

1           **The Experience of Having a Child with Cancer Relapse: A qualitative study**

2           **A Experiência de Ter uma Criança com Recaída de Câncer: Um estudo qualitativo**

4           **Running-head: Parents with a child with cancer relapse**

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## The Experience of Having a Child with Cancer Relapse: A qualitative study

### Abstract

**Background:** Upon completion of cancer treatment, the predominant fear among parents is the potential recurrence of the tumor. Consequently, the relapse of pediatric cancer can trigger feelings of depression, anxiety, and stress among parents. **Purpose:** This study aimed to comprehend the common experiences among parents of children who have undergone a cancer relapse. **Method:** The final sample comprised 15 mothers and fathers of children and adolescents undergoing treatment for cancer relapse. Unstructured interviews were recorded on video and analyzed qualitatively using Content Analysis and Qualitative Comparative Analysis. **Results:** The results revealed that uncontrollability and the absence of active coping strategies, particularly the lack of distraction techniques and information-seeking, were pivotal factors associated with parental emotional problems. Additional contributing factors included the lack of social support, absence of religiosity/spirituality or acceptance, and the presence of repression strategies. **Conclusion:** The findings emphasize the importance of developing early interventions for parents of children with cancer recurrence to mitigate vulnerabilities in this population.

*Key-words:* recurrence, cancer in children, parents, oncological treatment, relapse.

## A Experiência de Ter uma Criança com Recaída de Câncer: Um estudo qualitativo

### Resumo

**Justificativa:** Depois do tratamento de câncer ser finalizado, um medo predominante nos pais é a possibilidade do tumor retornar. Assim, a recaída do câncer pediátrico pode acarretar sentimentos de depressão, ansiedade e estresse nos pais. **Objetivo:** Este estudo objetivou compreender as experiências comuns aos pais de crianças que passaram por uma recaída de câncer. **Método:** A amostra final consistiu em 15 mães e pais de crianças e adolescentes que estavam em tratamento ativo para recidiva de câncer. Entrevistas não-estruturadas foram gravadas em vídeo e analisadas qualitativamente através de Análise de Conteúdo e Análise Qualitativa Comparativa. **Resultados:** Os resultados mostraram que a incontrollabilidade e a falta de estratégias de enfrentamento ativas, particularmente a falta de técnicas de distração e busca de informação, foram fatores centrais associados com problemas emocionais parentais. Outros fatores contribuintes adicionais foram a falta de rede de apoio, a ausência de religiosidade/espiritualidade ou aceitação, e a presença de estratégias de repressão. **Conclusões:** Os dados enfatizam a importância do desenvolvimento de estratégias de intervenção precoces para pais de crianças com recidiva de câncer, a fim de mitigar as vulnerabilidades psicológicas desta população.

*Palavras-chave:* recidiva, câncer em crianças, pais, tratamento oncológico, recaída.

## Introduction

The diagnosis of cancer in a child is an immensely challenging and stressful experience for parents. Globally, it is estimated that approximately 400,000 families find themselves in this situation each year<sup>1</sup>. Throughout the treatment process, parents commonly undergo a decline in their quality of life, navigating a spectrum of emotions that include anxiety, fear, and hope<sup>2</sup>. Nevertheless, as the oncological treatment concludes, a prevalent concern among most parents is the potential recurrence of the tumor<sup>3</sup>.

Hence, when parents receive the distressing news of their child's cancer relapse, they feel frustration and distress, confronted by a more tangible prospect of death<sup>4,5</sup>. Despite the occurrence of pediatric cancer recurrence not being uncommon, the psychosocial impact on caregivers remains underexplored in scientific literature, with minimal evaluations of this specific population<sup>6</sup>. Qualitative studies that delve deeply into this experience are also notably scarce.

The existing literature in this field highlights substantial adjustment challenges for parents, including elevated rates of depression, anxiety, stress, and family or marital conflicts following the relapse diagnosis<sup>7,8</sup>. These outcomes are associated with the uncertainty and uncontrollability of the prognosis, as caregivers navigate between hope for a cure and the fear of potential loss<sup>4</sup>.

The heightened levels of uncontrollability lead to a phenomenon known as the "conspiracy of silence," where parents limit the information shared with their children to shield them from distress. However, this approach often results in increased feelings of uncertainty, reduced trust in healthcare professionals, and, consequently, lower adherence to treatment<sup>9,10</sup>. When children perceive that their parents are withholding information, it can impact their relationship, potentially escalating to heightened parental overprotection and hypervigilance<sup>11</sup>.

In this scenario, certain parental coping strategies have the potential to eliminate or alleviate aversive stimuli, as well as suppress or diminish the negative feelings arising from the cancer experience. Thus, coping strategies can be categorized into active strategies, aimed at eliminating aversive stimuli (taking actions to alleviate or remove the stressor, such as seeking information or social support) or passive strategies (escaping or avoiding the stressful stimulus, employing denial or isolation). Effective coping strategies in this context are more likely to be active, as they are associated with increased control over the situation and improved psychological adjustment<sup>12</sup>.

Nevertheless, when parents confront the uncontrollability associated with pediatric cancer recurrence, they tend to employ strategies linked to acceptance. Given the impossibility of physically escaping the situation, acknowledging that some level of suffering is unavoidable helps parents adjusting to the new treatment<sup>13</sup>.

On the other hand, prior research indicates emotional growth and increased family cohesion resulting from the experience of pediatric cancer recurrence<sup>5,14</sup>. As treatment for relapse is generally long, parents can accumulate experience and knowledge about the disease, aiding in reducing uncertainty and fostering emotional resilience<sup>10</sup>.

Therefore, given the inconsistencies in the literature and the scarcity of studies on parental feelings in the pediatric recurrence scenario, there is a need to enhance comprehension of the unique and common experiences among parents of children who have suffered one or more cancer relapses. Thus, the present study used a qualitative method to describe these experiences in depth. This research also aimed at understanding the relation between coping strategies and stressors experienced at the time of relapse with parents' psychological adjustment.

## Method

## **Participants**

Forty-eight parents of children who had experienced at least one cancer relapse and were currently undergoing active treatment were invited to participate in this research. These participants were recruited from two Brazilian public pediatric oncology hospitals. Parents were approached by the main researcher after analyzing the children's medical records to ensure they met the inclusion criteria.

The inclusion criteria for participants were as follows: (a) being the primary caregiver of the child; (b) the child undergoing active treatment for a cancer relapse, which could include a recurrence of the primary tumor, a second neoplasia (at least 12 months after completing the first tumor's treatment), or a progression of the first tumor (metastasis); (c) the child not being terminally ill; and (d) the child falling within the age range of 6 to 14 years old (due to the age limit of psychological tests applied to children in another part of this research).

Among the 48 individuals approached, 16 parents declined to participate in the research. The primary reason for non-participation was a lack of interest or time, accounting for 63% of cases (10 subjects). Conversely, 17 parents initially agreed to participate, but two were subsequently untraceable. Consequently, the final sample for this study comprised 15 mothers and fathers of children and adolescents actively undergoing treatment for cancer recurrence. Participants were contacted, on average, five months after their child's last diagnosis.

## **Instrument**

An unstructured interview format was employed, beginning with an initial question: "I would appreciate hearing about your experience of having a child with cancer recurrence. Please share whatever you feel comfortable discussing". This approach was selected to facilitate open expression of individuals' experiences without interference or predetermined themes.

## **Procedure**

## ***Data collection***

Parents who consented to participate in the study were individually invited to enter an unoccupied hospital room. In this setting, the researcher introduced the study, addressed any questions, and obtained the participant's signature on the Informed Consent Form. Following a brief *rappport*, the interview was recorded on video, lasting from 45 minutes to 1 hour and 30 minutes. Only one caregiver (mother/father) per child took part in this study.

## ***Data analysis***

The interviews were transcribed in full, and their content was analyzed following the approach proposed by Bardin<sup>15</sup>, with two researchers working independently. Initially, the interviews were read in their entirety, and then their content was categorized into the following thematic recording units: 1) parents' feelings regarding the cancer relapse, 2) distinctions between recurrence and the initial oncological treatment, 3) primary stressors encountered by parents, 4) psychosocial impact of treatment on participants' lives, 5) coping strategies employed by parents, and 6) the relationship between parents and patients.

Categorization was performed within these themes, based on the absence or presence of each category in each participant's speech. This was achieved through a descriptive analysis of the percentage of individuals. The creation of these categories was informed by the existing literature in the field<sup>10</sup>.

Subsequently, a qualitative comparative analysis was conducted (QCA)<sup>16</sup> to derive a model elucidating contributors to parental positive or negative outcomes. Coping strategies were categorized as active or passive, according to Gelkopf et al.<sup>17</sup>. Active strategies encompassed seeking support from the healthcare team, ventilating emotions, searching social support, seeking information, and utilizing distraction. Passive strategies were associated with relying on religion/spirituality, using denial, isolating oneself, and accepting uncontrollability.

Hence, for the comparative qualitative analysis, the variables “coping strategies” (categorized as active or passive) and “main stressors” were regarded as predictors of “negative feelings in the relapse situation” (with these feelings considered as indicators of psychological maladjustment). Negative feelings encompassed fear of loss, denial and/or shock, depressive feelings, and stress, all grouped into a unified category labeled “negative feelings”. Additionally, the interaction between predictors was examined.

The fuzzy sets of data were transformed into clear dichotomous sets of 0 or 1 (indicating absence or presence) by calibrating the categories based on their frequency (categories with a frequency equal to or greater than 50% were categorized as present, while those with a frequency less than 49% were categorized as absent for each participant). This calibration was applied to both the predictors and the dependent variable, considering that many participants' reports fell into conflicting categories (e.g., using both passive and active strategies; in such cases, the participant's main strategy was determined by the most frequent one—equal to or above 50%). Additionally, a minimum gross consistency of 0.8 was set as a parameter. In the logical minimization procedure of the first analysis, the category “active coping strategies” was excluded as it was redundant in the formula, being encompassed within the variable “coping strategies”.

A second analysis was conducted using the same qualitative comparative analysis method, with the aim of enhancing comprehension regarding the contributory role of coping strategies and stressors in parental psychological adjustment. In this analysis, all coping strategies (without categorizing them as active or passive) and all stressors (without grouping) were examined, along with their interactions. The procedures for this analysis mirrored those of the previous one. During the logical minimization stage, the variables “lack of information” and “routine” were excluded due to their very low frequencies. Additionally, the intersection



of the coping strategy "seeking support" with the stressor "lack of social support" was eliminated as it was redundant.

The intermediate solution was adopted in both QCA analyses, as it simplifies the assumptions about the main causal conditions. This solution was then compared with the parsimonious solution to delineate the "core" and "contributory" causal conditions influencing the psychological adjustment of parents with children undergoing cancer recurrence. All analyses were conducted using FsQCA software version 4.0.

### ***Ethical Considerations***

This research was approved by the Brazilian ethics committees of Hospital de Amor and Centro Infantil de Investigações Hematológicas Dr. Domingos A. Boldrini under the number 01576312.5.00.5376 in *Plataforma Brasil*.

## **Results**

The participants were predominantly women (86.7%), serving in the role of mothers (86.7%), with an average age of 35.36 years old ( $SD=5.78$ ). The majority were married or in a stable relationship (80%) and identified as religious (85.7%). Most participants had completed high school (38.5%), and the average family income was 2.14 minimum wages ( $SD=1.79$ ).

Concerning the children, 53.3% were male, with a mean age of 10.27 years-old ( $SD=2.34$ ). The majority received a diagnosis of acute lymphocytic leukemia (46.7%), experienced a single relapse (66.7%), were undergoing treatment for an average of 36 months ( $SD=28.01$ ), and were in the relapse situation for an average of 6.2 months ( $SD=8.48$ ).

### **Speech analysis**

#### ***1. Feelings regarding their children's cancer relapse***

The predominant emotions experienced by the participants (60%) during the relapse had depressive characteristics. P14 and P15 described feelings of apathy, loss of appetite, and

1 persistent crying, while P9 expressed emotions of impotence and defeat. P6 and P8 reported  
 2 sensations of chest tightness and ongoing anguish. P11, P13, P14, and P15 acknowledged  
 3 experiencing constant irritability and aggression, while P5 conveyed feelings of intense anger  
 4 and sadness. P1 encapsulated his situation, stating: *"It's as if I'm in a well that has no rope, no  
 5 way out, you know? There's nothing. (...) My wife feels the same way"*.

6 Eight participants (53.3%) reported apprehension about losing their child, given the  
 7 heightened aggressiveness of the disease. For instance, P14 described the relapse diagnosis as  
 8 *"So terrible... terrible! It seemed that it was a death sentence"*.

9 Denial and shock were also acknowledged by three parents (20.0%), while symptoms  
 10 of stress, including insomnia and irritability, were reported by five parents (33.4%).  
 11 Conversely, four participants (26.7%) expressed a sense of increased predictability in the  
 12 relapse situation. Another four (26.7%) conveyed experiencing emotional growth during the  
 13 relapse treatment, characterized by emotional fortitude and a more positive perspective on life.

## 14 ***2. Relapse versus first diagnosis***

15 Three participants (20%) expressed that the first diagnosis had been more challenging  
 16 (as it was something new and difficult to accept). Another six (40%) conveyed that the relapse  
 17 was more distressing than the initial diagnosis, since there was a more tangible threat of death:  
 18 *"Now that I know everything we've been through, I had to tell her (child) everything that  
 19 happened... But now I'm more scared than I was before (...) Scared of the worst-case scenario  
 20 becoming a reality"* (P3).

## 21 ***3. Major stressors experienced by the participants***

22 The most frequently mentioned stressor (46.7%) was the lack of social support, often  
 23 attributed to relocating to another city for the child's treatment. Participants associated the lack  
 24 of social support with a heightened level of stress, as exemplified by P2: *"Since all of this  
 25 happened, I've been the sole caregiver staying with him (child) at the hospital, you know? I*

1 *don't have anyone to switch shifts with me. So, I'm the one who must stay strong (...) If the*  
 2 *doctor tells me something, I'm the one who must confront this situation".* Additionally, three  
 3 participants (20%) mentioned having social support at the beginning of the first treatment, but  
 4 over time, this network diminished as people gradually distanced themselves.

5 Three parents (20%) highlighted uncontrollability as a potential stressor, considering  
 6 the treatment's potential negative physiological reactions and complications. Additionally,  
 7 financial losses arising from job loss or treatment costs were identified as stressors by another  
 8 three participants (20%), while the hospital routine was mentioned by two participants (13.4%).

#### 9 ***4. Treatment's psychosocial impact***

10 Eight participants (53.3%) conveyed that their lives were put on hold during the  
 11 treatment for the relapse, discontinuing their work, studies, and/or physical exercise routines.  
 12 P14 shared the impact, stating: *"I wish I could be working, but I resigned from my job last*  
 13 *month. I truly love my job. After he (child) completed the first treatment, I began studying*  
 14 *pedagogy. But then he experienced a relapse, and I had to discontinue my studies".*

15 Moreover, cancer treatment resulted in job loss and/or financial setbacks, causing  
 16 apprehension for 40% of the participants, as exemplified by P13: *"Previously, we were*  
 17 *employed, but now we have financial obligations that we cannot meet or fulfill... It's very*  
 18 *stressful".*

19 The parent-sibling relationship experienced negative repercussions from the  
 20 oncological treatment for three participants (20%), primarily due to the imposed physical and  
 21 emotional distance. Marital life was also affected by cancer treatment for two participants  
 22 (13.4%). In contrast, another two participants (13.4%) expressed that the treatment for cancer  
 23 recurrence strengthened family cohesion, emerging as a crucial source of social support.

#### 24 ***5. Coping strategies***

Distraction was the most frequently reported strategy (60%). This often involved engaging in activities such as crafting or going out, as mentioned by P9: *“I gaze out of the window, watch TV, or iron clothes, you know? My relief valve is the internet”*.

Spirituality/religiosity was also mentioned by the majority of the participants (53.3%), as illustrated by P15: *“It's faith. It is the faith that strengthens me. Both me and him (child)”*. This spirituality was often associated with an acceptance of the uncontrollability of the relapse. A significant proportion (40%) explicitly mentioned this acceptance considering the uncertain prognosis: *“We cry, we let it out. It passes. That's how it goes. You have to accept it, don't you? I've come to accept the treatment once again...”* (P10).

Seven participants (45.7%) stated that receiving social support, especially from other parents whose children were also undergoing treatment, was their coping strategy, such as P8: *“We got to know a lot of people here (in the hospital). People we didn't even know, they're not our relatives, they're not related to us, yet offered us more support than our own family”*. Furthermore, support from family, the healthcare team, friends, teachers, and the religious community was also acknowledged.

One participant (6.7%) who had access to social support found it beneficial for venting their feelings. Additionally, four parents (26.7%) mentioned relying on support from the healthcare team as a coping strategy during their children's treatment. Seeking information, either through internet research or by consulting healthcare professionals, was cited by two parents (13.3%).

On the other hand, five participants (33.3%) adopted isolation, denial, or repression as coping strategies. The reasons for choosing isolation were associated with concerns about people's judgment and a lack of trust in others.

## **6. Relationship parents-patient**

Five participants (33.3%) characterized the relationship between parents and the patient as remarkably close and marked by intense attachment. In all these instances, mothers served as primary caregivers and conveyed that they engaged in all activities together with their children, as the latter were unable to be without them. Within this constant caregiving dynamic, hypervigilance (13.3%, two individuals) and overprotection (6.7%, one individual) were justified by the prevailing fear of loss.

Similarly, in an effort to shield their child from additional suffering, four participants (26.7%) revealed that they chose not to disclose details about their illness, treatment, or the gravity of the situation. Meanwhile, two mothers (13.4%) reported that the patients may still discern the situation and derive secondary benefits. On a different note, two participants (13.4%) highlighted their ability to maintain routines and discipline even during cancer recurrence treatment, in order to provide security and well-being to their children.

Three parents (20%) acknowledged being the primary coping models for their children, and consciously refrained from displaying emotions in front of their children as a means of supporting them through the treatment's challenges. Additionally, three mothers (20%) expressed that the patients served as a vital source of emotional support for them.

### **Qualitative comparative analysis**

The first comparative qualitative analysis aimed to examine the connection between coping strategies (both passive and active) and psychological adjustment problems among parents of children facing cancer relapse. Additionally, the association between the number of stressors and parents' psychopathological symptoms was explored. The results of this analysis indicate that the predominant use of passive coping strategies (such as relying on religion/spirituality, employing denial, isolation, or acceptance) is more closely linked to parental "negative feelings". This association is evident both in the absence of active coping strategies (such as seeking support from the healthcare team, expressing emotions, seeking

social support, searching for information, and engaging in distraction) and when passive strategies are combined with an increased number of stressors (as observed in the first analysis from Table 1).

The second analysis described in Table 1 provides a comprehensive examination of specific coping strategies and types of stressors associated with poorer parental adjustment (more negative feelings) in the context of a relapse situation. Path 1 stands out as a robust analysis, highlighting that the core factors contributing to a heightened presence of negative symptoms include the combination of uncontrollability, the lack of distraction strategies, and the absence of information-seeking behavior. Path 2 further elucidates that, beyond these core conditions, other factors also contribute to parental adjustment challenges. These additional factors encompass the use of repression, or the absence of coping strategies related to accepting uncontrollability, seeking social support, and/or employing religiosity/spirituality.

### Discussion

The results of this study suggest that the experience of having a child with cancer relapse is highly stressful for parents. Depressive symptoms and fear of loss were prevalent among most participants, consistent with previous research<sup>7,6</sup>. Indeed, some participants reported that the relapse situation caused a more significant emotional impact, as it represents a more tangible possibility of the child's death. Consequently, the second (or third) childhood oncological treatment imposes a substantial emotional burden on parents. Moreover, the first cancer experience may contribute to heightened parental psychological vulnerability when faced with a new diagnosis<sup>18</sup>

In the context of a relapse situation, the analysis has revealed that the core contributive factors to parental negative feelings are associated with a higher number of stressors, particularly those related to uncontrollability, and their interaction with the lack of active

1 coping strategies (such as information seeking and distraction). These results align with  
2 observations from previous research<sup>17,12</sup>.

3         Given the heightened uncontrollability and uncertainty surrounding the prognosis  
4 during a relapse, which significantly impacts parents' quality of life, their relationship with  
5 their children, and their marital dynamics, the cultivation of active coping skills becomes  
6 paramount<sup>4,8</sup>. These coping strategies play a crucial role in facilitating decision-making,  
7 regulating emotions, and fostering a greater sense of control, ultimately reducing parental stress  
8 in this highly demanding situation<sup>12,13</sup>.

9         The results of this study also reveal that coping with uncontrollable circumstances and  
10 its consequential impact on parents' mental health can be facilitated through secondary  
11 strategies such as acceptance, social support, and religious/spiritual coping mechanisms. The  
12 acceptance that suffering is inevitable to some extent appears to enhance the psychological  
13 adjustment of participants facing highly uncontrollable situations<sup>13</sup>. Conversely, spirituality  
14 often offers comfort, hope, and aids in acceptance and coping, enabling parents to maintain  
15 their emotional connection with the child<sup>19</sup>.

16         Furthermore, actively seeking social support can significantly alleviate adjustment  
17 problems for parents, especially those in low socioeconomic families and those geographically  
18 distant from their places of origin<sup>20,21</sup>. The distance resulting from the treatment's routine  
19 creates a new support network, wherein parents who are distanced from their families find  
20 mutual support, functioning as both an expansion of the support network and a coping model<sup>22</sup>.

21         In contrast, participants facing the challenges of relapse often resorted to repression  
22 strategies, which significantly contributed to greater emotional difficulties, consistent with  
23 earlier findings<sup>7,23</sup>. Repression was also associated with the lack of searching for social support,  
24 as parents relying on repression mentioned a preference for isolation and not sharing treatment-  
25 related worries.

1           Nevertheless, it is important to note that the sample in this study was composed mostly  
2 of low-income families, which already have several risk factors for parental and child  
3 psychological adjustment<sup>24</sup>. In this context, financial losses—another contributive condition—  
4 caused by layoffs, job resignations, or an increase in medical and non-medical expenses, can  
5 have a greater impact and increase the burden on low-income families<sup>25</sup>. Moreover, low-  
6 income families tend to have a poorer perception of social support than families from other  
7 socioeconomic strata<sup>26</sup>.

8           Thus, we can assume that a deficient family income and the absence of social support,  
9 combined with late diagnosis and lower treatment adherence, commonly observed in low-  
10 income families, may contribute to a poorer prognosis<sup>20</sup>. In fact, this scenario can intensify the  
11 negative feelings experienced by parents of children facing cancer relapse.

12           On the other hand, similar to the observed variations in the literature regarding the  
13 psychological adjustment of parents of children with cancer, the present study also reflects a  
14 diverse range of responses<sup>6</sup>. While many participants exhibited depressive symptoms, a  
15 minority demonstrated resilience and emotional growth, aligning with findings from other  
16 research studies<sup>5,14</sup>. The initial diagnosis was considered a valuable learning opportunity for  
17 anticipating and navigating potential challenges during relapse, ultimately providing a sense of  
18 control<sup>10</sup>. However, despite the insights gained, the experience of relapse was emotionally more  
19 challenging than the initial diagnosis, leading to difficulties in adjustment and adaptation.

20           Overall, the present study underscores the significance of active coping skills in  
21 mitigating negative emotions, such as fear of loss, stress, and depressive symptoms, among  
22 parents of children in cancer relapse. While the effectiveness of activating the support network  
23 is supported by robust scientific evidence, the role of distraction for this population remains  
24 underexplored in the literature. Although distraction techniques are employed with adult cancer  
25 patients<sup>27</sup>, discussions surrounding distraction strategies for children's caregivers primarily



focus on the pediatric patient, with parents mainly serving as mediators<sup>28</sup>. Therefore, future research could benefit from a more comprehensive assessment of the impact of distraction strategies on the psychological adjustment of parents of children with cancer.

Finally, this study has some limitations. Firstly, the small sample size makes it challenging to comprehend the common experiences of parents of children with cancer relapse, although the qualitative methodology allows for an in-depth exploration. One study bias may be associated with the use of unstructured interviews. While they enabled parents to express themselves more freely, they may have omitted other relevant factors in this context that were not mentioned by the participants.

## **Conclusion**

This study revealed that the uncontrollability is a central stressor in childhood cancer relapse, leading to negative feelings among parents. The findings underscore the significance of active coping strategies, particularly those related to distraction and information seeking, in mitigating these negative emotions. Additionally, secondary contributive factors for parental adjustment problems included the absence of social support, a lack of religiosity/spirituality and/or acceptance, as well as the use of repression strategies. Recognizing these conditions is crucial, as it can guide healthcare teams in designing specific interventions for these families, addressing the most relevant and urgent aspects for this population.

In this sense, parents could benefit from early interventions that teach them active coping skills, starting at the relapse diagnosis. This approach aims to expand their repertoire of dealing with stressors and facilitate not only their own adjustment but also their child's. It is, therefore, suggested the promotion of distraction strategies through various spaces and opportunities. Additionally, increasing the quantity and quality of information provided to parents is recommended. This approach aligns with the goal of achieving more humanized

1 assistance and fostering greater communication between parents and the healthcare team, in  
2 line with the guidelines of the Brazilian National Cancer Institute – Inca<sup>29</sup>.

3         Given the challenges inherent to pediatric cancer recurrence, it is crucial to provide  
4 psychological and spiritual support to parents and activate the support network. This aims to  
5 minimize their vulnerability to the uncontrollability of the situation and prevent the emergence  
6 of possible psychopathologies. Therefore, a transdisciplinary approach in caring for parents of  
7 pediatric cancer patients is essential, along with the integration of prevention, promotion, and  
8 treatment actions, as outlined by the Brazilian Health Ministry<sup>30</sup>.

9         Moreover, this study underscores the importance of incorporating qualitative  
10 assessments for caregivers alongside quantitative evaluations. Since parents of children with  
11 cancer relapse are dealing with an abnormal situation, traditional standardized instruments may  
12 not adequately capture their specific challenges, potentially pathologizing parental adaptation  
13 to this condition<sup>23</sup>. Therefore, a qualitative assessment becomes essential to capture the unique  
14 experiences of this population.

15         In light of these findings, it is suggested that parents of children undergoing cancer  
16 relapse, particularly those with psychosocial vulnerabilities, may constitute a group at  
17 psychological risk requiring immediate and early interventions. Specifically within the  
18 Brazilian context, there is a need for the development of accessible and low-cost interventions.  
19 This is essential to align available resources with the needs and demands of families whose  
20 children are undergoing treatment for cancer recurrence.

21

## 1 Table 1

2 *Configurational paths about psychological adjustment problems (negative feelings) in*  
 3 *parents of children with cancer relapse.*

Path	Configuration	Raw cover	Individual cover	Consis tency
First analysis				
1	~Activecoping*passivecoping	0.43	0.14	1
2	Passivecoping*stressors	0.43	0.14	1
Solution cover: 0.57				
Solution consistency: 1				
Second analysis				
1	~distraction*~informationseek*~uncontrol lability	0.67	0.67	1
2	~distraction*~religion*~acceptance*~soci alsupportdeek*~informationseek	0.08	0.08	1
3	~distraction*repression*~informationseek *uncontrollability*finantialloss	0.08	0.08	1
Total solution cover total of the 3 models: 0.83				
Total solution consistency of the 3 models: 1				

4 *Note:* Active coping= seeking support from the healthcare team, ventilating emotions,  
 5 activating social support, seeking information and utilizing distraction. Passive coping=relying  
 6 on religion/ spirituality, negating, self-isolating and accepting uncontrollability. ~ = absence; \*  
 7 = interaction.

8

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