

THEORETICAL ARTICLE

Health psychology

Editor

Raquel Souza Lobo Guzzo

Support

Universidade Federal do Triângulo Mineiro (Edital PIBIC/UFTM n.º. 08/2019/PROPPG, April 15, 2019).

Conflict of interest

The authors declare they have no conflicts of interest.

Received

March 26, 2021

Final version

October 26, 2022

Approved

July 26, 2023

Mothers' life context and coping in childhood cancer remission

Contexto de vida e enfrentamento materno na remissão do câncer infantil

Rayssa Martins Morais¹ , Fabiana Pinheiro Ramos² , Beatriz Oliveira Valeri³ 

¹ Universidade Federal do Triângulo Mineiro, Curso de Psicologia. Uberaba, MG, Brasil.

² Universidade Federal do Espírito Santo, Departamento de Psicologia, Programa de Pós-Graduação em Psicologia. Vitória, ES, Brasil.

³ Universidade Federal do Triângulo Mineiro, Departamento de Psicologia da, Curso de Psicologia. Uberaba, MG, Brasil. Correspondence to: B. O. VALERI. E-mail: <beatriz.valeri@uftm.edu.br>.

Article based on the Scientific Initiation study of R. M. MORAIS, entitled "Estratégias de coping em cuidadores de crianças na fase de remissão onco-hematológica". Universidade Federal do Triângulo Mineiro, 2020.

How to cite this article: Morais, R. M., Ramos F. P., & Valeri, B. O. (2024). Mothers' life context and coping in childhood cancer remission. *Estudos de Psicologia (Campinas)*, 41, e210039. <https://doi.org/10.1590/1982-0275202441e210039>

Abstract

Objective

The study examined the life context and coping strategies of mothers whose children and adolescents were in the remission phase following a diagnosis of onco-hematological conditions.

Method

In this descriptive qualitative-quantitative cross-sectional approach study, six mothers answered a semi-structured interview and the Ways of Coping inventory.

Results

Important changes in the routine and life context of the mothers, experiences of helplessness, and the use of the support network were noted throughout the journey from the diagnosis of the disease to its treatment. Coping in the remission phase was predominantly adaptive, with the use of strategies such as negotiation and seeking support, although maladaptive strategies such as delegation were also present.

Conclusion

The results highlighted relevant aspects for promoting the psychological health of mothers throughout the journey of coping with childhood cancer, from diagnosis to remission.

Keywords: Cancer survivors; Lymphoid leukemia; Mothers; Psychological adaptation.

Resumo

Objetivo

Investigou-se o contexto de vida e as estratégias de enfrentamento adotadas por mães de crianças e adolescentes com diagnóstico onco-hematológico, na fase de remissão da doença.

Método

Nessa pesquisa descritiva quali-quantitativa, de corte transversal, seis mães responderam a uma entrevista semiestruturada e ao Inventário de Estratégias de Coping.

Resultado

Foram identificadas mudanças importantes na rotina e no contexto de vida das mães, vivências de desamparo, e uso da rede de apoio como suporte no percurso entre o diagnóstico e o tratamento da doença. O coping na fase de remissão foi predominantemente adaptativo, com uso de estratégias como negociação e busca de suporte, embora estratégias mal adaptativas, como delegação, também estiveram presentes.

Conclusão

Os resultados evidenciaram aspectos relevantes para a promoção da saúde psicológica das mães, no percurso do enfrentamento do diagnóstico à remissão do câncer infantil.

Palavras-chave *Adaptação psicológica; Leucemia linfóide; Mães; Sobreviventes de câncer.*

Cancer is a global public health problem. In Brazil, 450 thousand new cases of the disease (excluding non-melanoma skin cancer cases, which would increase this total to 625 thousand) is estimated for the 2020–2022 triennium. Of the total new cases, more than eight thousand would occur in the child and adolescent period (0 to 19 years old). Cancer is characterized by the abnormal proliferation of cells that can occur anywhere in the body. When this proliferation occurs in blood cells, it is called leukemia, which is the most common type of cancer in individuals under the age of 15. Currently, 80% of cases can be cured if diagnosed early and treated appropriately, and after the treatment is completed, most individuals experience a good quality of life (Instituto Nacional de Câncer José Alencar Gomes da Silva [INCA], 2019).

At the end of treatment, it is expected that the child will enter a remission phase, which can be of two types: complete, in which there are no indications of cancer in the exams; and partial, when there is a considerable decrease in malignant cells. During this period, doctor consultations are still a part of the routine for the child and adolescent, and monitoring and care remain frequent. Being in remission is, therefore, a step towards a cure, but the transition period is long, requires ongoing treatment, and can vary from two to ten years depending on the type of cancer. After entering this phase, the patient is considered cured only when they do not present any symptoms or cancer cells in the blood, and the probability of relapse is minimal (Associação Brasileira de Linfoma e Leucemia [ABRALE], 2018).

Considering this, oncological remission does not imply the survival of cancer, since this transition period to a cure, especially in its initial phase, requires constant vigilance, and the fear of relapse is present. Studies that address the remission phase of childhood cancer are still scarce, but existing studies indicate that the perception of illness undergoes a process of resignification by patients and family members, including greater optimism regarding the disease when already cured (Castro et al., 2018). In this context, post-treatment care is relevant to prevent possible relapses and to establish healthier physical and psychosocial behaviors (Neris & Nascimento, 2021), thus justifying the relevance of evaluating how primary caregivers experience this stage of their children's illness.

Given the weakness caused by illness and treatment, cancer patients, especially children, require attention and assistance in their daily lives. Usually, a family member takes on this role and dedicates themselves to the patient's care (Visoná et al., 2012). Thus, the caregiver is identified as the patient's social representative and is always present in environments that promote health care (Barros et al., 2013). Studies indicate that, in most cases of childhood illness, the mother is the family member responsible for providing care (Kozan et al., 2016; Oliveira et al., 2020; Trentin et al., 2020). Due to the high level of stress associated with being involved with the disease, family members of children who have survived cancer may experience symptoms of psychological illness (Lawrenz et al., 2016).

Living with cancer brings about new challenges for the family, including concerns about mortality and significant changes in family dynamics due to the experiences and treatments associated with the illness (Mattos et al., 2016). Specifically, there may be moments of suffering, physical and emotional exhaustion, as well as fear and anguish that accompany the diagnosis of cancer, often associated with stigmas. Mothers' experiences are characterized by changes in routine, in the professional and personal fields, and consequent "self-annulment" due to exclusive dedication to the sick child (Vieira et al., 2020).

In this sense, psychological impacts on parents of children with cancer, such as stress and post-traumatic stress, depression, and anxiety, can cause restrictions in daily experiences and fears of a possible loss. Despite this, there are positive aspects to this process, such as the social and spiritual support received (Siqueira et al., 2019). Thus, when faced with events with which they are not accustomed to dealing, caregivers must discover new ways to think and act in the face of illness, a situation that can be perceived as stressful (Figueiredo et al., 2020).

Regarding stress, Lazarus and Folkman defined it as "[...] a response to an interaction between person and environment that exceeds their coping resources, thereby threatening their well-being" (Lazarus & Folkman, 1984, p. 19). In this sense, coping is defined as actions that aim at adapting or adjusting to stressful situations individuals face throughout life, such as in the case of parents of children undergoing oncological treatment (Lazarus & Folkman, 1984; Skinner & Wellborn, 1994).

Since the 1960s, literature from the field of psychology has presented different theoretical models for understanding the concept of coping (Antoniazzi et al., 1998; Lazarus & Folkman, 1984). In the 1990s, Skinner and colleagues' Motivational Theory of Coping (MTC) proposed an understanding of coping as a regulatory action, analyzing it from a developmental perspective (Ramos et al., 2015). The MTC has a theoretical model grounded in Developmental Psychology, allowing for articulating issues related to coping with their possible long-term outcomes: resilience or psychopathology (Vasconcelos & Nascimento, 2016).

Coping is therefore seen as a process of self-regulation of behavior, emotion, and motivational orientation in situations of psychological stress, with the intention of maintaining or restoring basic psychological needs of relatedness, autonomy, and competence, and in which stressors can be perceived as threats to the self or the context (Skinner et al., 2003). Thus, Skinner and colleagues understand coping as a dynamic, structural, and hierarchical system, in which behavioral responses, coping strategies, and adaptive processes interact at different levels.

In this system, coping families (which are macrocategories and occupy the highest hierarchical level of the coping structure) organize strategies according to their functions and their probable long-term outcome, some of which are adaptive and others maladaptive. Each family relates to one of the three basic psychological needs (relatedness, competence, or autonomy), to one type of adaptive process (coordinating actions and contingencies in the environment, coordinating trust and available social resources, or coordinating preferences and options available), and the perception of the stressor as a threat or challenge to the self (oneself) or the context (Ramos et al., 2015). The 12 families proposed by the MTC are: self-reliance, support seeking, problem solving, information seeking, accommodation, and negotiation (possible adaptive outcome); and delegation, isolation, helplessness, escape, submission, and opposition, associated with maladaptive outcomes (Skinner et al., 2003).

Despite the growing interest in the MTC by Brazilian researchers, as indicated by Ramos et al. (2016), the national context still lacks validated instruments for the Brazilian population based on this theoretical framework. An alternative in this scenario is to use instruments that evaluate the

coping construct which are already validated for the Brazilian population, even if from a different theoretical perspective, performing their analysis from the categories of the MTC, as in the present study.

Coping is triggered when a given experience is perceived by the subject as a threat or challenge to one or more of their basic psychological needs. In this sense, considering the diagnosis of childhood and adolescent cancer and its threatening repercussions, it is evident that the primary caregiver is also exposed to various changes and stressors related to the child's oncological illness. Therefore, the present study sought to identify the life context, impacts, and changes caused by the onco-hematological treatment of children in the lives of caregivers, as well as to identify coping strategies adopted by the caregiver during the disease's remission phase.

Method

This is a descriptive, qualitative, and quantitative cross-sectional study. It was approved by the Research Ethics Committee of the *Universidade Federal do Triângulo Mineiro* (Opinion No. 3.461.662 of August 9, 2019) and is supported by Resolutions No. 466/12 and No. 510/16 of the Brazilian National Health Council.

Participants

The inclusion criteria were: 1) being the primary caregiver of children aged 2 to 14 years in the onco-hematological remission phase (full or partial) and under monitoring at the designated data collection unit; and 2) having kinship with the child. Being illiterate was the sole exclusion criterion. Out of the 13 eligible participants for data collection, one refused to participate and two did not attend the scheduled medical follow-up appointment. Four caregivers were not contacted as the follow-ups and data collection were interrupted due to the institution's implementation of COVID-19 biosafety measures. All the participants were mothers of children undergoing treatment. Hence, six mothers of children in onco-hematological remission phase, either full or complete, treated at a tertiary health unit, participated in the study.

Instruments

For data collection, firstly, a semi-structured interview guide was used, which was specifically developed for this research. It is composed of questions aimed at characterizing the sociodemographic data of the participants and guiding questions that address the onco-hematological journey of the child in treatment (encompassing the life context of the mothers from diagnosis to remission), and the repercussions of this illness in the caregivers' lives. After the interview, the mothers were given instructions to complete Lazarus and Folkman's Ways of Coping Inventory, adapted and validated for the Portuguese language by Savoia et al. (1996).

The inventory consists of 66 items that portray thoughts and actions used to cope with internal and external demands arising from stressful situations, and the participants were asked to respond considering the coping strategies used in the current cancer remission phase. For each item, the intensity by which the strategy was used was measured through Likert scale responses ranging from 0 (not used) to 3 (used a great deal). Although this instrument originates from a theoretical framework different from the MTC, it was chosen because it is a well-established measure of coping in the literature and has been properly validated and adapted for the Portuguese language.

Procedures

Initially, to recruit participants for the study, the researcher contacted the psychologist in charge of the onco-hematology department at the hospital where data collection took place. This person indicated the days on which the children who were under follow-up in the unit had their medical appointments, and whose caregivers met the inclusion criteria. Once eligible participants were identified, they were informed about the research objectives, the participation process, the ethical procedures involved, and any questions they had were addressed. The participants were provided with the Informed Consent Forms and the authorization for audio recording. Once the forms were signed, the application of the instruments occurred in a location that ensured the participants' privacy, i.e., in a hospital environment free from external interferences. Throughout the data collection period, the researcher was available to address any doubts regarding any aspect of the study, as well as any difficulties in completing the instrument. The data collection sessions had an average duration of twenty minutes and were audio recorded.

For the quantitative analysis of the Ways of Coping Inventory data, a reclassification of the original 66 items into the 12 coping families proposed by the MTC (Skinner et al., 2003) was initially performed. Thus, each of the 66 items was associated with one of the 12 families. This analysis was initially carried out independently by each of the authors of this manuscript. Subsequently, the classifications were compared and discussed, resulting in the final version of item classification. Out of the 66 instrument items, 40 were related to families classified as adaptive, and 26 to families classified as maladaptive. Next, the Likert scale responses were recorded in an Excel® 2016 program spreadsheet. The calculation of the percentage of strategy usage by the mothers was performed for each coping family, considering the intensity of usage. The strategies that were considered most used were those that received responses of "used quite a bit" (2 on the scale) and "used a great deal" (3 on the scale). In addition, the frequency of usage for each of the 12 coping families was described in terms of median, range of variation, and percentage.

Regarding the interviews, after being transcribed in full, they were analyzed using the Content Analysis approach (Bardin, 2011). Through this technique, the contents that emerged during the interviews were treated in stages: pre-analysis, material exploration, treatment of the results, inference, and interpretation. The categorization corpus led to the grouping of five thematic axes discussed in light of the literature, namely: "The normality of pre-diagnosis living", "The support network: multiprofessional team, other mothers, family, and volunteers", "Loneliness and 'self-annulment' in the mother-child dyad", "The possibility of resignification with religious support", and "The implications of the 'new life': the beauty and fear of returning to normality". Finally, some relations were established between the results of the interview analysis and the quantitative results of the applied inventory, aiming to answer the research objectives.

Results and Discussion

The following section is organized into three stages. First, the sociodemographic characteristics of the participants. Second, the results and discussion of the interviews based on the thematic axes. Finally, the coping strategies identified through the coping instrument.

Sociodemographic Data of the Participants

The caregivers' age ranged from 23 to 44 years ($M = 33.5$; $SD \pm 7.4$), and not all of them lived in the city where their children's oncological treatment was taking place, having to travel constantly for that purpose. Most participants were married, and their educational level varied from incomplete elementary education to incomplete higher education. Regarding their occupation at the time of data collection, many reported being unemployed due to exclusive dedication to the treatment of their sick child. Only one mother reported having a formal job for the past two years after five years dedicated solely to her daughter's treatment.

The characterization of the participants reflects aspects highlighted in the literature: families with a member suffering from cancer go through adaptations to provide adequate care (Silva & Barros, 2019; Waidman & Elsen, 2004). Thus, specific changes often occur, such as the primary caregiver leaving their job because treatment, along with the numerous changes it provokes in the family routine, demands them to provide exclusive care to the patient. This phenomenon was identified in the lives of all participants since they all had formal employment prior to treatment, but only one mother returned to formal employment after her daughter's treatment ended.

Therefore, considering the specificities of each family and the demands of each treatment, experiencing the illness of one of their members causes various changes in their routine and life organization. Although the literature emphasizes the importance of personalized care that focuses on the basic needs of each family, aiming to reduce the burden on its members (Waidman & Elsen, 2004), the results of this study showed this burden mainly on the primary caregiver, which was universally the mothers. Whether for being the sole caregiver or through family agreements, the participants found themselves obliged to dedicate themselves exclusively to the care of their child.

Regarding the characteristics of the children under treatment, four were female and two were male. Their ages ranged from 4 to 12 years ($M = 8.8$; $SD \pm 2.8$), and all of them had the same diagnosis, which was ACUTE LYMPHOBLASTIC LEUKEMIA (ALL). This diagnostic similarity is justified because the most common type of childhood cancer is hematological, and among them, leukemia has the highest incidence, particularly ALL (INCA, 2019; Paixão et al., 2018), which represents approximately 93.4% of pediatric leukemia cases in Central and South America (Silva, 2019).

Presented next, the qualitative results regarding the identified thematic categories from the interview analysis. To illustrate and discuss each of these categories, excerpts from participants' statements will be provided, using fictitious names inspired by Caribbean islands.

The Normality of Pre-Diagnosis Living

Throughout the interviews, the mothers addressed various moments of their journey accompanying their children's illness, from diagnosis to the current remission phase. Thus, the mothers ($n = 6$) described the moment before discovering their children's illness as normal, revealing that the changes came abruptly, as there were no indications or potential exposure of the child to any risk factor that could result in a decline in their health. Participant Aruba described this experience as follows: "Before? It was normal. She studied, I worked, my husband worked, we went out, she played. She was always very active, playful, and fun. She always ate well. She had a lot of energy since she was born. Everything was fine".

Regarding the mothers' daily routines, the activities that were previously performed had to be restructured to provide proper care for their children, as an intense marathon of medical

appointments and hospitalizations began. Thus, the results of this study align with the literature, as it is observed that the routines and experiences of families underwent significant changes after the diagnosis, demanding a reorganization of the family context (Silva & Barros, 2019; Vieira et al., 2020). In this way, the period prior to the diagnosis is understood by the mothers as the normalcy of life and family routine, which is disrupted by the various adaptations required by the treatment and care of their children.

Still within this context, mothers constantly deal with the fear of death that arises with the cancer diagnosis - feelings that can persist throughout the treatment process (Menezes et al., 2007). This fear is evident, for example, when describing the name of the disease/diagnosis (which its pronunciation is often avoided), causing the word "cancer" to be seen as a taboo, as exemplified in Névis' statement:

Before, everything was normal, whenever we could, we would go out, I worked... [...] When she was close to turning 3 years old, we found out that she had... Now she is about to turn 10, it will be this next Monday. [...] I gave up everything to be with her, it was difficult." (Névis)

The participants also provided detailed information about the process of investigating and receiving the diagnosis of their children, describing the difficulties they encountered along the way:

She started feeling pain in her leg, and then it got really painful. Then, came a fever which medicine did not help. We took her to the hospital; she had a blood exam. Took her to the orthopedist; he said it could be growing pains. They asked to redo the blood test, and that's when they found out. My mother had gone with her this time, and she said that the doctor just bluntly said it was leukemia. (Aruba)

Since the initial symptoms of childhood cancer are like those of non-serious and common childhood illnesses, there may be a delay in diagnosis. An effective diagnosis can identify the disease at an early stage, contributing to a treatment with higher chances of success and reducing morbidity and mortality (Paixão et al., 2018; Rodrigues & Camargo, 2003). The anguish of waiting for the diagnosis and the painful experience of learning about the illness are challenges mentioned by mothers during this stage (Santos et al., 2011), which aligns with the accounts of the participants in this study.

The Support Network: Multiprofessional Team, Other Mothers, Family, and Volunteers

Given the changes experienced by the family after the diagnosis and during treatment, the indispensability of a social support network becomes evident, which can be formed by professionals who will assist the family throughout this journey (Waidman & Elsen, 2004). The participants in this study ($n = 4$) emphasized the support received by the multidisciplinary team that took care of their children, providing a biopsychosocial care approach, as well as highlighting the importance of family ($n = 5$) as a support system during this delicate time.

"The psychology part is wonderful, that's where they brought her joy to endure getting pricked, it alleviated the sadness, the pain, the anguish (...). And all the nurses, the entire hospital, from the cleaning staff to all the other departments, I never had any problems with anyone, it's a wonderful team. My friends, my family, my then-husband never abandoned me (sic) at any time. (Guadalupe)

The importance of a support network for coping during the period of caring for their children was evident in the accounts of all participants. Similarly, in a study with family members of oncology patients, the need for comprehensive psychosocial support was highlighted as a means of helping caregivers face this moment with lower levels of stress (Almeida et al., 2020). The mothers ($n = 2$) also described moments of interaction with others who were in the same condition. This sharing of experiences among peers was considered beneficial by the participants, as these exchanges represent significant support and acceptance, as seen in the following account:

One thing I have been doing is talking a lot with the other mothers, which helps a lot, especially with those who are just starting out, I give them advice. [...] When I started, many people did that for me, so I think it's important to put myself in someone else's shoes. (Dominica)

In the same regard, the establishment of bonds and friendship among mothers during their children's hospitalization was a positive indication, providing a decrease in feelings of loneliness and overcoming the absence of family when they spent long periods away from home in the hospital for treatment, as also indicated in the literature (Kozan et al., 2016).

Another aspect observed in one mother's report was the supportive network of volunteers, characterized by welcoming patients and/or family members who do not have or cannot rely on any family members in the city where treatment is being conducted.

The girl who welcomed me here was sent by God. She lived near my city, but I didn't know her. She let me stay in her house when I was here for my son's hospitalization. I'm really grateful to her. (Martinica)

It is important to consider the impact of being away from home, as half of the participants in this study did not reside in the city where their child was treated. Being away from home and from one's hometown are described in the literature as limiting factors for the connection between mothers of children with cancer and other family members (Oliveira et al., 2020). In this sense, the participants' speeches highlighted that, even though the connection with the support network is not the same as that of family, the existence of people who offer social support facilitates coping with the effects of being far from home.

Loneliness and 'Self-Annulment' in the Mother-Child Dyad

Full dedication to the care of their children was a theme addressed by the mothers ($n = 5$): according to their accounts, their careers, leisure time, and self-care were placed in the background. Endres et al. (2021) indicate that caregivers, when assuming this role, start to experience potential health problems as they primarily focus on providing care, leading to frequent episodes of insomnia, poor nutrition, stress, depression, and anxiety in their daily lives.

The biggest impact is not going out, being confined; I didn't go out because of her. Before, I had my leisure time. Afterwards, I didn't have it anymore. I couldn't leave her with anyone. If everyone else was going out, I would already start worrying that she might catch a cold. It was a great concern. I miss how things were before. (Anquilla)

It is known that caregivers who report not having any enjoyable leisure activities have a lower perception of quality of life (Silva et al., 2020). Generally, in an attempt to provide support

and protect the child from extreme suffering, family members do not prioritize their own well-being, compromising their emotional state and giving rise to feelings of helplessness (Menezes et al., 2007).

Through all of this, my relationship with my other children became more distant; V.G. didn't want to stay with anyone else but me, I was everything to him. In the middle of his treatment, I found out I was pregnant with my other child. I didn't know how to deal with it, I tried not to show weakness so that V.G. wouldn't be affected. (Dominica)

Statements like those of Dominica and Anguilla highlight the presence of feelings of guilt and helplessness during the post-diagnosis adaptation. Dealing with this reality, mothers need to restructure their daily experiences to learn how to cope with the new demands arising from caring for their sick child (Oliveira et al., 2020). This restructuring needs to be carefully observed and handled, aiming to maintain the caregivers' quality of life and physical and emotional health.

The Possibility of Resignification with Religious Support

According to the results of the present study, faith played a leading role in how mothers dealt with the challenges of caring for children with cancer. All mothers ($n = 6$) reported relying on God during this process, whether through one religion or even several, which highlights spirituality as a relevant resource and support for resignifying the lived experience. Schneider and Mannell (2006) emphasize the importance of support and the feeling of comfort through spirituality in parents of children with cancer. This phenomenon was also revealed in the present study, as can be observed in Névis' statement, "God helped me a lot. I embraced all religions, and, for me, it meant the same thing, God taking care of us."

The literature also confirms that mothers of children with hematological cancer undergoing hematopoietic stem cell transplantation seek support in spirituality and religiosity. In the study by Freitas et al. (2017), for example, caregivers reported that during the child's illness, the frequency of prayers and visits to religious institutions increased. The search for spirituality was also expressed in the statements of the participating mothers in the present study, as seen in the following account:

The strength comes from there... It comes from God, from the family. Nowadays, after this shock, I find myself stronger. Nothing can bring me down easily. It's all a learning process. I used to do many things wrong, now I value the little things and my faith has increased 100%. My connection with God is stronger, my habits have changed, now I value my family and children more. (Martinica)

Spirituality and faith were identified by the participants as important in the journey of coping with their child's cancer. Although the MTC does not address religious coping as one of its macrocategories, coping strategies with a focus on spirituality are often classified as "seeking support" or "self-reliance", depending on their function of providing social support or emotional regulation, respectively. The literature also points to the potential positive impacts of religious coping strategies on health and quality of life, as indicated in a recent review (Foch et al., 2017).

In this context, Schneider and Mannell (2006) draw a parallel between this journey of support in spirituality and a lighthouse guiding ships during a storm, where there is a focal point of light that assists in navigating through turbulent paths. This analogy resonates with the results of the present study, as all the mothers attributed the fact that they found resources and overcame challenges throughout the treatment to their religious belief, i.e., to God, ultimately reaching the maintenance phase of their children's treatment.

The Implications of the ‘New Life’: The Beauty and Fear of Returning to Normality

During the interviews, the mothers reported experiencing ambivalence during the remission phase of their children’s illness, characterized by the joy ($n = 6$) of this stage, as it represents the possibility of complete cure, but on the other hand, the fear of relapse ($n = 4$). Such ambivalence can be noted in Anguilla’s statement: “Now my expectation is for her to be free from all medications, and my fear is that the disease will return, it’s everyone’s fear, right? There’s always that thought of whether everything will be alright”.

This fear, which was described by the participant, is related to Damocles Syndrome. Specifically, something experienced by children and adults who survive cancer, as well as by their caregivers, who live under a continuous state of uncertainty and the fear of relapse (Pires et al., 2020). The occurrence of this syndrome has been associated with the prevalence of Post-Traumatic Stress Disorder in mothers of children with cancer (Cupit-Link et al., 2018). In Guadalupe’s statement, feelings of hope and fear are observed simultaneously, as well as the initial steps towards returning to activities performed prior to the illness:

She will go back to school next year, and God willing, I want to go back to work too. I also hope to return to that normal life we used to have. That’s my wish. And health. My concern is that since she already had the disease, you know (...) But I believe that she is already cured, that she won’t need it anymore. But deep down, for example, if next month she gets a fever, it will become a concern. Anything that happens, even if it’s just a simple flu. For a mother who has never been through this type of treatment with a child, it will be normal... For us, it’s terrifying. (Guadalupe)

When the child’s treatment enters the maintenance phase, families begin a restructuring process. The journey through cancer is a turning point in the lives of its members, and the process of resuming activities is gradual and still requires care. Recovering old habits and adapting to a new routine away from constant medical interventions demands reorganization from the caregiver. Furthermore, reaching this stage of treatment is seen as a great victory (Menezes et al., 2007).

In a study on optimism and perceived gain of caregivers of children with oncological illness, participants who had been in treatment for over a year and/or had already completed the chemotherapy phase reported a higher perceived gain, particularly regarding new possibilities for valuing life (Pagung et al., 2021). Such a perspective is established as advancing through and overcoming the various stages of cancer treatment demonstrates that the disease can be controlled. The statement made by participant Aruba makes this aspect of resignifying experiences clear during the remission phase:

The habits have changed. I used to drink, go to many parties, now I value my family and children more. From now on, it’s a new life, she’s healthy, a young woman. I hope the best for my daughter, that she moves forward.

The following section presents quantitative results regarding the coping strategies of mothers during the remission phase.

Coping Strategies Used by Mothers During the Remission Phase of their Children's Cancer

In addition to the interviews, the responses obtained through the Ways of Coping Inventory made it possible to evaluate the coping strategies used by mothers during the remission phase of their children's cancer. The results of the quantitative analysis based on the MTC's 12 families will be presented and discussed below. Table 1 presents the median, range of variation for each of these categories, as well as the percentage of utilization for each strategy. Only strategies with responses 2 (used quite a bit) and 3 (used a great deal) were considered for each strategy, based on their classification as adaptive or maladaptive.

Table 1

Median, range of variation, and percentage of strategy use of the 12 coping families, as adapted from the Ways of Coping Inventory

Families of coping	Median (Min–Max)	Responses 2 and 3 (%)*	Classification of Coping Families
Self-reliance	2 (0.75–2.5)	62.5	Adaptive
Support seeking	2.5 (1.5–3)	80.5	
Problem solving	2 (1.1–2.1)	60.4	
Information seeking	2 (1.4–2.6)	63.3	
Accommodation	2 (1.6–2.06)	66.6	
Negotiation	2.75 (1.5–3)	83.3	
Total (%)		67.5	
Delegation	3 (2.2–3)	100	Maladaptive
Isolation	0.25 (0.25–1.75)	25	
Helplessness	0.5 (0–2)	16.6	
Escape	0.5 (0.3–1.6)	37.5	
Submission	1 (0.4–2.4)	46.6	
Opposition	0 (0.25–1.5)	20.8	
Total (%)		40.4	

Note: *Responses 2 and 3 (%): percentage of responses 2 (used quite a bit) and 3 (used a great deal).

It can be observed that the three highest medians and percentages of use refer to the following coping families: delegation, negotiation, and support seeking. The delegation family, according to Skinner et al. (2003), comprises strategies related to complaining, self-blame, and lamentation, posing a threat to the self and the need for relatedness. The negotiation family (second highest median) is associated with seeking new options when faced with the stressor as a challenge, through the use of strategies such as, for example, persuasion and bargaining. Finally, the support seeking family (third highest median) reflects behaviors related to accessing available social resources, involving the basic psychological need for relatedness (Ramos et al., 2015).

Although the most frequently used strategy corresponds to a category with a likely maladaptive outcome, it is clear (when combining the results obtained from adaptive and maladaptive families) that a significant portion of the strategies most used by mothers belong to families with an adaptive outcome. The highest percentage of the use of delegation strategies may indicate that, during the remission phase, there are still perceived threats to the mothers' relatedness needs, especially considering that the support from the healthcare team tends to be reduced during this period compared to earlier stages of the treatment. In addition, during this phase, mothers still expressed feelings of exhaustion, fear, and anxiety despite the relief. Thus, coordinating trust

and available social resources is a challenge for mothers during this period, and in this sense, it is important for the healthcare team to continue providing psychosocial support for these families even during the remission period, enabling ongoing monitoring and care.

The delegation category can also be observed through qualitative data from the interviews. As it is a moment of disease remission, which is temporally distant from the threatening stimulus (diagnosis), it was expected that mothers would predominantly indicate perceptions that express challenge and hope, which would be related to adaptive strategies. However, despite their success with their children during the remission phase, they mentioned employing delegation. This category encompasses behaviors and strategies indicative of dependency, be it on the social support network, family, or even the healthcare team, as the remission phase still involves medical follow-up for an extended period for monitoring the disease. Although the mothers possess the perception of competence for having completed the entire treatment and reaching the long-awaited remission phase, this perception may be associated with tiredness and exhaustion in the face of the need to continue the monitoring process. Thus, the high percentage of the delegation category may indicate that these mothers preferred someone else to take charge of the situation on their behalf.

Even though the responses to the Inventory referred to the remission period, all participants indicated using quite a bit or to a great deal, the strategies: *“I felt that time would make a difference – the only thing to do was to wait”*; *“Hoped a miracle would happen”*; and *“I daydreamed or imagined a better time or place than the one I was in”*; which suggest uncertainty or escaping from the still very threatening reality. This could also be identified in the qualitative analysis, in excerpts such as the following:

I miss how things were before. (Anguilla)

Now it's all about faith, victory, gratitude to God. God helped me a lot. I embraced all religions, and, for me, it meant the same thing, God taking care of us. I hope now that she grows into a young woman, graduates, studies, and is happy (...). (Névis)

It's hard to process that something bad came into your life. We're used to good things. Nobody expects an illness, but I took a lot of good things from it: resilience, waiting for things to play out in God's time, becoming more human too (...). (Guadalupe)

Religious coping, also frequently reported by the participants during the interviews, was represented in the coping instrument by items such as *“I prayed”* and *“Found new faith”*, classified under the families of support seeking (80.5% use frequency) and accommodation (66% use frequency), respectively. These represent the third and fourth most commonly used sets of strategies during the remission phase. The strategies of support seeking and accommodation are considered adaptive, and in the specific case of behaviors related to religion or spirituality, they may be associated with better quality of life, psychological well-being, decreased depression and post-traumatic stress, and increased perception of self-efficacy (Foch et al., 2017).

The results showed that the participants also utilized problem solving strategies (60.4%) and self-reliance strategies (62.5%), which are also adaptive in nature. In this sense, adaptive strategies can have long-term beneficial effects on the health promotion of caregivers and, consequently, on their interaction with their child. Thus, positive effects of coping can be observed in the relationship between parents and children with cancer (Rodriguez et al., 2015).

Despite the instrument referring to the period of remission, the use of coping strategies by mothers throughout their children's illness ranges from the moment of diagnosis to remission, which is predominantly faced with the use of adaptive strategies, as indicated in the inventory results.

The content addressed by the mothers' statements, as analyzed within the thematic axes, allowed the identification of different forms of psychological adaptation at different stages of illness. Thus, the results allow us to observe that coping is carried out using different strategies, both adaptive and maladaptive. Therefore, only longitudinal studies can evaluate the long-term effects of using these strategies.

The use of coping strategies prior to remission was observed throughout the mothers' verbalizations about their emotional, individual, and social experiences. Although not the objective of the interview guide, social support (MTC "support seeking" family), for example, was mentioned in the thematic axis "The support network: multiprofessional team, other mothers, family, and volunteers", as well as aspects of self-blame and lamentation (MTC "delegation" family) in the thematic axis "loneliness and 'self-annulment' in the mother-child dyad".

Even though the remission treatment phase represents a transition towards healing, ambivalence was observed in the interviews during this phase (joy of remission vs fear of relapse), as well as the use of both adaptive (negotiation) and maladaptive (delegation) coping strategies. This indicates that situations are perceived as both threats and challenges to the self and the context, despite the stressful stimulus (diagnosis) not being imminent. In this sense, the convergences between the results of the instruments in this study suggest the dynamic and processual nature of coping, highlighting how certain strategies aid in adapting to the stressor over time, from the moment of cancer diagnosis to the remission phase of the disease.

Conclusion

The aim of this study was to understand the life context of mothers of children with onco-hematological illnesses during the remission phase, as well as the most used coping strategies for dealing with this period. It was identified that when prioritizing the care of their child and placing self-care as a secondary task, feelings of isolation and helplessness arise. Furthermore, drastic changes in the mothers' routines were highlighted, as well as the importance of a supportive network and the support of spirituality as significant facilitators in the process of redefining this experience. It was also observed that during the remission phase, mothers primarily utilized coping strategies belonging to the categories of delegation, negotiation, and support seeking, with a predominance of strategies that have adaptive outcomes. Specifically, when faced with feelings of isolation and helplessness, mothers seek support networks and perceive their relatedness need as threatened or challenged, thus employing delegation and support seeking strategies. Moreover, negotiation is related to the basic need for autonomy, which is crucial during this period of returning to "normalcy", as evidenced by the relief of reaching the maintenance phase of treatment and the desire to regain their pre-illness routines and having more time for themselves.

The present study has some limitations. Specifically, it was not possible to access all eligible participants, impacting the convenience-based sample size. Therefore, one should be careful not to generalize the findings of this group to the entire population of mothers of children and adolescents with cancer in the remission phase. Additionally, the instrument used to assess coping was analyzed based on a theoretical framework different from the one originally proposed, which requires caution in interpreting the results, given that no analysis of agreement between external judges was carried out. Despite this, the adaptation of the instrument to the theoretical model of the 12 MTC families was individually carried out by the authors, and subsequently, each item was discussed synchronously to reach a consensus on the classification of those that were discordant.

Nevertheless, this study adds important scientific evidence to the literature, as it refers to the life context and coping strategies of mothers whose children were in the period of oncological remission, a period underexplored in the literature. In this context, the findings of this study indicate the relevance of adequate social support for coping with the challenging and often traumatic experience of childhood and adolescent cancer. Also, measures that promote and safeguard maternal psychological well-being should be implemented within healthcare units, providing support and care for these mothers who bear the greatest impact in this process. This support should extend beyond the initial stage of diagnosis and intensive treatment, encompassing the entire treatment journey, including the remission and maintenance phase.

Finally, there is a need for new longitudinal studies with mixed methodologies that enable a broader and more comprehensive understanding of coping in mothers who provide care, emotional support, and security to their children in a time of extreme vulnerability, assessing its long-term effects on the emotional well-being of these women. Identifying and comprehensively understanding the dynamic nature of coping in this population could provide evidence for the development of effective instruments to identify this processual and dynamic nature as proposed by the MTC, as well as for the development of effective strategies for maternal health care and, consequently, for the care of their children during oncological treatment.

References

- Almeida, E. S. F., Carneiro, S. D., Alves, J. C., Teixeira, A. G., Barbosa, C. M., Silva, M. C. M., Veas, T. H. L., & Porto, A. C. S. (2020). Avaliação das estratégias de coping de familiares diretamente envolvidos no cuidado de pacientes oncológicos. *Brazilian Journal of Development*, 6(7), 51471–51492. <https://doi.org/10.34117/bjdv6n7-697>
- Antoniazzi, A. S., Dell'Aglio, D. D., & Bandeira, D. R. (1998). O conceito de coping: Uma revisão teórica. *Estudos de Psicologia*, 3(2), 273–294. <https://doi.org/10.1590/S1413-294X1998000200006>
- Associação Brasileira de Linfoma e Leucemia. (2018, October 17). *A alegria da remissão de um câncer*. Revista ABRALÉ On-line. <https://revista.abrale.org.br/a-alegria-da-remissao/>
- Bardin, L. (2011). *Análise de conteúdo*. Edições 70.
- Barros, S. D., Andrade, M. C., & Siqueira, F. A. (2013). Cuidar de um familiar com câncer: Contribuições da terapia familiar sistêmica. *Pensando Famílias*, 17(2), 96–110. <http://pepsic.bvsalud.org/pdf/penf/v17n2/v17n2a08>
- Castro, E. K., Peloso, F. C., Vital, L., & Armiliato, M. J. (2018). Crenças sobre o câncer infantil: Percepção de sobreviventes e mães. *Psicologia: Teoria e Prática*, 20(2), 293–308. <https://www.redalyc.org/articulo.oa?id=193860123011>
- Cupit-Link, M., Syrjala, K. L., & Hashmi, S. K. (2018). Damocles' syndrome revisited: update on the fear of cancer recurrence in the complex world of today's treatments and survivorship. *Hematology/Oncology and Stem Cell Therapy*, 11(3), 129–134. <https://doi.org/10.1016/j.hemonc.2018.01.005>
- Endres, M., Tabacinski, C., & Zanin, S. C. (2021). Características de personalidade de mães de crianças e adolescentes com câncer: Análise a partir da bateria fatorial de personalidade (BFP). *Revista Universo Psi*, 2(1), 42–56. <http://seer.faccat.br/index.php/psi/article/view/1906>
- Figueiredo, B. L., de Barros, S. M. M., & Andrade, M. A. C. (2020). Da suspeita ao diagnóstico de câncer infantojuvenil: A experiência de familiares em serviços de saúde. *Nova Perspectiva Sistêmica*, 29(67), 98–113. <https://doi.org/10.38034/nps.v29i67.563>
- Foch, G. F. L., Silva, A. M. B., & Enumo, S. R. F. (2017). Coping religioso/espiritual: Uma revisão sistemática de literatura (2003–2013). *Arquivos Brasileiros de Psicologia*, 69(2), 53–71. <https://www.redalyc.org/articulo.oa?id=229053873005>

- Freitas, I. S., Oliveira-Cardoso, E. A., & Santos, M. A. (2017). Espiritualidade e religiosidade em mães de crianças com câncer hematológico. *Psicologia em Estudo*, 22(3), 433–447. <https://doi.org/10.4025/psicoestud.v22i3.34606>
- Instituto Nacional de Câncer Jose Alencar Gomes da Silva. (2019). *Estimativa 2020: Incidência de câncer no Brasil*. Coordenação de Prevenção e Vigilância. <https://www.inca.gov.br/publicacoes/livros/estimativa-2020-incidencia-de-cancer-no-brasil>
- Kozan, L., Wanderbroocke, A. C. N., & Polli, G. M. (2016). Apoio social entre acompanhantes de crianças hospitalizadas em uma unidade de hematopediatria. *Psicologia Hospitalar*, 14(1), 53–78. <http://pepsic.bvsalud.org/pdf/ph/v14n1/14n1a04>
- Lawrenz, P., Peuker, A. C., & Castro, E. K. (2016). Illness perceptions and indicators of PTSD in mothers of childhood cancer survivors. *Temas em Psicologia*, 24(2), 427–438. <https://doi.org/10.9788/TP2016.2-03Pt>
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. Springer Publishing Company.
- Mattos, K., Blomer, T. H., Campos, A. C. B. F., & Silvério, M. R. (2016). Estratégias de enfrentamento do câncer adotadas por familiares de indivíduos em tratamento oncológico. *Revista Psicologia e Saúde*, 8(1), 1–6. <https://doi.org/10.20435/2177093X2016101>
- Menezes, C. B., Passareli, P. M., Drude, F. S., Santos, M. A., & Valle, E. M. (2007). Câncer infantil: Organização familiar e doença. *Revista Subjetividades*, 7(1), 191–210. <https://periodicos.unifor.br/rmes/article/view/1579>
- Neris, R. R., & Nascimento, L. C. (2021). Sobrevivência ao câncer infantojuvenil: reflexões emergentes à enfermagem em oncologia pediátrica. *Revista da Escola de Enfermagem da USP*, 55, e03761. <https://doi.org/10.1590/S1980-220X2020041803761>
- Oliveira, J. A., Oliveira-Cardoso, E. A., & Santos, M. A. (2020). O cuidado de crianças e adolescentes após o transplante de medula óssea: Vivências de mães. *Vínculo*, 17(1), 25–51. <https://doi.org/10.32467/issn.19982-1492v17n1p25-51>
- Pagung, L. B., Silveira, K. A., & Motta, A. B. (2021). Otimismo e ganho percebido em cuidadores de crianças com câncer. *Psico*, 52(1), e34179. <https://doi.org/10.15448/1980-8623.2021.1.34179>
- Paixão, T. M. D., Farias, S. N. P. D., Rosas, A. M. M. T. F., & Coropes, V. D. S. (2018). Detecção precoce e abordagem do câncer infantil na atenção primária. *Revista de Enfermagem UFPE Online*, 12(5), 1437–1443. <https://doi.org/10.5205/1981-8963-v12i5a230982p1437-1443-2018>
- Pires, R., Santos, M. R., & Pinto, C. (2020). Percepção dos pais sobre o futuro da criança com cancro. *Revista ROL de Enfermería*, 43(1), 458–463. <http://hdl.handle.net/10400.26/31680>
- Ramos, F. P., Caprini, F. R., Reis, L. B., Vicente, S. R. C. R. M., Motta, A. B., Paula, K. M. P., & Enumo, S. R. F. (2016). Enfrentamento do Estresse: Um panorama nacional a partir dos estudos da Teoria Motivacional do Coping. In L. S. Borges, B. B. Coutinho, L. B. Reis, & S. C. Pylro (Orgs.), *Interloquções Psicológicas: Construindo significados entre a teoria e a prática* (1st ed., pp. 55–79). CRV.
- Ramos, F. P., Enumo, S. R. F., & Paula, K. M. P. D. (2015). Teoria Motivacional do Coping: uma proposta desenvolvimentista de análise do enfrentamento do estresse. *Estudos de Psicologia (Campinas)*, 32(2), 269–279. DOI: <https://doi.org/10.1590/0103-166X2015000200011>
- Rodrigues, K. E., & Camargo, B. D. (2003). Diagnóstico precoce do câncer infantil: Responsabilidade de todos. *Revista da Associação Médica Brasileira*, 49(1), 29–34. <https://doi.org/10.1590/S0104-42302003000100030>
- Rodriguez, E. M., Murphy, L., Vannatta, K., Gerhardt, C. A., Young-Saleme, T., Saylor, M., Bemis, H., Desjardins, L., Dunn, M. J., & Compas, B. E. (2015). Maternal coping and depressive symptoms as predictors of mother-child communication about a child's cancer. *Journal of Pediatric Psychology*, 41(3), 329–339. <https://doi.org/10.1093/jpepsy/jsv106>
- Santos, L. F., Marinho, K. C., Oliveira, R. R., Siqueira, K. M., Oliveira, L. M. A. C., Peixoto, M. K. A. V., & Salge, A. K. M. (2011). Ser mãe de criança com câncer: Uma investigação fenomenológica. *Revista Enfermagem UERJ*, 19(4), 626–631. <https://repositorio.bc.ufg.br/handle/ri/15789>

- Savoia, M. G., Santana, P., & Mejias, N. P. (1996). Adaptação do Inventário de Estratégias de Coping de Folkman e Lazarus para o Português. *Revista de Psicologia USP*, 7(1-2), 183-201. <https://doi.org/10.1590/S1678-51771996000100009>
- Schneider, M. A., & Mannell, R. C. (2006). Beacon in the storm: An exploration of the spirituality and faith of parents whose children have cancer. *Issues in Comprehensive Pediatric Nursing*, 29(1), 3-24. <https://doi.org/10.1080/01460860500523731>
- Silva, F. F. (2019). *Epidemiologia das leucemias infantis de 1997 a 2013* [Tese de doutorado, Universidade de São Paulo]. Biblioteca Digital de Reses e Dissertações da USP. Universidade de São Paulo. <https://doi.org/10.11606/T.6.2019.tde-27022019-160813>
- Silva, G. V. D., Moraes, D. E. B. D., Konstantyner, T., & Leite, H. P. (2020). Apoio social e qualidade de vida de famílias de crianças com cardiopatia congênita. *Ciência & Saúde Coletiva*, 25, 3153-3162. <https://doi.org/10.1590/1413-81232020258.18402018>
- Silva, I. C. B., & Barros, M. M. A. (2019). Las experiencias de los cuidadores familiares de niños y adolescentes con cáncer. *Revista Chilena de Terapia Ocupacional*, 19(1), 35-48. <https://doi.org/10.5354/0719-5346.2019.49807>
- Siqueira H. C. H, Bick, M. A., Sampaio, A. D., Medeiros, A. C., Bento, A. S., & Severo, D. F. (2019). Repercussões do câncer infantil no ambiente familiar. *RENOME: Revista Norte Mineira de Enfermagem*, 8(1), 20-29. <https://www.periodicos.unimontes.br/index.php/renome/article/view/2250>
- Skinner, E. A, Edge, K., Altman, J., & Sherwood, H. (2003). Searching for the structure of coping: A review and critique of category systems for classifying ways of coping. *Psychological Bulletin*, 129(2), 216-269. <https://doi.org/10.1037/0033-2909.129.2.216>
- Skinner, E. A., & Wellborn, J. G. (1994). Coping during childhood and adolescence: A motivacional perspective. In D. L. Featherman, R. M. Lerner, & M. Perlmutter (Eds.), *Life-Span development and behavior* (Vol. 12, pp. 91-133). Lawrence Erlbaum Associates.
- Trentin, P. A., Chiavon, S. D., Brum, C. N. de, Zuge, S. S., Rodrigues, M. E. de C., Rosa, O. M., Pozzebon, A., Sabino, V. P., Walter, M. de O., & Coutinho, T. B. (2020). Daily life of family members who care for children in a Pediatric Intensive Care Unit. *Research, Society and Development*, 9(11), e68491110208. <https://doi.org/10.33448/rsd-v9i11.10208>
- Vasconcelos, A. G., & do Nascimento, E. (2016). Teoria Motivacional do Coping: Um modelo hierárquico e desenvolvimental. *Avaliação Psicológica: Interamerican Journal of Psychological Assessment*, 15(2), 77-87. <https://doi.org/10.15689/ap.2016.15ee.08>
- Vieira, R. C., do Espírito Santo, F. H., & Lima, F. D. S. (2020). Vivência familiar da criança hospitalizada com câncer. *Revista de Enfermagem do Centro-Oeste Mineiro*, 10, e3546. <https://doi.org/10.19175/recom.v0i0.3546>
- Visoná, F., Prevedello, M., & de Souza, E. N. (2012). Câncer na família: Percepções de familiares. *Revista de Enfermagem da UFSM*, 2(1), 145-155. <https://doi.org/10.5902/217976923943>
- Waidman, M. A. P., & Elsen, I. (2004). Família e necessidades...revendo estudos. *Acta Scientiarum Health Sciences*, 26(1), 147-157. <https://doi.org/10.4025/actascihealthsci.v26i1.1643>

Contributors

Conceptualization: R. M. MORAIS and B. O. VALERI; Data curation: R. M. MORAIS; Formal analysis: R. M. MORAIS, B. O. VALERI and F. P. RAMOS; Methodology: R. M. MORAIS and B. O. VALERI; Supervision: B. O. VALERI; Writing – original draft: R. M. MORAIS and B. O. VALERI; Writing – review & editing: R. M. MORAIS, B. O. VALERI and F. P. RAMOS.