

EXPERIENCE OF MOTHERS OF PEDIATRIC PATIENTS UNDERGOING CANCER TREATMENT

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ABSTRACT

Introduction: Children diagnosed with neoplasms face drastic changes in their life routine. Continuous care for cancer patients requires years of assistance, and a family member is often assigned the responsibility of caring during treatment, dispensing his or her life for the benefit of the patient, resulting in depersonalization. Studies indicate that the female sex plays this crucial role, in most cases, which results in greater wear and overload. **Objective:** To understand the experience of mothers of children during cancer treatment.

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Methodology: This is a cross-sectional, descriptive study with a qualitative design, carried out in the Pediatric Oncology Units of a maternal and child teaching hospital in a city in the interior of the state of São Paulo, Brazil. 10 mothers of patients who had been undergoing cancer treatment for at least six months and who represented the main care throughout the treatment were invited to participate in the study. Two instruments were used, a sociodemographic questionnaire and a semi-structured questionnaire. Results: A total of 10 mothers were eligible for the study, with a mean age of 35.2 years, with a standard deviation of approximately 4.64, and most of them reported being married (60%). Regarding education, half of the sample (50%) had completed high school and the other half (50%) had completed higher education. With regard to religion, Catholic (40%) and Evangelical (40%) stood out and (90%) reported receiving more than one minimum wage. There was a predominance of mothers who reported working (80%) and the average number of children was two. Regarding the characterization of the patients, the mean age was 5.1 years, with a standard deviation of 3.47, being the same amount of sample for females and males (50%), with 100% diagnosed with Acute Lymphoblastic Leukemia and mean treatment time of thirteen months. The units of meaning identified and discriminated were "the emotional impact of the illness", "the structural changes in the face of cancer treatment", "the main challenges perceived during the treatment" and "being a mother in a scenario of illness". Conclusion: The results point to the description of the maternal experience throughout the oncological treatment of a child, contemplating the emotional and structural aspects, main challenges and analysis of the maternal role. The importance of adequate emotional support and social support for coping with the experience is understood.

Keywords: Oncology. Perception. Mothers.



INTRODUCTION

Paediatric oncology is an area in constant advancement, whose objective is not only to cure, but also to ensure the best possible quality of life and minimize side effects for patients (MELARAGNO & CAMARGO, 2013).

Oncological treatments involve several modalities, such as surgery, chemotherapy, radiotherapy, and bone marrow transplantation. These procedures are often long, painful, and invasive, resulting in side effects that profoundly impact the child's life (NATIONAL CANCER INSTITUTE - INCA, 2020).

In addition to the physical pain caused by the treatment, the children's routine undergoes profound changes. Activities that were previously part of their daily lives, such as attending school, are replaced by frequent visits to the hospital, which directly impacts their development and well-being (MARCON *et al.*, 2020).

The psychological impact is also significant, as children face restrictions and losses, such as separation from friends, school, family, in addition to limitations in recreational activities. These changes can cause feelings of frustration and sadness, making it even more difficult to cope with the disease (FONSECA, *et al.*, 2021).

The treatment of chronic disease, such as cancer, can extend for years, requiring constant assistance. In this context, it is common for a family member, mostly the mother, to take on the responsibility of caring for the patient, often sacrificing their personal life for the child's well-being. This process can lead to depersonalization, in which the caregiver cancels himself out and focuses exclusively on the patient's physical needs (ARAÚJO, 2020).

As a result, the caregiver can deprive themselves of their daily family life, in addition to sacrificing their leisure time, social life, and even their personal identity, since they perceive themselves solely as the father or mother of a child with cancer (PINHEIRO, 2019).

These changes can result in a loss of subjectivity and disinterest in anything that is not directly related to your child's treatment. Consequently, this contributes to an emotional overload and significant stress, affecting the family's well-being during the child's hospitalization (PINHEIRO, 2019).

Studies show that, in most cases, women assume the primary responsibility for the daily care of the child, which imposes a great emotional and physical burden on them. In addition, mothers are often also responsible for other household chores, which increases the level of stress (OLIVEIRA, 2021).



A child's cancer diagnosis represents a terrifying experience for the mother. She is taken by uncertainty and fear of loss, in addition to worrying about her ability to continue taking care of the child autonomously. The changes in daily life, caused by the treatment, trigger internal conflicts and strengthen feelings of powerlessness, physical and mental exhaustion (SILVA, 2024).

Even after treatment ends, the psychological damage faced by mothers can persist for a long time. Studies indicate that mothers of children with cancer are more likely to develop psychological disorders, such as depression and anxiety, due to fear of loss, uncertainties about the effectiveness of treatment, and drastic changes in family and social routine. Therefore, it is essential that the psychological care of mothers be considered as part of the treatment of a chronic disease (ENDRES, *et al.*, 2021). Therefore, the objective of the present study is to understand the experience of mothers during the treatment of their children in the Pediatric Oncology Units, highlighting the emotional challenges and psychological repercussions of this experience.

METHODOLOGY

STUDY DESIGN AND LOCATION

This is a cross-sectional, descriptive study with a qualitative design carried out in the Pediatric Oncology Units (outpatient clinic and ward) in a maternal and child teaching hospital in the interior of the state of São Paulo.

PARTICIPANTS

10 mothers of patients who had been undergoing cancer treatment for at least six months and who represented the main care throughout the treatment were invited to participate in the study.

INCLUSION AND EXCLUSION CRITERIA

The present study included mothers of patients who had been on treatment for at least six months and who represented the main care throughout the treatment.

Mothers who had cognitive and/or emotional difficulties that prevented them from understanding the instructions given or needed third parties to answer the questionnaires were excluded from the present study.

INSTRUMENTS



Sociodemographic Questionnaire: developed by the researcher, in order to identify the sociodemographic characteristics of the sample studied, such as initials of the guardian, age, education, marital status, religion, profession, current work, family income, has how many children, initials of the child under treatment, age, diagnosis and time of treatment.

Semi-structured interview: a questionnaire was developed by the researcher with the following questions: "What are the main changes in your life after the diagnosis?"; "What are the main emotions aroused throughout your child's cancer treatment?" "What is being most challenging during treatment?"; "Can you identify losses in your life after your child's diagnosis?" "What does the experience of being a mother of a child undergoing cancer treatment mean to you?"

The verbalization was recorded in an app located in a secure folder on a phone device, protected by a password to ensure the confidentiality of the data. In addition, to protect the identity of the participants, their names were omitted from the transcript, and indicated as M1, M2, M3, following successively.

ETHICAL ASPECTS

The research project and the Informed Consent Registry were approved by the Research Ethics Committee, under opinion No. 7.014.571 (CAAE: 80897224.6.0000.5415).

PROCEDURES

Data collection took place from July to September 2024. The sample was recruited by convenience, described in the procedure below, considering the ethical aspects. The research was initiated after the project was approved by the Research Ethics Committee. An analysis of the medical records was performed to evaluate the inclusion and exclusion criteria and the sample was selected by convenience.

The mothers were approached in the outpatient waiting room or in the ward and invited to participate in the research. Then, they were directed to a place reserved individually. After reading and signing the Informed Consent Record, the interview began.

The interviews were audio-recorded, starting with the application of the sociodemographic questionnaire, followed by the semi-structured interview, which was transcribed in full, and after this period they were excluded in order to safeguard the confidentiality of the answers. Next, the answers related to the experience of mothers of patients undergoing cancer treatment were analyzed for later data comparison.



DATA ANALYSIS

The interviews were submitted following the content analysis method proposed by Bardin (1977/2010). In this context, content analysis can be understood as the integration of methodological instruments that have controlled interpretation, aiming to enrich the information of the message and overcome uncertainties. This method seeks to unite quantitative and qualitative indicators, oscillating between the rigor of objectivity with the informative richness of subjectivity. (CASTRO, *et al.*, 2011). Thus, thematic categories were constructed according to the answers obtained for later comparison with the data present in the literature.

RESULTS AND DISCUSSION

The present study was composed of a sample of ten mothers of children undergoing cancer treatment in the Pediatric Oncology Units, highlighting the emotional challenges and psychological repercussions of this experience. The sociodemographic data of the participants will be presented in Table 1 and Table 2. The characterization of the patients containing gender, age, diagnosis and treatment time, presented in Table 3. Subsequently, the units of meanings will be presented in Table 4, which were grouped into four categories:

- 1. The emotional impact of the illness; 2. Structural changes in the face of cancer treatment;
- 3. The main challenges perceived throughout the treatment and 4. Being a mother in a scenario of illness.

Table 1. Characterization of the mothers' sociodemographic data (N=10)

Participants		A	ge	Marital status		S	chooling		
	N	I.M	D.P		N	%		N	%
Mothers	10	35,2	4,64	Married woman	6	60	E.M.C	5	50
-	-	-	-	Single	2	20	E.S.C	5	50
-	-	-	-	Divorced	1	10	-	-	-
-	-	-	-	Stable Union	1	10	-	-	-

Note: N. – Sample number; I.M – Middle Ages; D.V – Standard Deviation; E.M.C – Complete High School; E.S.C – Complete Higher Education.

The analysis of the sociodemographic profile of the sample revealed a mean age of 35.2 years, (± 4.64). These data corroborate the findings of Silva *et al.*, (2020), who also observed a predominance of participants in the age group of 30 to 40 years in their research on the implications of the diagnosis on the socioeconomic conditions of the families of children and adolescents with solid tumors.



Regarding marital status, most mothers reported being married 60% (N=6), which is an important source of support during treatment, as highlighted by Silva *et al.*, (2020) in their study, which also found a relationship between marital support and coping with the disease. Regarding the level of education, half of the sample 50% (N=5) had completed high school, while the other half 50% (N=5) had completed higher education. These results reflect a trend observed in Brazilian educational studies, where the proportion of individuals with higher education has increased over the years, following the growth of access to higher education in the country, according to data from IBGE (2020).

Table 2. Characterization of mothers' sociodemographic data in relation to religion, work, family income and number of children.

Religion			Work		Hous	sehold ince (salary)	ome		No. Offspring		
	N	%		N	%		N	%		N	%
Catholic	4	40	No	7	70	≤ 1	1	10	1	4	40
Evangelical	4	40	Yes	3	30	1 to 2	3	30	2	3	30
Tes. Jehovah	1	10	-			3 to 4	3	30	3	2	20
N.P	1	10	-			≥ 4	3	30	4	1	10

Note: Tes. Jehovah – Jehovah's Witness; N.P - Does not have one; N. – Sample number.

Regarding religion, it was observed that the participants were mostly Catholic 40% (N=4) and Evangelical 40% (N=4). These data are in line with the results of Carrijo *et al.*, (2022), who also identified a greater presence of these two religions in an oncology referral hospital. Another relevant fact is that many participants interrupted their professional activities to dedicate themselves fully to the care of their children. Similarly, 70% (N=7) of the mothers in this study reported not working during treatment, which corroborates the study by Sá *et al.*, (2021), where this interruption in work was identified among mothers of children with cancer. Regarding family income, 90% (N=9) of the participants reported receiving more than one minimum wage (\$1,412.00). Although income is often significantly impacted during cancer treatment due to the change in routine and the need for continuous care, however, the financial impact was not uniform among the participants. These data contrast with studies found in other studies, such as that of Sá *et al.*, (2021), which indicated that most of the sample lived on an income of less than one minimum wage.

Regarding the number of children, they identified that 40% (N=4) had only one child, 30% (N=3) had two children, 20% (N=2) had three children, and 10% (N=1) had four children. This data is consistent with a trend observed in Brazil, which has registered a drop in the fertility rate over the last decades. According to the IBGE (2020), the average number



of children per woman in Brazil is currently around 1.7, below the population replacement level, which is around 2.1 children per woman.

Table 3. Characterization of patients in relation to gender, age, diagnosis and duration of treatment.

Gender			Α	ge	Diagnosis			Treatment		
	N	%	I.M	D.P		N	%		N	%
Male	5	50	5,1	3,47	L.L.A	10	100	0 - 6 m	1	40
Female	5	50	-	-	-	-	-	7 - 12 m	4	40
-	-	-	-	-	-	-	-	13 - 18 m	4	40
-	-	-	-	-	-	-	-	≥ 18 m	1	10

Note: N. – Sample number; I.M – Middle Ages; D.V – Standard Deviation; L.L.A – Acute Lymphoblastic Leukemia; m – Months of life.

Regarding the characterization of patients undergoing cancer treatment, the mean age was 5.1 years, (± 3.47). The sample was equally distributed among genders, with 50% (N=5) of the total composed of males and 50% (N=5) of females. The only diagnosis identified in the study was Acute Lymphoblastic Leukemia (ALL), which is in agreement with the literature, considering that ALL is the main childhood neoplasm, followed by central nervous system tumors and lymphomas (INCA, 2022). The mean treatment time of the patients was approximately 13 months.

Following the objective of the present study, which sought to understand the experience of mothers during the treatment of their children, highlighting the emotional challenges and psychological repercussions of this experience, it was possible to identify the units of meanings discussed below, through the open questions.

Table 4 – Definition of the units of meaning according to the questions elaborated in the form.

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Category 1 - The emotional impact of illness					
What are the main changes in your life after diagnosis?					
What are the main emotions aroused throughout your child's cancer					
treatment?					
What is being most challenging during the treatment?					
Can you identify losses in your life after your child's diagnosis?					
Category 2 - Structural changes in the face of cancer treatment					
What are the main changes in your life after diagnosis?					
Can you identify losses in your life after your child's diagnosis?					
Category 3 - The main challenges perceived throughout the					
treatment					
What is being most challenging during the treatment?					
Can you identify losses in your life after your child's diagnosis?					
Category 4 - Being a mother in a scenario of illness					
What the experience of being a mother of a child in treatment means to					
you					
oncological?					



CATEGORY 1 - THE EMOTIONAL IMPACT OF ILLNESS

The first unit of meanings described discourses that addressed emotional changes and intensified feelings after the diagnosis, reflecting the complexity of cancer treatment, which can generate profound physical and psychological transformations.

Table 5 – Reports on the emotional impact of illness.

Change in emotional structure

M1: Emotional, the emotional has changed a lot.

M2: [...] that I stay like this, yes, let's say, yes, under pressure all day, right. As much as she's fine, you're like this, you're breathing, you're eating, you're sleeping, you know, medicine.
M10: Emotional damage. [...] If you ask me how your emotional is, your psychological, I would answer you that it is destroyed.

More intense feelings

M5: Despair is the main thing, despair. We get desperate, we are afraid all the time.
M6: Fear, anxiety, worry, a lot of worry.
M9: Anxiety, quilt, yes, sadness. I think it's a mix of feelings, right.

Childhood cancer significantly impacts the mental health of children and their families, who face physical pain, stress, and fears associated with the disease on a daily basis, negatively impacting quality of life and emotions (MORAES, 2023).

When receiving her child's oncological diagnosis, the mother often assumes the role of the main pillar of support and care. In addition to following the treatment continuously, her position as a parent intensifies the emotional experience, generating deep feelings and expectations, whether positive or negative, in relation to the evolution of the disease (SANTOS *et al.*, 2018).

During this journey, it is common for mothers to experience a wide range of intense emotions. Studies indicate that, in this context, both mothers and children face feelings such as anxiety, fear, despair, uncertainties, and emotional distress, which corroborates the findings of the present research (BEAL, *et al.*, 2022). Mothers reported experiencing constant afflictions, uncertainty, and sadness (SÁ *et al.*, 2021).

The literature also shows that the feeling of uncertainty regarding the severity of the disease, fear of the future, and anguish, frequently mentioned by the participants, accompany the patient from diagnosis to the end of treatment (SILVA et al., 2024). Another recurring feeling among mothers is guilt, which can arise as a reaction to the diagnosis, invasive treatment or the child's suffering. The study by Assumpção (2022) highlights that this guilt is often related to the sadness caused by the limitations imposed by the disease, the associated losses, and the unpredictable nature of the illness, deepening emotional suffering.



These feelings significantly transform the emotional structure of mothers. In line with these findings, the research by Ponte *et al.*, (2020) describes the psychological impact of the oncological diagnosis, which profoundly shakes the emotional balance of families. In addition, the diagnosis of cancer often raises awareness of the possibility of death, which intensifies feelings of frustration, sadness, and suffering among mothers (MAZER-GONÇALVES *et al.*, 2016).

In view of the above, the presence of a support network, including family, friends, spirituality, and health professionals, is essential to help mothers cope with the disease and maintain their mental health (BLANC *et al.*, 2021).

CATEGORY 2 - STRUCTURAL CHANGES IN THE FACE OF CANCER TREATMENT

In this category, it was possible to identify the depersonalization of the mothers, projects that could not be fulfilled and changes in the routine, since cancer treatment can impose different modifications that require a reorganization of the family dynamics in its daily activities and plans in favor of the patient's care.

Table 6 – Structural changes in the face of cancer treatment.

Changes in different contexts

M2: Everything, everything changed. Since, yes, professional, personal, family, financial, everything has changed. Everything, everything, everything.

M3: I think it was staying more on top of him, right, not going out so much, that we don't even like to go out a lot, stay more at home, more reserved, more careful, much more careful.

M9: It has totally changed, it has changed routine, it has changed food, it has changed that we can't really leave the house, you know, to preserve it. It changed that I left work, so everything changed.

M10: First it was, we were more deprived, you know, less contact with people, less partying, yes, we used to go to the mall and we also stopped, birthday parties, we had to stop school.

Changes to idealized projects

M2: [...] And there were other things that we wanted to do too, that changed everything, everything, everything.

M5: Everything I planned, that was going to be was not materialized, you know. Our concern is that she starts going to school, learning to read, learning to write and now my concern is just to keep her alive.

Depersonalization

M6: I live, you know, I lived and I live only for him. My life itself has no leisure area, a hobby, it's practically indoors.

M7: We changed everything. Thus, we dedicate ourselves totally to it and end up forgetting about ourselves a little. The main focus is her.

The testimonies demonstrate that the experiences in cancer treatment transcend the discovery of the diagnosis, advancing through the family, social and professional nuclei, altering routines and implying changes that reverberate in different aspects of the lives of all those involved, a fact that corroborates the research of Rossato *et al.*, (2021), when it is said that cancer is a remarkable event that causes disruptions in development, resulting in



profound physical, cognitive, and psychosocial implications, modifying daily activities and impacting relationships.

Regarding the core meaning of the changes, the mothers reported changes in their affective and social networks, including distancing from friends and family. The literature points out that, in the search to adapt to the new reality imposed by the diagnosis, social and family dynamics are often redefined, with roles and priorities being restructured (BOMFIM, *et al.*, 2021).

The results also indicated that mothers stay at home longer and care for their children, leading to the renunciation of activities such as parties, outings, religious practices, and even the interruption of school life, all with the aim of minimizing the risks to the health of immunocompromised children. These transformations reflect the adaptation necessary to ensure the patient's well-being, considering that chemotherapy drugs affect both diseased cells and healthy tissues, weakening the immune system and requiring changes in family lifestyle (SILVA et al., 2022). However, this increase in care can lead to the development of overprotective behaviors in relation to the child, considering that the constant fear of losing the child and the anxiety generated by its condition can cause parents to adopt attitudes of extreme care. Such behaviors reflect the desire to protect the child from any suffering, creating the safest possible environment in the face of the fragility and challenges imposed by cancer (CUNHA & PENSO, 2022).

Another significant change concerns the professional and financial lives of mothers. Most of the participants in this study gave up their jobs to dedicate themselves exclusively to the care of their children, which directly impacted the family income. This finding corroborates the research by Lopes *et al.*, (2024), which highlights the high demand for care as one of the main causes of the decrease or loss of income.

In addition, some mothers reported having plans and desires interrupted due to the demands of the treatment, which sparked reflections on their roles and aspirations. The outbreak of the disease symbolizes the collapse of dreams and expectations, confronting them with the unexpected and the impossible (MENDES, 2023).

Mothers also experience a process of depersonalization, in which they abdicate their needs and desires, prioritizing the care of their children. In this process, they place themselves in the background, with a focus centered on the maternal figure and the child's demands, as evidenced by the mothers' reports in the present study. In view of this, an abrupt rupture in the pre-existing dynamics of the family is observed, especially in the social life of the mothers, which is replaced by activities such as frequent visits to the hospital,



care with medication and food, in addition to periods of hospitalization of the child. Such changes can trigger feelings of suffering, despair, and other negative repercussions (SIQUEIRA, *et al.*, 2019; PAULA, *et al.*, 2019).

Pinheiro *et al.*, (2021) observed in their research that many mothers, in addition to facing a significant burden because they are primarily responsible for the care of the sick child, often put their own personal lives in the background. They end up neglecting their own needs to devote all their time and effort exclusively to their children. This full commitment to maternal care is reinforced by Oliveira *et al.*, (2024), who highlight the complete renunciation of mothers to their previous routine, who assume the role of full-time caregivers. This care is not perceived by the participants as a loss, even if it implies neglecting their own physical and psychological needs, as well as renouncing their personal desires. The data obtained are in line with the literature, since it highlights that the care of a child is not interpreted by mothers as a sacrifice, but as an expression of love, emotional comfort, and strengthening of affective bonds (ARAÚJO, 2020).

CATEGORY 3 - THE MAIN CHALLENGES PERCEIVED THROUGHOUT THE TREATMENT

Reports about healthy siblings, invasive procedures and side effects, behavioral changes, and exposure to the other's pain were included in this category.

Table 7 – Narratives about the challenges perceived throughout the treatment

Healthy siblings

M2: [...] She says it like this, then she's older, she understands more, but no, it's the same feeling of "wow, she left me, I'm standing aside, I'm not paying attention", it's the same thing.

M8: [...] We feel, like this, yes, not being able to hold both ends, to give the best to both, we always think it's missing.

Invasive procedures and side effects

M8: [...] His suffering, you know, whether he wants to or not, no matter how well he is, there are periods when he has fever, neutropenia, he has to go back to the hospital, so he is hospitalized for five or six days, so everyone says that the catheter is fine, but he is only two years old, so every time he punctures, he pierces a two-year-old child twice a week, He doesn't understand, he cries, so it's painful for us to see this.
M3: The chemo, right, depending on the chemos he does, which are very strong, there are some that give a reaction, I think that's it

Behavioral changes

M6: I's changed behavior. It's like this, every time he has a different behavior, so it's like this, I don't know how to deal with his new emotions, that, at the same time, when we're learning to deal with some emotion, he already changes again, the behavior, so he became more aggressive too, he is afraid.

Exposure to suffering

M2: I became even more sensitive these times, because of the losses of friends, you know, that we talk like this, you know, that insecure hit, and then you say, what is happening, right? Whether we like it or not, we also cling to the other children, right, the other stories and one supports the other, right.

M5: We are afraid of anything that can happen, especially when we hear some stories from the people in the circle that some of them end up happening intercurrence, which ends up going to the ICU or something like that.



In addition to the transformations faced by mothers during treatment, they experience numerous challenges, including distancing from the healthy child, caused by changes in routine and the need to concentrate care and attention on the other child. As a result, the treatment of a sick child can trigger reactions and emotions in healthy siblings, such as insecurity, contributing to the emergence of internal conflicts and feelings of incapacity and exhaustion in mothers (HONICKY & GALVÃO, 2020; OLIVEIRA, *et al.*, 2021).

In some cases, healthy children with sick siblings may suppress their own emotional needs to adapt to the sick sibling-centered family dynamics. This adaptation can lead parents to believe that the healthy sibling is coping well, potentially neglecting their emotional needs (HILKNER, *et al.*, 2019).

The study by Nogueira & Ribeiro, (2020), investigated the psychological experience of siblings of children in palliative care. The results indicated that these siblings face significant transformations in their lives, taking on new domestic and care responsibilities. They may also develop fears and doubts, resulting in somatic reactions and feelings of jealousy and abandonment, despite understanding the needs of the sick sibling. Another study by Honicky & Galvão (2020), from the perspective of mothers, analyzed changes in the relationships of healthy siblings in the family, social, and school context. The results suggest that the process of illness and treatment can cause emotional impact, influence the dynamics and routine of the whole family, affecting the relationships of healthy siblings.

Linked to this experience, mothers face the worsening of their suffering resulting from the challenge of witnessing their child undergoing cancer treatment undergoing invasive and painful procedures, long periods of hospitalization, exams, chemotherapy, and various reactions, such as changes in appetite (MORAES, 2023). Borba *et al.*, (2023) highlight that the treatment generates changes in the patients' diet, intensifying the feeling of anguish in children and families, findings that are in line with the data from the present study.

As a result of this exposure, the psychological dimension of those involved in this process is affected, which can cause emotional reactions linked to suffering and behavioral changes, which have the potential to foster changes in interpersonal relationships, causing biopsychosocial impacts (SANTOS, 2021).

Another challenge portrayed by the mothers is the exposure to pain in the face of the bonds established. With the long journey of treatment, mothers and children relate in a deep way, developing a network of welcome and mutual understanding, especially in moments of vulnerability, considering that the painful shared experience provides a feeling



of union, support and helps in adapting to the moment experienced (EZEQUIEL, *et al.*, 2023).

However, in the face of complications with a child, mothers find themselves facing a whirlwind of feelings, where fear and insecurity become constant companions. The fragility of their child's health awakens in them a deep fear, an anguish that makes them question their ability to protect and face uncertainty, generating an emotional scenario that is difficult to navigate, as presented in the study by Mazer-Gonçalves *et al.*, (2016) in which the participants reported feeling afraid in the face of complications resulting from the therapy and the death of a child, because this raised the thought of the possibility of the death of his own son.

CATEGORY 4 - BEING A MOTHER IN A SCENARIO OF ILLNESS

In addition to the patients' experience, through the present study, it was possible to understand the experience of being the mother of a patient undergoing cancer treatment, considering her subjectivity in each phase of the disease.

Table 8 – Answers about "being a mother" in a scenario of illness

Positive outlook

M6: Wow, it's a lot, a lot of it, teaching, every day we learn something new, yes, both with the treatment and with his behavior.

M7: Love increases everything, yes, the vision is different, it's general.

M8: It means relearning how to live. You discover a strength you didn't know you had. [...] So we learn to value the small details of life.

M10: It's putting faith into action, very, very, very much, and that's why I can face all of that.

Challenging

M2: Suffered. [...] It's as if we didn't live. **M4:** It's difficult, the experience is difficult.

The experience of being the mother of a child undergoing cancer treatment is unique and permeated by a wide range of feelings and experiences. Despite being similar to the experiences of other mothers in similar situations, each report reflects the subjectivity and particularities of each phase of the disease. This singularity makes evident the importance of understanding the meanings attributed to this experience, which go beyond the patient's own experience as identified in the reports.

Facing the illness of a child is a process marked by deep emotions and learning. In this research, several meanings attributed by mothers to the experience of caring for a child undergoing cancer treatment were identified. Among the most cited aspects are unconditional love, which sustains their actions and decisions, and the essential connection with the experience of their children. Rocha (2020) highlights that, for these mothers, love is



configured as the foundation that gives meaning to their lives. In addition, during the treatment process, they often transform pain into courage and uncertainty into hope, as pointed out by Fonseca *et al.*, (2021).

Another dimension of this experience is the change in the perspective of life. Facing the unexpected makes many mothers value aspects that were previously neglected, recognizing the importance of simple moments and meaningful experiences, as observed by Riva (2022).

At the same time, they develop coping strategies to deal with the challenges imposed by the disease. The search for detailed information about the treatment and the disease is one of the main strategies, helping them to feel more confident and secure in the care of their children. According to Guimarães, *et al.*, (2021), problem-solving and self-confidence also emerge as adaptive mechanisms, allowing greater control over the situation. Adapting to the new reality, known as accommodation, is another frequently used resource. This strategy helps mothers adjust expectations and routines, making it easier to live with cancer treatment. In addition, social support, from family, friends or support groups, offers a welcoming space, reducing stress and isolation (BECK & LOPES, 2007).

However, some mothers resort to less adaptive strategies, such as social isolation and submission, especially when they feel a lack of support or autonomy. In this sense, it is essential that health professionals are attentive, promoting interventions that strengthen positive strategies and encourage emotional support (GUIMARÃES, *et al.*, 2021). In addition, the literature emphasizes the importance of psychological interventions that allow mothers to share their experiences and develop internal resources to cope with difficulties. The performance of multidisciplinary teams, which recognize the family as a biopsychosocial unit, is essential to create an environment of welcome and humanization (ALVES & UCHÔA-FIGUEIREDO, 2017). Among the most effective coping strategies, the use of spirituality stands out, which helps mothers find the strength to continue caring for their children in the midst of day-to-day challenges (BOMFIM, 2021).

Despite resilience and learning, the experience of being a mother of a child with cancer is accompanied by intense emotional and physical overload. Studies reveal that the suffering generated by seeing children vulnerable and facing the adverse effects of treatment is profound and significant (BEAL, et al., 2022; SALÓES & CAVALCANTI, 2023). Even so, many mothers demonstrate resilience, a fundamental characteristic to overcome adversity and remain present in the care of their children (GONÇALVES, 2020).



Finally, it is essential that health professionals recognize and value the experiences of these mothers, offering emotional support and acceptance. This comprehensive approach contributes to the promotion of mothers' mental health and, consequently, to the well-being of the child undergoing treatment (BEAL, *et al.*, 2022). Being a mother in a context of childhood cancer is a complex journey that requires adequate support and empathy so that these women can maintain their strength and resilience throughout the process.

CONCLUSION

The present study aimed to understand the experience of mothers during the cancer treatment of their children in the Pediatric Oncology Units, highlighting the emotional challenges and psychological repercussions of this experience.

In addition to the sociodemographic data identified, it was possible to analyze four thematic categories in the participants' discourses. These analyses showed that the maternal experience in this context causes profound impacts on the emotional sphere, modifying its structure and generating a wide range of intense feelings.

It was also observed that this experience causes transformations in the family, social, financial and professional context of the mothers, affecting their personal projects.

Often, this process results in a phenomenon of depersonalization, in which mothers cancel themselves out due to the needs and care of their children. In addition, the difficult journey of treatment contributes to considerable challenges, impacting the maternal role.

In this scenario, the importance of adequate emotional support and effective social support becomes essential to help mothers face this experience.



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