissions.

Receiving a diagnosis of cancer is often perceived by the patient as a death sentence, and the family serves as a safe haven that helps cope with the disease in a different way. Having the family as caregivers can positively influence attitudes toward the illness and, consequently, its treatment. This study aimed to understand family behavior in the face of a diagnosis of childhood and adolescent cancer.

Method

This is an integrative literature review. A search for scientific journals and articles, as well as theses and dissertations, was conducted in the databases Latin American and Caribbean Health Sciences Literature (LILACS), Scientific Electronic Library Online (SciELO) and the Virtual Health Library (VHL). The following descriptors were used to select the articles: “*família or family or familia and criança or child or niño and câncer/neoplasia or cancer/neoplasm or câncer/neoplasia*,” following the search criteria established in each database.

A review and evaluation of the studies included in the integrative review were carried out. The selected studies were organized according to journal classification, year of publication and article characteristics; subsequently, a sample was chosen for assessment of the quality of the research.

Table 1. Overview of descriptor combinations used and articles found and selected

Boolean combination	Database	Found	Selected
Family	Lilacs	32	8
Child	SciELO	25	2
Cancer/neoplasm	VHL	23	5

VHL: Virtual Health Library

The inclusion criteria were publications that addressed family behavior in the face of a diagnosis of childhood and adolescent cancer as the main topic of the study; full-text articles in Portuguese published between July 2017 and January 2024 by researchers in the health field; and studies that provided context related to the subject under investigation.

Publications whose research participants were adults, texts published before the proposed period and duplicate records in the databases were not included. Articles that were not available in full text and those that did not meet the objective of the study were also excluded.

A total of 80 studies were identified. Following the initial search, the first screening was carried

out by reading the titles and abstracts available in the respective databases. It was found that 32 were duplicates and nine did not address the variables of interest for this review, resulting in 39 articles, which were then read in full. Of these, 15 met the eligibility criteria.

Results and discussion

After data collection, three descriptive charts were prepared summarizing the 15 selected studies, which address feelings, changes in daily life and the disruption of dreams as experienced by families in the face of a child's illness.

Chart 1. Breakdown of scientific articles on family behavior in response to a child's illness

Author; year	Title	Database	Main outcomes
Fernandes and collaborators; 2017 ¹¹	<i>Vivências maternas na realidade de ter um filho com câncer</i>	VHL	The disclosure of a cancer diagnosis is received as unexpected news and generates in many mothers' feelings that are initially difficult to explain, such as sadness, fear and resignation. Sadness is a feeling that is part of the life of any individual, and every human being is subject to it.
Ferreira and collaborators; 2019 ¹²	<i>Um olhar fenomenológico sobre o cuidador familiar e os cuidados paliativos ao paciente oncológico</i>	VHL	It is understood that there are differences in the experiences of each family caregiver, even though some factors are similar; and, despite the situation of extreme changes in their lives, the role is carried out in such a way that these caregivers feel fulfilled, rewarded and dignified.
Bastos; 2019 ¹³	<i>Na iminência da morte: cuidado paliativo e luto antecipatório para crianças/adolescentes e os seus cuidadores</i>	SciELO	The experience of the child, the adolescent and the parents proved to be regulated in an interdependent manner, and anticipatory grief resembled the process of disenfranchised grief, as there is no social space for its expression and processing. The parents' anticipatory grief involves an intense emotional burden, which was shown to restrict the capacity for imagining the future, thereby directing the construction of meaning toward the present.
Santos and collaborators; 2018 ¹⁴	<i>Vivências de mães com crianças internadas com diagnóstico de câncer</i>	LILACS	In view of the physical and mental exhaustion experienced by mothers, this study reveals the need for healthcare professionals to be sensitive to emotional support needs, in addition to developing emotional skills to provide comprehensive care for the child and the family, with a socio-affective support network constituting a mechanism of comfort for the mothers.

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Chart 1. Continuation

Author; year	Title	Database	Main outcomes
Silva and collaborators; 2021 ¹⁵	<i>Resiliência de cuidadores familiares de crianças e adolescentes em tratamento de neoplasias e fatores associados</i>	LILACS	Weak to moderate direct correlations were observed between level of resilience and quality of life, and inverse correlations were found between stress and minor psychological disorders.
Vieira and collaborators; 2017 ¹⁶	<i>Mães/acompanhantes de crianças com câncer: apreensão da cultura hospitalar</i>	SciELO	Receiving the news of a child's cancer causes physical, emotional and social transformations within the family unit. The family feels as if they are living a nightmare, in a world filled with fear and distress, and experiences guilt over the child's illness. These reactions occur because the context of cancer inevitably reminds the family of mortality. They interpret the words they receive with pain and with feelings of sadness, hopelessness and fear of death.
Oliveira and Gaspar; 2024 ¹⁷	<i>Câncer infantil e resiliência familiar: estudo com famílias que vivenciaram o tratamento</i>	LILACS	During the initial process of coping with cancer, the most common feelings experienced by family members are related to shock, despair, fright, revolt and distress in response to the diagnosis, which cause disruption in the lives of the families of cancer patients.

VHL: Virtual Health Library

The family plays a central role in the formation of an individual's beliefs, values and knowledge, and, in general, when an individual becomes ill, the entire family suffers and experiences the consequences¹⁸. In addition to fear and feelings of loss and helplessness, sadness and abandonment were expressions of the family's suffering during the child's recovery process. When they perceived themselves as torn between the need to care for the recovering child and other responsibilities, the family felt unable to provide the resources necessary for the child's recovery¹⁹.

In painful moments of life, sadness and distress are expected feelings; however, it is important to identify when depressive disorder

or anxiety sets in so that family members can be referred for appropriate treatment. Such feelings interfere with the comfort of the patient and their relatives, as well as with decision-making ability, adherence to treatment and the quality of life of these individuals²⁰.

The family recognizes that the child shows fear and fragility and therefore feels the need to remain cheerful, put on a brave face or even "cry in private" so that this does not affect the child, who is already living with so much suffering and pain. Thus, it is necessary to hide emotions and tears in order to provide comfort to the children and help them face the situation, since they feel supported by their mothers²¹.

Chart 2. Breakdown of scientific articles on changes in family daily life in response to a child's illness

Author; year	Title	Database	Main outcomes
Tensini; 2017 ²²	<i>Percepção de pais que vivenciam o câncer de crianças e adolescentes, sem possibilidades de terapia curativa</i>	SciELO	Upon recognizing themselves as individuals experiencing an existential relationship with oncology, parents develop a sense of change in daily life that guides them in coping with their child's illness.

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Chart 2. Continuation

Author; year	Title	Database	Main outcomes
Rossato; 2022 ²³	<i>Religiosidade/ espiritualidade no câncer infantojuvenil: implicações psicossociais para crianças/ adolescentes adoecidos, familiares/cuidadores e equipe de saúde</i>	VHL	The importance of religiosity/spirituality in the Brazilian sociocultural context should be considered, as it influences subjectivity, behaviors and, consequently, lifestyle habits and ways of responding to health-disease processes. Understanding the meanings attributed to people's religious and spiritual dimensions can guide the planning and implementation of actions aimed at incorporating this aspect into healthcare, with a focus on care and the prevention of psychological illness.
Trainoti and collaborators; 2022 ²⁴	<i>Paliar, cuidando além da dor: uma reflexão dos profissionais de saúde na oncologia pediátrica</i>	LILACS	Families should be present in the daily life of the hospitalized child because their presence provides the hospitalized child with comfort, security and reassurance. At the same time, they also require attention and spaces for discussion,
Negreiros and collaborators; 2017 ²⁵	<i>A importância do apoio familiar para efetividade no tratamento do câncer infantil: uma vivência hospitalar</i>	SciELO	Neoplasms generate various impacts that affect not only the patient but also the entire family, imposing changes and requiring a reorganization of family dynamics to incorporate the care demanded by the illness and its treatment into daily life activities.

VHL: Virtual Health Library

A child's illness causes changes and imposes new routines within the family, as their necessary hospitalization requires the presence of a family member, who may stop providing care and attention to other children and to the spouse, resulting in a disruption of family planning²⁶.

Current paradigms recommend the presence of parents during the child's hospitalization²⁷. Consequently, this may lead to separation from other children and further complicate the situation for mothers, generating significant internal conflicts and intensifying feelings of distress and guilt related

to parental responsibilities⁷. Prioritizing attention to the ill child can promote distancing from the family unit and domestic responsibilities, and requires assistance from other family members²⁸.

Mothers of children with cancer often feel obliged to dedicate themselves entirely to their child's care, depriving themselves of activities that previously afforded them pleasure and were part of their daily lives, such as leisure, work and social interaction. They may spend most of their time in the hospital, which effectively becomes their primary place of residence²⁹.

Chart 3. Breakdown of scientific articles on the deconstruction of family dreams in response to a child's illness

Author; year	Title	Database	Main outcomes
Freitas, de Oliveira, 2018 ³⁰	Aspectos psicológicos envolvidos na sobrevivência do câncer infantil	SciELO	After the impact of the diagnosis, both the child and the family must cope with uncertainty about the future. The child will also face the challenge of loss of control, becoming dependent on others for many tasks they previously managed alone, losing privacy, having to comply with rules and treatments imposed by the caregiving team, experiencing limitations in their activities and dealing with parental overprotection.

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Chart 3. Continuation

Author; year	Title	Database	Main outcomes
Avanci and collaborators; 2019 ³¹	Cuidados paliativos à criança oncológica na situação do viver/morrer: a ótica do cuidar em enfermagem	LILACS	When a child is diagnosed with cancer, the family perceives the disease as uniquely cruel, as it affects a being at the very beginning of life who requires protection, care and emotional investment. The cancer diagnosis disrupts expectations of continuous, healthy development, introduces the tangible possibility of death and destabilizes the horizon of dreams, plans and achievements built around childhood.
Bernardo and collaborators; 2024 ³²	A importância dos cuidados paliativos prestados pelo enfermeiro à criança com câncer em estágio terminal	VHL	At the moment the disease is discovered, it seems as if all the dreams and hopes for the future invested in that young life have been stolen.
Fernandes Júnior, Bifulco and Barboza; 2020 ³³	Câncer: uma visão multiprofissional	VHL	The diagnosis of cancer raises many concerns, and after its confirmation, the future seems bleak for many patients.

VHL: Virtual Health Library

When a pathology affects a child, the emotional impact is far greater, since the child represents the future and parents feel as though the future has been abruptly taken away, interrupting the dreams they had for their child’s development. An inversion of the natural order of life occurs, as the illness raises fears of premature death among family members²⁴.

Faith may also be shaken during moments of crisis, and the unhappiness experienced reveals concerns about the unjust distribution of suffering in the world. This often leads to a confrontation with the concept of a benevolent God who provides strength, hope and meaning to life. When people are going through periods of suffering, they expect to be able to rely on the support of family, neighbors, the community and the church; yet it is precisely at this moment, when they need it most, that they may feel forsaken³⁴.

The family confronts the child’s illness and treatment with determination, perseverance and resilience, changing habits and clinging to beliefs and religious faith. They recognize that the effort to overcome the crisis contributes to the reorganization of family life and to fulfilling the responsibilities imposed by the condition of illness. However, this process is permeated by a persistent sense of loss related to the disruption of routine, previously established plans and the expectation of normality³⁵.

Attempting to protect their children, parents ask God to let them take their place and bear the illness instead, in order to spare the children the suffering and pain that afflict them. Religiosity and/or spirituality are coping strategies when facing a diagnosis of cancer, a disease that is culturally and socially stigmatized³⁶.

These anxieties trigger a crisis within the family, creating an opportunity to define and redefine roles within the family unit. There is a sense that the family’s future is compromised by the threat to the child’s life. In this context, affection becomes intensified in an effort to alleviate the child’s suffering in the face of the adversities of treatment³⁷.

The family experiences feelings related to loss and sorrow. Cancer symbolizes the loss not only of the patient’s physical capacity but also of bonds, family structure, a promising future and control over life. The process of becoming ill creates the possibility of rupture, as a person’s normal life undergoes a profound change in its natural course³⁸.

When asked about the impact on their lives of a cancer diagnosis in one of their children, all family members mentioned the words “distress” or “death,” expressing these feelings through gestures such as furrowing their brows, intertwining their fingers, and covering their faces with their hands and then running them through their hair, as if trying to wake from a bad dream³⁹.

Professional bioethics in relationships with family members

Professional bioethics plays a key role in mediating the relationship between the healthcare team and the families of children diagnosed with cancer. In times of great emotional vulnerability, bioethical principles should guide all communication and care provided to families, especially at the most difficult moment, which is the diagnosis. Respect for family autonomy is expressed through active listening, consideration of cultural and religious values, and the involvement of parents or guardians in decision-making regarding therapies, avoiding unilateral impositions by healthcare professionals⁴⁰.

The health team caring for these families and children must be sensitive to the ethical dilemmas surrounding family suffering in order to build a relationship of trust and support. Rather than adopting a purely technical approach, healthcare professionals must recognize the psychological, spiritual and existential impact of the illness on the family unit. The ethics of care are manifested in clinical conduct and in support for the distress experienced by family members, ensuring dignified care throughout the process of coping with the illness⁴¹.

Delivering bad news, such as a diagnosis or worsening clinical conditions, should follow clear bioethical guidelines and consider the family's right to honest yet sensitive information. Professional confidentiality is also necessary to preserve the privacy of the child and the family, limiting the exposure of their suffering. Situations involving palliative care, for example, require a particularly careful ethical approach, balancing truth and hope without creating false expectations⁴².

Professional bioethics requires care that is not fragmented or solely patient-centered. The family must be considered an integral part of the therapeutic network and a direct beneficiary of institutional support. Psychological and social support for family members, when systematically provided, represents a bioethical practice committed to justice and equity in access to comprehensive healthcare. In this way, family suffering is validated as a clinical and ethical element to be addressed throughout the treatment process⁴³.

In the training of healthcare professionals, it is extremely important to include aspects of bioethics applied to pediatric oncology from the undergraduate level, reinforcing the importance of compassionate and respectful practices⁴⁴. Ethics should not be treated as an appendage to technical practice but as a structuring pillar of clinical and relational conduct. In a context as delicate as childhood and adolescent cancer, where suffering is shared between patient and family, the ethical perspective of the professional can represent the point of balance between pain and the possibility of facing the situation with dignity.

Final considerations

The family plays an important role in the treatment of a child with cancer, as it can provide a sense of security and thereby improve the child's quality of life. It contributes to the treatment by helping the child respond better to it. When the child is not close to a family member, they may feel abandoned, which can hinder the positive progression of the disease. Therefore, the family should be present at all times so that the child does not become emotionally distressed.

However, the family itself also requires support, as it is not prepared to receive bad news, especially when it concerns the health of their children. For this reason, nursing professionals must have the sensitivity to offer support when complications related to the illness arise.

Because of the illness, families are often forced to change their daily routines so that the child is not abandoned or left alone. Some mothers leave their homes in order to stay with their children. In this context, religiosity becomes a source of support for some families, while others become disillusioned, believing that God is not watching over their child.

Amid so many anxieties, the disease may be seen as a threat to the child's future, since parents fear that cancer may put an end to the dreams they had envisioned for their children. The feeling of imminent loss often generates anticipatory grief. In this regard, bioethics is expressed in the professional's duty not only to treat the disease but also to provide emotional support, respecting the

family's vulnerability and offering multidisciplinary care grounded in human dignity.

Nurses play a key role both for the child with cancer and for the family. Their task is not limited to providing care; they also act as collaborators in the therapeutic plan with a view to offering

comprehensive, high-quality healthcare. Professional ethics must permeate all stages of care, ensuring that those responsible for hospitalized children receive adequate guidance and participate in a care process grounded in family-centered practices, technical responsibility and efficiency in health services.


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Participation of the authors

Laercio Medeiros Silva Junior participated in the conceptualization, methodology, investigation, data curation, formal analysis, writing (original draft), and visualization. Rui Nunes participated in the supervision, validation, project administration, writing (review) and editing.

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