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The routine and mental health of hospitalized children with cancer: family perspectives

La rutina de los niños hospitalizados con cáncer y su salud mental: perspectivas familiares

The routine of hospitalized children with cancer and their mental health: family perspective

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ABSTRACT

Objective: To understand the routine and implications on the mental health of hospitalized children with cancer, from the perspective of family members.

Method: Qualitative research, carried out with 11 relatives of children hospitalized in an oncopediatric inpatient unit, during the month of September 2022. The information was produced through semi-structured interviews and was analyzed according to Minayo's Thematic Analysis, emerging two categories: "The child's routine during hospitalization" and "The child's mental health during hospitalization".

Results: In the child's routine, participants noticed changes caused by the hospital environment that do not coincide with family dynamics. However, the presence of the multidisciplinary team mitigates the strangeness experienced in this process. Regarding mental health, the feelings experienced by these children included anger, longing, and sadness, resulting in behaviors such as discouragement and aggression. These repercussions are associated with the child's confused understanding of their illness.

Final Considerations: The perspectives of family members contributed for a reflection on the health and illness process of pediatric patients undergoing cancer treatments, as they play an essential role in care, closely monitoring everything that comes to pass in the daily lives of these children in the hospital environment.

Descriptors: Mental Health. Pediatrics. Medical Oncology. Pediatric Nursing. Child Care.

RESUMO

Objetivo: Compreender a rotina e as implicações à saúde mental de crianças com câncer hospitalizadas, na perspectiva dos familiares.

Método: Pesquisa qualitativa, realizada com 11 familiares de crianças hospitalizadas em uma unidade de internação oncopediátrica, durante o mês de setembro de 2022. Os dados foram produzidos por meio de entrevistas semiestruturadas e analisados conforme Análise Temática de Minayo. Emergiram duas categorias: "A rotina da criança durante a hospitalização" e "A saúde mental da criança durante a hospitalização".

Resultados: Na rotina da criança, os participantes perceberam mudanças provocadas pelo ambiente hospitalar que não coincidem com a dinâmica familiar, no entanto, a presença da equipe multiprofissional atenua o estranhamento vivenciado nesse processo. Em relação à saúde mental, entre os sentimentos experienciados pelas crianças surgiram raiva, saudade e tristeza, repercutindo em comportamentos como desânimo e agressividade. Essas repercussões possuem interface com o entendimento confuso da criança sobre a sua doença.

Considerações Finais: As perspectivas dos familiares contribuíram para a reflexão sobre o processo de saúde e doença de pacientes pediátricos em tratamento oncológico, em virtude dos mesmos desempenharem um papel essencial no cuidado, acompanhando de perto tudo aquilo que emerge no dia a dia dessas crianças no ambiente hospitalar.

Descritores: Saúde Mental. Pediatria. Oncologia. Enfermagem Pediátrica. Cuidado da Criança.

RESUMEN

Objetivo: Comprender la rutina y las implicaciones para la salud mental de los niños hospitalizados con cáncer, desde la perspectiva de los familiares.

Método: Investigación cualitativa, realizada con 11 familiares de niños hospitalizados en una unidad de internación oncopediatrica, en el mes de septiembre de 2022. Los datos fueron producidos a través de entrevistas semiestructuradas y analizados según el Análisis Temático de Minayo, surgiendo dos categorías: "La rutina del niño durante la hospitalización" y "La salud mental del niño durante la hospitalización".

Resultados: En la rutina del niño, los participantes notaron cambios provocados por el ambiente hospitalario que no coinciden con la dinámica familiar. Sin embargo, la presencia del equipo multidisciplinario mitiga la extrañeza vivida en este proceso. En relación con la salud mental, los sentimientos experimentados por los niños incluyeron ira, añoranza y tristeza, resultando en conductas como el desánimo y la agresión. Estas repercusiones interactúan con la comprensión confusa que tiene el niño de su enfermedad.

Consideraciones finales: Las perspectivas de los familiares contribuyeron para una reflexión sobre el proceso de salud y enfermedad de los pacientes pediátricos en tratamiento oncológico, ya que ellos tienen un papel esencial en el cuidado, acompañando de cerca todo lo que emerge en el cotidiano de estos niños en el ambiente hospitalario.

Descriptores: Salud Mental. Pediatría. Oncología Médica. Enfermería Pediátrica. Cuidado del Niño.

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INTRODUCTION

Childhood cancer is a group of diseases that emerge from the uncontrolled proliferation of abnormal cells. It can take place in any part of the body and usually affects blood cells and supporting tissues. The most common tumors in childhood and adolescence are leukemias, tumors in the central nervous system, lymphomas, neuroblastomas, and retinoblastomas[1].

Nearly 10% of childhood cancer cases are related to previous genetic and hereditary abnormalities. Although, in Brazil, it is the leading cause of death by disease in children and adolescents (8%), the progress in the treatment of childhood cancer has been significant in the last four decades, and currently, 80% of children with cancer can be cured[1].

Child hospitalization is usually necessary, as it is impossible to continue care out of this environment. This, in turn, means that the child is removed from their routine and support networks. This situation can cause fear, insecurity, and lack of trust on the part of the child. These characteristics can be observed in behavioral changes, such as crying and distressed behavior, leading to discomfort and stress in the child and their family[2].

When a child is hospitalized, they are removed from their routine and exposed to physical and emotional suffering. They have to deal with new experiences, including exams, medications, consultations and invasive procedures, resulting in physical weakness and passivity in face of their illness[3].

Considering this delicate moment, the multiprofessional team must be mindful of the signs that a child with cancer is going through psychic suffering, regardless of the phase of the treatment. In pediatric units, the main challenge is finding and, later, dealing with emotional, affective, and mental suffering associated with stressful conditions and contexts of life, before, during, and after hospitalization[4].

The perspective of psychosocial attention in the care for children in mental suffering is one of the main strategies to make it so the pediatric clinic provides more integral care, conscious of the emotional demands of the children in this situation. There are efforts to create strategies to prevent and contain the suffering of children and adolescents who are becoming ill and being hospitalized[5], minimizing the harmful effects of this process in the child.

The family has an important role in the care to pediatric patients, following their development even in times where they are vulnerable, such as when they need hospitalization. They are the ones who notice the first signs of suffering caused by the change in routine, which is related to the stages of health-disease and to the treatment process. As a result, they become the main source of care, allies to the multiprofessional team[6].

In literature, research has discussed the mental health of relatives of children with cancer[7–10]. There are also studies that emphasize the psychiatric disorders in children who are undergoing an oncological treatment[11–13]. Nonetheless, studies that discuss routine in the hospitalization and the mental health of children diagnosed with cancer from the perspectives of family members are still necessary, as the topic needs to be explored further.

Corroborating this setting, this study was motivated by the experience of the authors in a childhood cancer hospitalization ward, in which they could observe the routines of children and their families during hospitalization. During this experience, it was found that, in the treatment of childhood cancer, there are pervasive situations and moments in the routine of the child that can corroborate or increase different types of suffering. These include having to follow too many rules, controlling time, dealing with medications side effects, undergoing invasive and painful procedures, in addition to seeing how these events affect their parents and/or guardians.

Considering the complex and multifaceted experience of childhood cancer, in addition to the subjectivity and the uncertainties about the disease, the guiding question of this study was: What is the perspective of family members concerning the routine and mental health of hospitalized children with cancer? Thus, the goal of this research was to understand the routine if children hospitalized with cancer and its implications, from the perspective of their relatives.

METHOD

This is an exploratory and descriptive qualitative research[14], guided by the Standards for Reporting Qualitative Research (SRQR) instrument[15], in order to strengthen methodological rigor.

The study was carried out in the Childhood Cancer Hospitalization Unit of a hospital in the south of Brazil. The unit had 24 beds for children and adolescents from 0 to 18 years of age who have been diagnosed with cancer. It is one of the main centers for the treatment of childhood cancer in the country.

The unit provides psychosocial support for the children and their relatives. It provides recreation specialists, psychologists, physicians, a nursing team, and social workers, who help reduce the damage of childhood cancer in all spheres of the life of the patient and their families.

Data collection took place in September 2022, through a semistructured interview in the hospital unit itself. It was carried out in a private room, respecting the privacy of the participants. Participants were invited, in an intentional sampling. The nursing team let potential participants know that they could participate in the research. The goals of the study were presented by an investigator with previous experience in qualitative research, and participants agreed to take part in the study.

The target population were the families of children who were hospitalized in the unit. The study included the relatives of children from 0 to 12 years old, who had received a conclusive diagnosis of cancer at least three months earlier, had been hospitalized for cancer treatment at least twice before, and were involved in the care of the child. This study considers that three months is a length of time significant for the emergence of changes in the child's routine, a point in time when the first changes that diagnosis and treatment cause in the family are already present.

This research did not include relatives under 18 years of age or who had difficulties with verbal communication, which would make it impossible to transcribe the recordings of the interviews. This includes relatives who communicated using the Brazilian sign language, had dyslalia, or dysarthria. These persons were identified with the help of nurses who knew about these characteristics. Eleven relatives were in accordance with inclusion criteria and participated, and the criteria of data saturation was respected.

The interview followed a script with closed questions regarding kinship degree, sociodemographic profile of participant and child, and some open questions, such as: "Tell me about the discovery of cancer for (name of the child)"; "Tell me about (name of the child)'s daily life during hospitalization"; "Tell me about (name of the child)'s mental health in regard to the disease". Interviews lasted from 10 to 25 minutes, were recorded in audio, and later transcribed in full. They were identified using the letter "F", for "family", followed by a number representing the order in which they were interviewed (F1, F2, F3,.. F11).

The transcriptions were analyzed using Minayo's Thematic Analysis[14], which has three stages: 1) Pre-analysis - all empirical material was organized and put through a comprehensive reading of all available information, the corpus was formed, and the goals of the study were brought to bear so we could choose markers able to guide the final reflection; 2) Material exploration - there was a close reading of the transcripts, and materials were grouped in previous categories to organize content, in order to understand the text. During categorization, the transcription of the interviews was reduced, data was classified, aggregated, and then, divided in categories responsible for specifying the topics; 3) Interpretation - the information found was brought forth, and used to form inferences and interpretations, associating the information with a new theoretical dimension, based on literature.

This analysis led to the creation of the following thematic categories: The routine of the child during hospitalization; and Children's mental health during hospitalization.

This study was approved by the Research Ethics Committee of the health institution that was its setting, under No. 60923722.30000.5327. Ethical principles were ensured and participants signed two copies of an Informed Consent Form, one of which stayed with the relative, while the other was kept by the researcher. This study presented minimal risks, all related to emotional integrity, discomfort, or embarrassment caused by the content of the questions.

RESULTS

The participants were eight women (72.7%) and three men (27.3%), from 20 to 53 years old. Their educational level ranged from complete elementary school to complete higher education. Regarding their relationship with the child, eight were mothers (72.7%) and three were fathers (27.3%). As for the children, seven were girls (63.6%) and four were boys (36.4%), aged from 11 months to 11 years.

The routine of the child during hospitalization

In this categories, particicpants mentioned the changes caused by this experience, and two subcategories emerged: The daily life in hospitalization, and The contact with the multiprofessional team.

The daily life of a child with cancer who has been hospitalized in a childhood cancer hospitalization unit is different from their experiences at home. Among the topics discussed by the relatives, it was found that daily life in the hospital, with many rules, was different from life at home, where the child has greater freedom.

> *At home, she doesn't have a routine, she does things whenever she wants: she wakes up when she wants, she eats when she wants, she takes a shower if she wants. Here, it's different, she has to take a shower, she has to eat, and everything on a schedule. If she doesn't eat, the food goes away and she'll get hungry. Then she thinks it's my fault. At home, it's different, I give her food when she wants, when she feels hungry.* (F1).

The fact that the environment is unfamiliar seems to have an effect as well, since the child is far from their own room and bed and wants to go home, to the environment they are used to.

> *It's hard for a child to accept that they'll sleep in the hospital and not in their bed, in their room. I noticed that in the first few days. He accepts it, because we talk to him and he's very smart. We explain that we are just coming here for him to take his medication, and then we go home, but after two days he's asking "when do I go back?", why he doesn't go back, why the others go but he doesn't, that's harsh.* (F5).

As time passes, however, some children seem to adapt to this routine and understand it as part of their lives.

> *He got used to the rhythm of having breakfast, playing, coming back, having lunch, and taking a nap. I even said I didn't know if he knew where his home is [...]. His routine has always been like this: wake up, have breakfast, take medicine, have breakfast, take another medicine, play a little, come back, have lunch, sometimes naps a bit, sometimes not, plays a bit more, take another medication, come back, have dinner, take medicine again. It's so much medicine.* (F10).

The contact with the multiprofessional team, in turn, is part of the routine of the hospitalized children. This helps mitigate the hospitalization process, since the owkrers are worried and attentive to the demands of patients. The relatives mentioned that their children like the multiprofessional team, that they feel safe around them, and form bonds that go beyond their needs for care, finding close relationships, support, and affection.

> *I think she feels comfortable here. Everyone treats her very well. I think they really care for her. She likes everyone, she doesn't fight, doesn't complain [...] I don't have a bad word to say, she was treated very well by everyone since she stepped foot in here [...] She likes the people a lot, and that, at least, distracts her. She talks a lot.* (F1).

> *It was hard, he got used even after we went through COVID, after we went to the tenth floor (pediatric COVID unit). We went there and there was no one he knew. When he came down and found the workers he had known before, the bed he had known, he felt much safer, he smiled and played with everyone. He became happier.* (F10).

The child's mental health and hospitalization

In this category, participants discussed the feelings caused by this experience. This led to the emergence of three subcategories: Feelings and behaviors of the child, How the child understands the disease, and Adverse efects of chemotherapy and of the excessive procedures.

The pediatric patient is, unavoidably, affected by the experience of cancer and hospitalization, which causes changes to their feelings and behaviors. The consequences of child hospitalizations and the repercussions of the disease can cause anger, sadness, irritability, stress, preoccupation, insecurity, and longing. As a way to express themselves, and as a consequence of these feelings, the parents noticed behavioral changes in the children, who became more despondent and aggressive. This was put into words in the following statements.

> *She's not very energetic here. She keeps quiet, keeps to herself, I don't know if she feels strange, but she isn't very well here, I noticed that many times. It's different because she's not comfortable here, so she's on the phone all the time, looking at the TV, sleeping, she doesn't even like going to the play area that much.* (F9).

> *I noticed my daughter changed a lot. She's still happy, but she's a bit more aggressive, more stressed [...] I know that she was really psychologically affected when we were at the PICU. I think she'll never forget this, she'll remember everything. She says she doesn't want to go back there [...] She used to miss it so, so much.* (F4).

> *She could stand staying here a week, ten days maybe, but more than that and she'd get mad. The longer she stays, the more nervous she gets, she starts scratching herself, hurting herself. That's when the doctors started giving her anxiety medication [...] Because she's locked in here all the time and can't do nothing "I can't do anything", that's all she says "I can't do anything, I don't want to stay here, I want to go away".* (F1).

From the perspective of participants, the understanding the children with cancer have of their disease is confusing and varied. Pediatric patients see the hospital as a new environment, they do not understand that the hospitalization is the result of a disease that they also cannot understand.

> *She didn't understand much. For her, being here in the hospital was new, because she had never been hospitalized before she was diagnosed with cancer. She couldn't*

understand what she had, and I hadn't explained it to her, until the psychologist told me "talk to her, explain why she's here, why she's doing this", then I had to tell her that her belly was not ok, and now she understands, but she didn't before that. (F9).

The parents were afraid of explaining the disease and how serious it was to their children. However, preoccupation with the seriousness of the disease did not seem to worry the babies and older children as it does their relatives, as they do not understand the actual severity of the disease.

He couldn't really know because of his age. We found out when he was about three months old. He was still discovering the world, I think he's still discovering the world [...] He doesn't understand what's going on around him yet.(F3)

Actually, I never explained it to her. I just explained that her hair would fall and she'd have to take some injections [...] I think she dealt with the situation better than I did, I thought she'd be worse, but she isn't. (F4).

Parents reported how strongly the treatment and the procedures interfere in the mental health of their children, leading to uncomfortable changes in the child undergoing antineoplastic treatment and leaving them more debilitated and despondent.

When she knows she'll come here, she starts "no mom, I don't want to go, you go, they'll prick my chest, and here in my arm". This is necessary, if it wasn't I wouldn't bring here, but since she needs it I have to bring her. (F4).

What gets him the saddest is how uncomfortable the effects of the chemo are, when he's lacking appetite, which happens often. After chemo, he feels very unconfortable from the colic. (F3).

He got angrier. He's agitated, but he used to be more affectionate. Now, whenever he has to undergo a procedure or something, he gets nervous with me after it [...] in his mind, he's all right there in his home, and then his mother takes him alway where people hurt him, that's why they get angry at their mothers. With the others he's OK, but not with me, because whenever he does something he's looking at me right, I'm always holding him, so I think that affects the child a lot.(F7)

The statements of the participants showed that the children had a negative perception regarding the invasive procedures, especially those involving needles. The pediatric patients are afraid of these interventions, and become more irritable. For some mothers, their children seem to believe that they give permission for the child to be held and hurt, something completely opposed to the usual understanding of this caregiver as someone who will protect the child.

DISCUSSION

In the field of mental health, working with a person's routine is an important aspect of humanized, integral care, as it involves actions that can recognize the value of their lives. For that to happen, changes caused by a disease and their repercussions encourage health workers to rethink the spaces of care that can help build and attribute new meanings to these routines.

Regarding the daily life of hospitalized patients, previous research corroborate our findings, according to which the hospitalization of the child triggers changes in their lives and, sometimes, their routine may be underappreciated. Hospital routine is part of dealing with the disease for the child, since adapting to a new environment is challenging[16]. Therefore, the change in the environment and the hospitalization routine are factors that generate anxiety in this population. It represents the separation of the child's support systems, which is clear due to their stress and the desire to go back home[17–18].

Children with complex chronic diseases have an intense care routine.CT 42 Daily life of hospitalized children includes several activities, such as hygiene, eating, drug administration, procedures, clinical care, play, and rest. It stands out that, in most cases, treatment-related care demands more attention than play and social activities[19], not because they require more time, but because of how complex these processes are.

Considering the need for treatment in specialized centers, the family is in a fragile state, as they are directly involved in the daily treatment of their relative[7]. Some difficulties in caring for a child with cancer are related to the process of adaptation to their social reality, in order to cure the child and ensure their wellbeing[8].

After numerous long hospitalizations, the child can internalize the hospitalization routine, learning the routine and the professionals that are part of it. This involves daily experiences and repetition, which the patient goes through in

their long hospitalization periods. Thus, they get acquainted with the objects, people, and interventions there, epxloring and recognizing themselves in this group[19].

As for contact with the multiprofessional team, literature mentions that, during hospitalization, relatives generally see bonds being formed with the health team as an important aspect of the treatment and follow up care[20]. Furthermore, the emotions of the child are affected, and the help and understanding become essential, enabling the creation of a context of care and participatory decision-making[21]. Therefore, health workers must provide care in a welcoming and sensitive posture, favoring the approximation of the child, so bonds can be formed.

This movement allows establishing relationships of trust, which can facilitate care directed to the specific needs of each child, while it calls professionals to develop care that involves the child with tools such as touch, listening, sensitivity, and an attentive look to the expressions of psychic suffering and their repercussions[21].

Raising the awareness of health worker to the uniqueness of each child establishes not only superficially harmonious relationships, but an effective communication that can help the hospitalization of all those involved. Regarding nursing, authentic care, one that shows respect, attention, zeal, and affection is an experience involving genuine exchanges, strengthening the bond of trust between pediatric patient and health worker[22].

The management of the mental health of these children by the multiprofessional team is varied, and can be developed considering that which is imposed and the priorities of the patient at each stage. It must be understood that each meeting with the subject is unique[23].

Developing coping strategies, helping the child to understand and control their feelings, mediating family conflict, guiding the treatment and promoting their lives, these are actions of care that can be carried out for children with cancer[23].

Professional activities to deal with the mental health of children with cancer must follow ethical guidelines, applying technical procedures with empathy, in a humane way, associated with active listening and caring for any complaints. The life stories of each individual must be considered when dealing with their mental health, as well as their beliefs and limitations[23].

To do so, the emotional, physical, and spiritual specificities of these children must be considered in their care, treatment, and follow up. The pediatric patient must receive integral care, according with their particularities. This includes understanding and caring for their anxieties to help their adaptation to the new context of their lives, the environment, and the assistance.

Regarding the feelings and behaviors of the child, research corroborates our findings, according to which the child with cancer feels fear, pain, and anxiety, which in turn trigger changes in the child[9]. Cancer is a life-threatening disease, and pediatric patients associated it with negative feelings. Each subject experiences the disease in their own unique way, but in general, uncertainties and insecurities are pervasive, as their suffering is unexpected, often incomprehensible[22].

As a result, the hospital environment is riddled with ambivalent feelings. This can be a place that enables cure, but can also be controlling, aggressive, and unwanted. When a child is hospitalized, they are removed from their routine and exposed to physical and emotional suffering. They have to deal with new experiences, including exams, medications, consultations and invasive procedures, resulting in physical weakness and passivity in face of their illness[3].

Considering these aspects, identifying mental issues early in children with cancer is essential to reduce the negative effects of their disease. These can have a long term impact, as child cancer survivors have a high risk of developing anxiety and depression, even years after being cured[11].

Regarding how well the child understands their own illness, literature agrees with our results, suggesting that children often do not understand how serious their disease is, and, consequently, why it is necessary for them to be hospitalized and undergo the treatment. As these patients do not know the factors involving their cancer and hospitalization, they are more vulnerable during the process[24].

Even though the child is not always able to understand what is happening, they feel the changes in their bodies, and depending on the age group, they understand that the hospitalization is necessary for their symptoms to get better. When asked directly about their disease, these patients, within their limitations, explain it in a rational and direct way, formulating their diagnoses, justifying their hospitalization, and, thus, showing a better understanding of their health than is generally assumed[24].

The child tries to understand their condition and the space where they are, while trying to deal with uncertainties about the future. The conversation with these patients must consider their ability to understand what is happening. However, their understanding of the pathology can be affected by factors such as: cognitive capacity, age, emotion, affection, as well as familiar, social, and cultural contexts[25]. Thus, the knowledge of these patients should not be underestimated. It is, however, necessary to have conversations

with them about health, disease, and death, not only when they are hospitalized, but in all stages and environments of their lives[24].

When addressing these topics, one must use language accessible to these individuals, preferably involving some form of play. It is important to talk to the child about issues relative to their disease, in addition to reflections and explanations about the moment they are going through[25].

Literature suggests, agreeing with our results, that the adverse effects of chemotherapy and the excessive number of invasive procedures are among the main stressors for the pediatric population[26]. Peripheral venous punctures, for example, causes fear, insecurity, anxiety, and feelings that their privacy is being invaded. It is a moment that causes physical pain, which is made worse by the fact there are many interventions[27].

Pain, in general, is expressed in a particular, individual way. In pediatrics, the perception of the child about their pain is formed by the experiences they have gone through in the past, which have repercussions in the present[28].

It is, then, important for the multiprofessional team to consider their approach to painful procedures, guiding them in such a way as to relieve the suffering caused in this moment. In this regard, the professional may guide the pediatric patient, and walk them through what is about to happen, in order to relieve their fear using language and other strategies, taking into account their age group and cognitive level[27].

Furthermore, the pediatric antineoplastic chemotherapy treatment has adverse effects that can be managed by the nursing team, considering a less traumatic follow up for the child through the control and relief of their symptoms, and, consequently, of their physical and mental suffering[27].

The hospitalized child develops feelings of guilt, of being punished, and their psychological and cognitive development may even regress. These patients try to use their body to compensate for their inability to use words, making it into their language by resorting to behaviors and attitudes[3].

Due to the chemotherapy treatment, some children may have trouble with social interactions, bad moods, irritability, crying spells and psychomotor agitation[12–13]. Additionally, body image issues may play an important role in the suffering of children with cancer, due to the hair loss associated with some chemotherapy drugs[26].

Living with childhood cancer brings important repercussions and meanings to the life and routine of these children, since they are undergoing physical, cognitive, and psychosocial development. Health workers have an important role in supporting and giving strength to families and children, forming a support network that is present, specialized, and able to identify the actual needs of care, including mental health demands.

Therefore, the parents must be equipped to talk to their children about the disease, adapting their language to each stage of the child's development. Furthermore, a multiprofessional team must be able to aid in the identification of feelings that require psychosocial attention. This is especially true for nurses, as they are the professionals who spend the most time at the bedside.

FINAL CONSIDERATIONS

This study investigated the routine and mental health of children hospitalized due to cancer, from the perspective of their relatives. This can contribute to improve sensitive and comprehensive health .

From the perspective of these relatives, we could understand what the routine in the hospital is challenging for a child with cancer. These challenges can be mitigated by affective and welcoming professionals, who can give the pediatric patients feelings of comfort and wellbeing. Furthermore, regarding mental health, the child experienced feelings they had not felt before and, as a result, presented behavioral changes, owing to the fact they will have to relate to the world and understand it differently after being diagnosed and treated.

This study gained relevance as it got close to the subjective universe of the child through the parents. The choice to interview family members allowed accessing their perceptions from the very core of their experiences as the main caregivers of these children undergoing cancer treatments.

Limitations of this study included the fact that only one relative of each child participated, as this could lead to different perspectives being provided in a single family nucleus and context. This would not be possible due to the logistics of our research.

It became clear that it is necessary to include the family as a partner in this trajectory, considering the different spheres of a routine riddled with challenges that reverberate on the child's mental health. This study may also allow workers from the multiprofessional health team to overcome practices based on the biomedical model of care, in which the focus is still the disease and the diagnosis.

Therefore, this research contribute for a reflection on the health-disease process from the perspective of pediatric patients undergoing cancer treatments, and can help improving the quality of the health care provided.

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