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ORIGINAL

Perception of pediatric oncology patients and their caregivers regarding education and psycho-emotional support received from palliative care

Percepción de los pacientes oncológicos pediátricos y sus cuidadores sobre la educación y el apoyo psicoemocional recibidos de los cuidados paliativos

Adriana Marcela Monroy Garzón[1], Nathalya Casallas Hernández[2], Mildred Guarnizo Tole[3], Karin Perdomo Núñez[4], Jeisson Hincapié Carvajal[1], Kevin Julian Aya Roa[5], Alexander Casallas Vega[1]

[1]Health Care and Quality of Life Research Group, Faculty of Nursing, Universidad El Bosque, Bogotá, Colombia.
[2]Health and Sport Sciences Research Group, School of Health and Sport Sciences, Fundación Universitaria del Área Andina, Bogotá, Colombia.
[3]Health, Care and Society Research Group, Central Unit of Valle del Cauca (UCEVA), Valle del Cauca, Tuluá, Colombia.
[4]Pediatric Palliative Care Programme, Clínica Infantil Colsubsidio. Association of Palliative Care of Colombia (ASOCUPAC), Bogotá, Colombia.
[5]Division of Health Sciences and Engineering, Universidad de Guanajuato, Guanajuato, Celaya, México.

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Corresponding author: Alexander Casallas Vega

ABSTRACT

Introduction: education and psychoemotional support are key strategies in palliative care, implemented to improve the quality of life of pediatric patients and their families. To optimize these programs, it is essential to understand the experiences and perceptions of those who participate in them, thus making it possible to identify areas for improvement and adjust interventions according to their needs.
Method: fifteen interviews were conducted with caregivers and nine interviews with pediatric oncology patients aged 8 to 17. Data analysis was carried out using Lawrance Bardin's content analysis framework, with Atlas Ti software used for data management.
Results: two main categories were identified: the biomedicalization of education for the pediatric oncology patient-caregiver dyad, and the implementation of psycho-emotional support strategies within the hospital. Educational processes focused primarily on biomedical aspects and physical care, with little emphasis on psycho-emotional education. Psycho-emotional support for pediatric oncology patients was provided mainly through playful and educational activities, but it was perceived as intermittent or insufficient.
Conclusions: while educational strengths were observed in terms of physical care knowledge, it is necessary to incorporate psycho-emotional aspects into the education of pediatric oncology patients continuously and proactively as a psycho-emotional strategy. Playful strategies are appropriate and effective for pediatric patients.

Keywords: Palliative Care; Pediatrics; Health Education; Psychosocial Support Systems.

RESUMEN

Introducción: la educación y el apoyo psicoemocional son estrategias clave en cuidados paliativos, implementadas para mejorar la calidad de vida de pacientes pediátricos y sus familias. Para optimizar estos programas, es esencial comprender las experiencias y percepciones de quienes participan en ellos, permitiendo así identificar áreas de mejora y ajustar las intervenciones según sus necesidades.

Método: se realizaron 15 entrevistas a cuidadores y 9 entrevistas a pacientes oncológicos pediátricos de 8 a 17 años. El análisis de los datos se llevó a cabo mediante el marco de análisis de contenido de Lawrance Bardin, y se utilizó el software Atlas Ti para la gestión de los datos.

Resultados: se identificaron dos categorías principales: la biomedicalización de la educación para la díada paciente-cuidador de oncología pediátrica y la implementación de estrategias de apoyo psicoemocional dentro del hospital. Los procesos educativos se centraron principalmente en los aspectos biomédicos y los cuidados físicos, con escaso énfasis en la educación psicoemocional. El apoyo psicoemocional a los pacientes oncológicos pediátricos se proporcionaba principalmente a través de actividades lúdicas y educativas, pero se percibía como intermitente o insuficiente.

Conclusiones: si bien se observaron fortalezas educativas en cuanto a los conocimientos sobre cuidados físicos, es necesario incorporar aspectos psicoemocionales en la educación de los pacientes oncológicos pediátricos de forma continua y proactiva como estrategia psicoemocional. Las estrategias lúdicas son apropiadas y eficaces para los pacientes pediátricos.

Palabras clave: Cuidados Paliativos; Pediatría; Educación en Salud; Sistemas de Apoyo Psicosocial.

INTRODUCTION

Pediatric palliative care is a crucial approach in the treatment of children facing life-threatening illnesses. These services go beyond addressing the physical aspects of the disease, covering psychosocial, spiritual, and family support needs from diagnosis through the progression of the illness and its outcome. The primary goal of pediatric palliative care is to improve the quality of life of pediatric patients and their families by relieving pain and addressing physical, psychological, and spiritual needs.(1)

According to the International Children's Palliative Care Network, approximately 21 million children worldwide require pediatric palliative care each year, with a large proportion living in low- and middle-income countries.(2) In Latin America, the Palliative Care Atlas (2020) reports that there are 79 palliative care services in Colombia, nine of which are dedicated to pediatric patients. This equates to a rate of approximately 0,79 services per million inhabitants under 15 years of age,(3) highlighting the challenge faced by health systems in providing comprehensive care to children in need of palliative services.

Currently, it is recognized that children with serious illnesses, as well as their families, have different psychological, social, spiritual, and biological needs.(4) These include effective pharmacological and non-pharmacological symptom management, nutritional support, clear and developmentally appropriate communication, emotional support, and tools to foster personal development.(5) Additionally, continuing inclusive and individualized education during hospitalization is essential. Addressing these needs through educational processes that target both the pediatric patient and their caregivers regarding disease and quality of life is critical.(6) This area is a priority in pediatric palliative care research.(7) Therefore, the aim of the present study is to explore the perceptions of paediatric oncology patients and their carers regarding the education and psycho-emotional support they received during their hospital stay.

METHOD

Study Design

A qualitative study with a phenomenological approach was conducted, aiming to describe and understand the experiences of children and caregivers regarding the psycho-emotional support and educational processes perceived by families participating in a pediatric palliative care program. The phenomenological approach focuses on understanding the complex aspects of human life and the meanings behind lived experiences.(8)

Population

The study included hospitalized children and adolescents aged 8 to 17, as well as their primary caregivers, who were part of a pediatric palliative care program at a referral hospital in Bogotá. Convenience sampling was used, with participants eligible if they met the following inclusion criteria: children and adolescents referred to the pediatric palliative care program receiving interventions during their hospital stay. Children with cognitive impairments, hearing or speech limitations, or those in physical or psychological condition that prevented them from answering questions, as well as those who did not wish to participate, were excluded.

Data Collection

Data collection occurred over four months (August-November 2021). Semi-structured interviews were conducted, with language adapted to the age of the pediatric participants in three age groups. The lead investigator, in consultation with the pediatric palliative care program coordinator, verified which patients met the inclusion criteria. The head nurse in the hospitalization ward was then consulted about the patient's health status and clinical evolution before they participated in the interviews.

Subsequently, the lead investigator and a research team member approached the child and caregiver in the hospital room, following established biosecurity protocols. After introducing themselves and explaining the study, they invited the caregiver and child to participate, answering any questions they had. Consent and assent forms were signed voluntarily by both the caregiver and the child.

The interview questions were structured based on the principal investigator's experience in pediatrics and recommendations from the palliative care team. The questions aimed to explore the participants' experiences with the palliative care team regarding education about the disease and the psycho-social support received. A total of 24 interviews were conducted in person, lasting an average of 30 minutes. All interviews were audio-recorded and conducted by the principal investigator, a doctor and master's degree nurse with extensive professional and research experience in pediatric care and accompanied by nonparticipant observers.

Data Analysis

The interviews were transcribed verbatim for analysis. Transcriptions were returned to participants without requests for modifications. Data management was carried out using Atlas Ti software. The analysis was conducted using Lawrance Bardin's content analysis framework, (9,10) organizing data into codes and categories. Codes were assigned to interview fragments, with "EP" representing pediatric patients and "EC" representing caregivers. Categories were formed based on the relationships between sub-categories. Four researchers, including the lead investigator, participated in the coding and categorization process.

The analysis of the information was carried out in three phases: pre-analysis, exploration of the material, and inference and interpretation of the data.(9,10) The pre-analysis phase corresponded to the initial organisation of the material, in which the textual transcription of the interviews was carried out and a floating reading of the data was made as a first approach to the content, allowing initial impressions, emotions and expectations to be captured.

The second phase, corresponding to the exploration of the material, was the beginning of the data analysis. In this phase, significant fragments of the participants' discourses were identified, from which the recording units or codes were defined and created, considering the central theme of the study and its context.

Finally, in the third stage, inferences and interpretations of the data were developed. To this end, the categories of analysis were established based on the thematic axes identified, following the principles proposed by Bardin: homogeneity, pertinence, objectivity and fidelity. This process made it possible to give meaning and depth to the information to answer the research question.

It should be noted that this process was initially carried out individually by the principal investigator. Subsequently, a triangulation process was carried out with the co-authors, who carried out the analysis phases independently, and then the results were compared until a final consensus was reached.

Ethical Considerations

Following Resolution 8430 of 1993 from the Colombian Ministry of Health,(11) this study was classified as risk-free research. Data collection occurred after approval from the institutional ethics committee (No. 300-2, Clinical Colsubsidio Infantile). Informed consent and parental consent were obtained, as well as assent for children over 7 years old. To ensure confidentiality, codes were assigned to participant responses. The researchers declared no conflicts of interest and emphasized that the study's purpose was to generate knowledge for the benefit of the academic and scientific community. The study adhered to ethical and legal principles, ensuring informed consent and confidentiality of participants' data.(11,12)

Rigor

Intentional sampling was used to enhance data validity. The credibility of the data was ensured by the participation of experienced qualitative researchers who coded and analyzed the data from multiple perspectives. The COREQ checklist was used to ensure transparency in reporting.(13)

RESULTS

Sociodemographic and Clinical Characteristics

Of the pediatric participants, 56,6 % were female and 44,4 % were male. The majority (55,5 %) had been hospitalized for more than a month. The most common diagnoses were hematologic cancer (55,6 %), soft tissue cancer (22,2 %), bone cancer (11,1 %), and central nervous system tumors (11,1 %).

Among the caregivers, 73,3 % were women, and 90 % were the mothers of the pediatric patients. Most caregivers (46,6 %) were between the ages of 35 and 42. Regarding caregivers' educational levels, 39 % had higher education (technical, technological, or university degrees), and 13,3 % assumed the role of sole caregiver, while 86,7 % had support from two or more people in caring for the child.

Main Categories

Two main categories emerged from the data analysis: the biomedicalization of education for children with cancer, and psycho-emotional support within the hospital setting. Five subcategories were identified, informed by 30 codes (table 1). These results describe the experiences of children and their caregivers concerning health education and psycho-emotional support provided by the palliative care team during hospitalization.

Table 1. Examples of Codes, Subcategories, and Main Categories Identified from the Analysis Process

Categories	Subcategories	Codes
Biomedicalization of Education for the Pediatric Oncology Patient-Caregiver Dyad	Education about the Disease	Knowledge of cancer
		Continuity of education
		Information focused on physical/biological aspects
		Pharmacological knowledge
	Education about Care	Knowledge of procedures
		Information transfer
		Timely information
		Effective healthcare
		Participation in care
		Effective health education
		Education on self-care
		Self-Care
In-hospital Psycho-emotional Support	The Role of Play as a Psycho-emotional Strategy in Pediatric Palliative Care	Playful activities
		Absence of recreational activities
		Recreation as self-care
		Discontinuity in activities
	Support Networks as a Resource in the Care Journey	Support groups
		Healthcare team as a support network
		Overload
		Religious beliefs
		Effective support network
		Ineffective support network
	Challenges in Psycho-emotional Support Processes for Children and Caregivers	Lack of empathy
		Caregiver overload
		Physical and emotional fatigue
		Intermittent psycho-emotional support

Category 1: Biomedical Perception of Education in Children with Cancer

This main category refers to the experiences of children and their caregivers regarding the educational processes carried out from the moment of diagnosis and during hospitalization. It includes two subcategories: Education about the Disease and Education about Care.

Subcategory: Education about the Disease

This topic frequently appears, especially at the onset of the oncology diagnosis. Interview fragments related to the education and information received by participants were identified, addressing aspects such as biological and pathological knowledge about cancer and the procedures related to the established treatment. The information provided about the disease reflects a simplified interpretation of the illness. For instance, "EP3: They told me that these are like some glands that are here in my body" (table 2), and "EP7: A mass grew inside me, and it spread like little cells" (table 2). These explanations were likely adapted to be understandable to a child, often using metaphors to describe the body's fight against the disease. For example, EP3 refers to "good" and "bad" cells fighting in the body.

This suggests that, while children receive information about their condition, they tend to assimilate it in a way that aligns with their worldview—often as a battle between good and bad elements within their bodies. However, these explanations tend to focus more on physical restrictions and risks, reflecting a teaching approach geared toward preventing and managing the physical aspects of the disease, without addressing the emotional or psychological impact (table 2, EP4: "They told me I was high risk").

In all the fragments, it is observed that children receive some form of education about their disease, but this education tends to focus on physical and technical aspects, leaving out the psycho-emotional dimension. Children often understand the information through metaphors or simplified interpretations (table 2, EP5: "They told me there are some bacteria in my blood"), as they struggle to comprehend complex medical terms. While information about the diagnosis is provided, it may not be fully understood by the child, highlighting the need to adjust explanations according to the child's cognitive development level.

Subcategory: Education about Care

Interview fragments related to education and information received by participants were identified, which addressed topics such as self-care regarding infection prevention, nutrition, hygiene measures (handwashing, wearing masks, limiting visitors), and alarm signs, as well as care about pharmacological treatment.

Key aspects of care that were most frequently mentioned included nutrition, social isolation, and restrictions (table 3, EC8, EP7, EP8). Although children were informed about the risks and restrictions, this understanding could have a negative emotional impact. Dietary restrictions, combined with social isolation, may increase feelings of frustration and boredom, exacerbating emotional distress during prolonged hospitalization (table 3, EP1). This suggests that psycho-emotional interventions could focus on ways to offer a sense of normalcy and control to children within their limitations.

Concerning the caregivers, they described receiving a large amount of information about the care they need to provide at home, particularly about catheter management, infection prevention, and medication administration (table 3, EC12, EC8). It was mentioned that it is sometimes difficult to remember all the information provided, reflecting a common phenomenon in chronic illness contexts: informational overload. Caregivers often feel overwhelmed by the sheer volume of responsibilities and constant worry about making mistakes (table 3, EC12: "I forget so many things"). However, an evaluative protocol was in place, allowing the interdisciplinary team to assess the caregiver's retention of care-related knowledge (table 3, EC1).

Table 2. Participant Supporting Quotes – Subcategory: Education About the Disease

Participant identification	Interview quotes
EP3 (10-year-old girl)	"They told me that they're like little glands here in my... here (points to her neck), and the good glands are fighting the bad ones to defeat them so they die, and then the good ones are left, and that's how I'll get rid of this illness."
EP5 (11-year-old boy)	"They said it's called leukemia or blood cancer, that there are some bacteria in my blood and they're trying to get them out."
EP6 (14-year-old girl)	"Well, with the chemo, we get nausea, we can feel weak, lose our hair, and all that."
EP1 (8-year-old girl)	"Maybe we'll lose our hair and feel down, but that won't stop us from continuing with the process."
EC1 (Mother, 32 years old)	"Uh, the fact that they talked to me about a mass, that's the word that stuck in my mind. Uh, the neurosurgeon... he started telling me that he had hydrocephalus, caused by the pressure the mass was creating."
EC3 (Mother, 37 years old)	"The neurosurgeon explained to me that it's a very aggressive tumor, so it tends to grow very quickly... that's why he needs to start radiation sessions and chemotherapy cycles to control it. That's what they've explained to me about his illness."
EC9 (Mother, 36 years old)	"Some have told me that it's for him, for the vomiting, so he doesn't vomit because of the chemo... the chemo is supposed to help fight the cells, burn them, get rid of them, finish them, eradicate them."

Table 3. Participant Supporting Quotes – Subcategory: Education About Care

Participant identification	Interview quotes
EC8 (Mother, 38 years old)	"Now it's all about catheter care. We have to be really careful about any infection or bacteria he could catch. He could get bacteria from not washing his hands, a cold, poorly prepared food—everything has to be made the same day, no leftovers... nothing raw."
EC12 (Mother, 44 years old)	"Honestly, it's a lot of information, I forget so many things. Yes, they've given me information about care at home and food, medication care, and that no medication should be given without me knowing what it is."
EC1 (Mother, 32 years old)	"A lot of information from everywhere: nurses, assistants, the foundation, doctors, the head of palliative care. They all did evaluations to make sure I had a clear understanding of what needed to be done in the first month."

EP1 (8-year-old girl)	"Maybe we'll lose our hair and feel down, but that won't stop us from continuing with the process."
EP6 (14-year-old girl)	"From the explanations… they told me it's a medication through the vein, and that sometimes I might feel nausea, stomach pain, not want to do anything, feel depressed, angry, and bored."
EP8 (13-year-old boy)	"I can't eat cold cuts anymore, and all the vegetables have to be cooked. I can eat fruits with peels, but the ones without peels, I can't eat those."
EP7 (14-year-old boy)	"I can't be around a lot of people because I could get sick, and if I get sick, it could be something serious, like a fever. I need to keep washing my hands, and clean my mouth regularly to prevent sores from forming."

Category 2: Psycho-emotional Support in the Hospital Setting

This category describes the experiences of children and caregivers regarding the psycho-emotional support they received during hospitalization. It includes three subcategories: The Role of Play as Part of Psycho-emotional Support in Pediatric Palliative Care, Support Networks as a Resource in the Care Pathway, and Continuity of Psycho-emotional Support Processes for Children and Caregivers.

Subcategory 1: The Role of Play as Part of Psycho-emotional Support in Pediatric Palliative Care

From the pediatric patient's perspective, one of the most significant findings related to psycho-emotional support within the hospital setting is the importance of playful activities that promote children's emotional well-being. In this regard, three different sources of these activities were identified: the multidisciplinary palliative care team (table 4 - EC2, EP5), external organizations (table 4 - EC1), and the caregivers themselves (table 4 - EP1).

The power of play as a coping strategy is evident. Distraction becomes a protective mechanism against the stress and anxiety caused by oncological treatment, highlighting the importance of implementing activities that keep the child's mind engaged and foster emotional well-being (table 4, EP7: "When they get me to play, I forget about everything." EP4: "Sometimes I play with the other kids, and it passes.").

There is a combination of emotional support, play, recreational, and educational activities to help children cope with their hospital experience. While healthcare professionals and family members play specific and complementary roles, playful and academic activities offer an important means of escape and emotional strengthening (table 4 - EP3: "To help us with our mental health").

However, these playful strategies are usually initiated by the primary caregiver. Additionally, they are perceived as intermittent or scarce by both the children and their caregivers (table 4, EC5: "But it's very rare." EP3: "Sometimes the teachers come, but not often.").

Table 4. Participant Supporting Quotes – Subcategory: Play as Part of Psycho-emotional Support in Pediatric Palliative Care

Participant identification	Interview quotes
EP4 (9-year-old boy)	"When I'm sick, I'm not supposed to get up from my cubicle because I'm neutropenic, and I don't want to because I get bored. When I'm sad, I just hide it, and sometimes I play with the other kids, and then it goes away."
EP1 (8-year-old girl)	"I really like to draw, and my mom and I play board games when we're here. The game is called 'Penguin.' These games make me feel good, like I'm at home."
EP7 (14-year-old boy)	"Happy. I feel… I mean, sometimes when they get me to play, I forget about what I have because I like to do lots of things to forget what I'm going through."
EP3 (10-year-old girl)	"Sometimes the teachers come and give us an activity to do on a sheet of paper, and we have to solve it to help with our mental health. So, since I'm studying, sometimes I bring my notebooks here, and they bring me a worksheet."
EC5 (Mother, 36 years old)	"Here, no. Sometimes foundations come, but that's very rare. There aren't any daily activities or anything like that. If you look, the way they keep the kids distracted is with their phones, but there isn't really anything else. Sometimes the library comes, brings them books or does an activity, but that's very rare."

Subcategory 2: In-hospital Support Networks

This subcategory highlights the various sources and networks of support, including family, spiritual, and professional support.

From the pediatric patient's perspective, the mother is often seen as the primary emotional support (table 5, EP1 and EP2), especially when comfort is needed. On the other hand, healthcare professionals (nurses and doctors) are recognized as being primarily responsible for pain relief (table 5, EC2). Nurses, in particular, play a crucial role as they can identify situations in which the child and caregiver require psycho-emotional support (table 5, EP50, and EC10), although their approach can sometimes be limited. Spiritual support is closely linked to religious beliefs, providing an additional layer of comfort for some caregivers and patients (table 5, EC12).

Table 5. Participant Supporting Quotes – Subcategory: In-hospital Support Networks

Participant identification	Interview quotes
EP2 (15-year-old girl)	"I know my mom can help me with things like giving me a hug or when I feel like crying, and when it's pain, the nurses or doctors help with that."
EP5 (15-year-old boy)	"When the nurses see that I'm feeling down, they talk to me. They tell me to stay cheerful, that this is going to be a long treatment, but I also need to do my part to get better."
EC12 (Mother, 44 years old)	"His psychologist is God."
EC2 (Father, 45 years old)	"The psychologists come, the therapists come, and they start asking questions. One therapist, a psychologist, told me that if I ever felt bad, I should call her and she'd come. So, I feel like they're really concerned about this."
EC10 (Mother, 40 years old)	"Sometimes, when he's really sick or no one else is around, they (the nurses) see me crying and give me a hug, but other than that, not really."

DISCUSSION

This study explored the in-hospital experiences and perceptions of both pediatric oncology patients and their caregivers, who are primarily the children's parents, regarding two key aspects of palliative care: the education and information received, and the psycho-emotional support provided.

The results concerning the sociodemographic and pathological profile of the participants show that lymphohematopoietic cancer is the most common neoplasm in this pediatric population,(14) consistent with an epidemiological study conducted in Colombia, which reported that between 2013 and 2015, leukemias were the leading type of childhood cancer(15).

The role of the pediatric oncology patient's caregiver continues to be predominantly performed by women, particularly mothers. This finding reaffirms the conclusions of Montalvo(16) who found that caregiving for children with cancer is largely feminized, with mothers serving as the primary caregivers.

The first category, Biomedical Perception of Education in Children with Cancer, highlights that the educational processes provided to pediatric oncology patients focus on promoting self-care actions related to nutrition, medical device management, infection prevention, and recognition of warning signs. This biomedical approach aligns with the essential topics identified in standardized education checklists for pediatric oncology patients,(17) which include education on diagnosis, specific warning signs such as fever, biosecurity measures and infection prevention, handwashing, medication administration, and central catheter care.

However, within the concept of comprehensive palliative care, it is essential to inform and educate children and their families about the psycho-emotional aspects of the illness and its treatment. Participants' narratives indicate that this dimension is not addressed in the educational processes currently in place.

According to Sigurdardottir et al,(18) who evaluated the impact of an educational intervention on the quality of life of children with cancer, it is crucial to strengthen psycho-emotional aspects, such as providing information about psychosocial support and educating families on how to manage anxiety and cope with the challenges of raising a child with cancer.

Rodgers et al,(19) recommended that newly diagnosed pediatric cancer patients and their families receive psychosocial information covering topics such as adaptation, interaction and communication with friends and family, returning to school or studies, and planning for future career or educational goals. Furthermore, standardizing education for pediatric oncology patients should include addressing immediate psychosocial needs with a professional in the field.(20)

The category of In-hospital Psycho-emotional Support Strategies shows that psycho-emotional support is perceived by hospitalized pediatric oncology patients primarily through playful and educational activities organized by the interdisciplinary palliative care team.

Hospital pedagogy aims to mitigate and compensate for the effects of illness on children and their family environment, counteracting the impact of being in a hostile and unfamiliar setting, such as an oncology ward. Additionally, it affirms the child's right to continue their education, which is considered a form of care that contributes to building empathy between healthcare professionals—especially nurses—and the patients, fostering trust, and humanizing pediatric oncology care.(21)

Cantor(5) noted in their study of hospitalized pediatric patients that play, and recreational activities help identify children's priorities, which are primarily related to mood and the need for interaction with their caregivers.

However, these interventions need to be continuous and frequent, adjusted to the child's needs, age, and length of hospital stay, which is often prolonged, to have a greater impact on quality of life and provide adequate psycho-emotional support for the child. Regarding the psycho-emotional support perceived by caregivers, maintaining consistent contact with the interdisciplinary team strengthens the bond, trust, and communication between hospitalized children, their caregivers, and the healthcare team, resulting in higher-quality care.

Pediatric patients with oncological diagnoses, and children with chronic and life-threatening diseases in general, face numerous challenges that can negatively affect their mental health, leading to symptoms of anxiety, depression, and behavioral issues. These challenges pose a risk to both recovery and quality of life. It is therefore essential that healthcare services provide a welcoming environment where children and their families can freely express their anxieties, uncertainties, and fears in a safe setting that fosters individualized and humanized care.(22) Strategies must also be in place to encourage communication and the expression of emotions, concerns, fears, and needs, tailored to the child's stage of development.

Educational interventions and psycho-emotional support are relevant and have a positive impact on nursing care. According to Tovar & Cacante Caballero,(23) educational strategies are among the tools that nursing professionals use to exercise their role in the shared governance of care, establishing credibility in oncology care services. However, it is important to recognize that these processes require time and dedicated attention from nursing professionals to be effective. Parents have identified their need for communication and support from nurses, and nurses can enhance care by addressing parents' needs through supportive listening and promoting self-care.

CONCLUSIONS

This study has made it possible to highlight the importance of educational processes and psycho-emotional support for pediatric palliative care patients, recognizing that educational processes are fundamental to the care and quality of life of both the child and their caregiver. However, the disease, its treatment, and the required care impact all dimensions of human experience, making it essential that educational processes address all dimensions, particularly the psychosocial aspects that play a critical role in the health-illness-well-being continuum.

Children's and carers' perceptions of palliative care education tend to focus on the physical, technical and preventive aspects of the disease and its treatment. The educational content focuses on explaining the biological workings of cancer and medical procedures, leaving the emotional and psychological dimension associated with the experience of illness in the background. Although this biomedical perspective is understandable in terms of clinical care, its predominance limits a comprehensive understanding of the children's experience, as it does not sufficiently consider the emotional, affective and existential needs that arise during the disease process.

Children's and carers' perceptions of psycho-emotional support in palliative care highlight play as an essential tool for children's emotional wellbeing, acting as an escape from pain and anxiety, although its implementation is sporadic and often falls to carers. The support networks - family, professional and spiritual - play complementary roles, with the mother being the main emotional support figure and the health professionals responsible for physical relief. However, this support is rarely articulated as part of a comprehensive and sustained plan. These findings underline the need to strengthen institutional strategies that guarantee the continuity and systematisation of emotional support, integrating the playful, affective and spiritual as fundamental components of paediatric care.

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AUTHORSHIP CONTRIBUTION

Conceptualization: Adriana Marcela Monroy.

Data curation: Adriana Marcela Monroy, Karin Perdomo Núñez, Alexander Casallas Vega, Mildred Guarnizo Tole.

Formal analysis: Adriana Marcela Monroy, Nathalya Casallas Hernández, Karin Perdomo Núñez.

Research: Adriana Marcela Monroy, Nathalya Casallas Hernández, Karin Perdomo Núñez.

Methodology: Adriana Marcela Monroy, Alexander Casallas Vega, Jeisson Hincapié Carvajal.

Project management: Adriana Marcela Monroy, Alexander Casallas Vega.

Software: Alexander Casallas Vega.

Supervisión: Adriana Marcela Monroy.

Validation: Kevin Julian Aya Roa, Mildred Guarnizo Tole, Jeisson Hincapié Carvajal.

Display: Mildred Guarnizo Tole, Jeisson Hincapié Carvajal.

Drafting - original draft: Adriana Marcela Monroy, Karin Perdomo Núñez.

Writing - proofreading and editing: Adriana Marcela Monroy, Alexander Casallas Vega, Kevin Julian Aya Roa, Mildred Guarnizo Tole.