# Quality of life and coping in children with cancer

## *Qualidade de vida e coping em crianças com câncer*

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## Abstract

**Objective**
Cancer illness is a stressful event that affects children's quality of life. This study verified the association between coping and quality of life in 13 children with cancer (6 to 12 years old) from a public hospital in the Southeastern region of the country.

**Method**
The participants answered the Hospitalization Coping Scale and Pediatric Quality of Life 3.0 (Cancer Module). Descriptive and inferential statistical analyses were applied. A high average of adaptive coping and coping behaviors, such as talking, playing, and taking medicine, were observed.

**Results**
The results suggest a potential positive correlation between quality of life related to the domain nausea, which also showed high scores, and adaptive coping, demonstrating children's difficulty in dealing with nausea, even after using adaptive coping strategies, and this domain was significant in reducing the quality of life perceived.

**Conclusion**
Understanding coping and qualitywww of life may steer intervention in Pediatric Oncology.

**Keywords:** Adaptation, psychological; Child; Hospitalization; Neoplasms; Quality of life.

## *Resumo*

***Objetivo***
*O adoecimento por câncer é um evento estressor que afeta a qualidade de vida das crianças. Este estudo verificou associações entre coping e qualidade de vida em 13 crianças com câncer (6 a 12 anos), atendidas em um hospital público da região sudeste do país.*

***Método***
*Os participantes responderam a Escala de Coping da Hospitalização e Pediatric Quality of Life 3.0 (Cancer Module). Análises estatísticas descritivas e inferenciais foram aplicadas. Médias*

*elevadas de coping adaptativo e de comportamentos de coping, como conversar, brincar e tomar remédio, foram verificadas.*

***Resultados***
*Os resultados sugerem uma possível correlação positiva entre qualidade de vida relacionada ao domínio "enjoo", que também apresentou escores altos, e coping adaptativo, demonstrando a dificuldade das crianças para lidarem com náuseas, mesmo usando estratégias de coping adaptativo, sendo esse domínio significativo na diminuição da qualidade de vida percebida.*

***Conclusão***
*Foi concluído que a compreensão do coping e da qualidade de vida pode direcionar a assistência psicológica em Oncologia Pediátrica.*

**Palavras-chave:** *Adaptação psicológica; Criança; Hospitalização; Neoplasias; Qualidade de vida.*

Cancer is the disease that causes most deaths among children and adolescents in Brazil, and is the second leading cause of death in this age group, after accidents and violent deaths (*Instituto Nacional de Câncer* [INCA], 2016). Nevertheless, the survival rate can reach 80% through treatment, and especially through early diagnosis (INCA, 2019). As pediatric cancer survival rates have increased, the focus of studies have expanded to address daily functioning and quality of life in children with cancer during treatment and survival (Antwi et al., 2019; McDonnell et al., 2017; Pan et al., 2017; Siegwart et al., 2022).

It is known that the treatment for this disease is complex and aggressive. In addition to painful procedures and frequent hospital visits during the treatment (Andres et al., 2005), children with cancer experience a number of physical and psychosocial symptoms during their hospital stay (Keener, 2019; Leandro et al., 2018; Linder et al., 2018; Miladinia et al., 2016; Setoyama et al., 2016; Siqueira et al., 2015). Physical symptoms include nausea and vomiting, loss of appetite, difficulty falling asleep, discomfort, numbness/tingling, fatigue, and pain. Nausea and vomiting can be considered one of the worst manifestations of the side effects of cancer treatment. As a result of these symptoms, children lose their appetite, because when ingesting food, they may vomit afterwards. In addition, they also suffer alterations in taste and in the perception of the smell of food (Cicogna et al., 2010). Such physical symptoms affect aspects of quality of life related to socialization, behavioral changes, nutrition, sleep and rest (Polo & Moraes, 2009).

Regarding psychosocial issues, the fact of being away from the family for a long time is pointed out as one of the biggest difficulties in this period. Furthermore, regarding aspects of the hospital setting, there are factors that are difficult to deal with, such as the food and the hospital smell (Linder et al., 2018). Such conditions contribute to the fact that hospitalization and staying away from the family are situations that cause dissatisfaction of pediatric patients (Sommerfeld et al., 2011).

In the case of chronic diseases, such as cancer, the patient lives with the disease for a long time during the treatment and, when cure is not possible, the patient will live with the disease for his/her life. This coexistence of the patients with the disease affects their quality of life. For this reason, we ought to measure the impact of the illness and treatment on the quality of life of those individuals (Rodrigues et al., 2009).

The quality of life of children with cancer was investigated by Sommerfeld et al. (2011), who showed that children under these conditions have lower quality of life indicators when compared to their healthy peers. Also according to the authors, during the course of cancer treatment, the quality of life of these patients decreases due to deprivation, difficulties and impairment during

this period. Polo and Moraes (2009) state that the side effects of cancer treatment, as well as the signs and symptoms of the disease affect children's quality of life.

For Pan et al. (2017), the predictors of a better quality of life in children and adolescents with cancer are associated with healthy family functioning, being young, and having been diagnosed earlier. With regard to factors associated with the worsening of quality of life, fatigue, difficulties in relating to colleagues and in prosocial behavior are mentioned, in addition to receiving a delayed diagnosis.

These characteristics of illness and treatment, with a potential impact on the well-being of children with cancer, can be understood as stressors which children must deal with. At this point, coping stands as a significant process in the adaptation of children with cancer (Caprini & Motta, 2017), since it may mediate the relationship between the stressor and the developmental outcomes, such as the child's perception of well-being, that is, his/her quality of life.

From a developmental perspective, coping refers to a process of self-regulation of the individuals, regarding their behavior, emotion and guidance in the face of stressful conditions (Skinner & Wellborn, 1994). From this perspective of coping such as a regulatory action in stressful conditions, Skinner and Wellborn (1994) proposed the Coping Motivational Theory (CMT), according to which stressful events are those that threaten or cause damage to the basic psychological needs of the individual i.e.: (a) relationship, which refers to feeling securely in contact with other people, capable of loving and being loved; (b) competence, in which the individual seeks to achieve positive results and to avoid negative results, establishing effective interactions with the environment; and (c) autonomy, related to the individuals' freedom to make their own choices, establishing self-determined interactions with the environment (Skinner & Wellborn, 1994). In this connection, coping refers to the individuals' efforts to maintain, restore or repair these needs (Ramos et al., 2015; Skinner & Wellborn, 1994).

The measure of coping, based on the CMT, is grounded on a hierarchical structure, in which the instances of coping are at the base, that is, they constitute the numerous responses of the individuals in the management of stressors, and can be operationalized in the self-report of coping behaviors or real-time observations (Skinner et al., 2003). The coping strategies stand at a higher level, which correspond to the organization of coping instances in categories, according to their functional value; and the coping families, also referred to as higher order categories, characterized by being multidimensional and multifunctional, classify coping strategies and are associated to the adaptive process (Skinner et al., 2003). Coping families can be grouped into (a) adaptive, defined by the assessment of the stressor as a challenge and relating to a positive developmental outcome; they include: self-confidence, support-seeking, problem-solving, information-seeking, accommodation and negotiation; and (b) maladaptive, defined by the assessment of the stressor as being a threat and related to a negative developmental outcome, namely: delegation; isolation; helplessness; escape; submission; and opposition (Skinner et al., 2003; Skinner & Zimmer-Gembeck, 2007). The developmental outcomes refer to the repercussions that the use of coping families in the face of the encounters that the stressor had over time, on the physical and mental health of the individual (Ramos et al., 2015).

The CMT has been the basis for the development of studies on the understanding of coping in children under stressful situations, such as childhood cancer (Caprini & Motta, 2017; Hostert et al., 2015; Pagung et al., 2017; Padovani et al., 2021), and for different diseases that require hospitalization (Garioli, 2016; Moraes & Enumo, 2008; Vicente, 2017). These studies stem from the work of the *Grupo de Trabalho em Psicologia da Saúde da Criança e do Adolescente*

(Working Group on Child and Adolescent Health Psychology), linked to the *Associação Nacional de Pesquisa e Pós-Graduação em Psicologi*a (National Association for Research and Post-Graduate Studies in Psychology). In a review of studies on stress and coping conducted by researchers from the Working Group on Child and Adolescent Health Psychology (Enumo et al., 2019), it was found that most of these studies investigated coping, using the *Instrumento de Avaliação das Estratégias de Enfrentamento da Hospitalização* (AEH, Assessment of Hospitalization Coping Strategies in its manual version (Motta & Enumo 2002, 2004) and computerized version (Moraes & Enumo, 2008; Motta & Enumo, 2010). Also according to the review authors, the AEH was adapted to a scale version, resulting in the Hospitalization Coping Scale (COPE-H), which was validated in the study by Garioli (2016), and also used in the study by Vicente (2017). As a result of these studies, it appears that hospitalized children and adolescents (6 to 12 years old) use, to a greater extent, strategies related to the perception of the stressor as a challenge to the psychological needs of competence, with family coping strategies to solve the problem; relationship, with support-seeking coping families strategies; and autonomy, with family distraction strategies from coping families accommodation. Coping family strategies related to threat perception, especially the need for autonomy, with the use of rumination strategies and magical thinking, were also identified, but to a lesser extent (Enumo et al., 2019).

Given the above and considering the understanding about the process of illness and hospitalization for cancer, with regard to the repercussions on the well-being of children affected by the disease, this study proposes the hypothesis that variables of the children themselves, such as their strategies for coping affect their quality of life. This investigation aimed to verify the relationship between coping of children hospitalized with cancer and quality of life indicators.

## Method

### Participants

Thirteen children with cancer participated in this investigation. They were aged between 6 and 12 years, with an average age of 7.92 years; were attended at the Onco-Hematology Service of the *Hospital Estadual Infantil Nossa Senhora da Glória* (Nossa Senhora da Glória State Children's Hospital), located in the southeastern region of Brazil. A total of 6 participants were girls and 7 were boys. The children formed a convenience sample, considering the following inclusion criteria: (a) having been diagnosed with cancer; (b) be between 6 and 12 years old, considering the need that they understood the investigation instruments; (c) being in-patients in the context of hospitalization or hospital/day; and (d) have previous hospital experience on cancer treatment. Cases of children in critical condition and/or hospitalized in the intensive care unit were excluded. Their parents and/or guardians also participated as informants.

All children who participated in the study were accompanied by a family caregiver, responsible for providing consent for them to participate in the study. Thus, those who gave their consent to participate were included in the investigation, after they would read the free and informed consent form and the assent form. The identity of the participants was kept confidential.

Table 1 describes clinical and sociodemographic data of the participating children and adolescents; this information was obtained from the medical records and interviews with the patients' parents and/or guardians. Such data are presented with the aim of characterizing the sample and in the context of the study.

**Table 1**
*Sociodemographic and clinical characterization of the sample (N = 13)*

| Variables | Amounts |
|---|---|
| Sociodemographic characteristics | |
|     Age [*M (SD)*] | 7.92 (1.71) |
|     Education [*M (SD)*] | 3.92 (1.93) |
| Gender [*n* (%)] | |
|     Female | 6 (46.2) |
|     Male | 7 (53.9) |
| Origin [*n* (%)] | |
|     Interior of the State | 5 (38.5) |
|     Metropolitan region | 5 (38.5) |
|     Rural area/other state | 3 (23.1) |
| Attending school [*n* (%)] | |
|     Yes | 5 (38.5) |
|     No | 8 (61.5) |
| Attending Hospital School [*n* (%)] | |
|     Yes | 12 (92.3) |
|     No | 1 (7.7) |
| Parents' marital status [*n* (%)] | |
|     Divorced | 6 (46.2) |
|     Married or common law marriage | 7 (53.9) |
| Clinical characteristics | |
|     Type of Cancer [*n* (%)] | |
|         Leukemias | 5 (38.5) |
|         Lymphoma | 1 (7.7) |
|         Solid tumors | 7 (53.8) |
| Diagnosis time in months [*M (SD)*] | 21.62 (21.36) |
| Length of stay during treatment in days [*M (SD)*] | 44.45 (8.37) |
|     Context of hospitalization [*n* (%)] | |
|         Day hospital | 8 (61.5) |
|         Hospitalization | 5 (38.5) |

Most of the children came from the metropolitan region (38.5%) and from inland municipalities (38.5%), and had an average of 3.92 years schooling. At the time of the study, most children were not attending regular school (61.5%), but almost the entire sample had already attended or was attending the Hospital School offered by the hospital (92.3%). A little over half of the children had parents who were married or in a common law marriage (53.9%), and most families had two children (46.2%) or more (30.8%), and the child with cancer was the second or third child in 61.5% of cases. Regarding the monthly income of families, the majority received less than 1 minimum wage (61.5%).

Regarding the clinical characteristics, the type of cancer showed variability in the sample, with a higher proportion of leukemias (38.5%). The mean time (in months) elapsed from the diagnosis of cancer was 21.62 (SD = 21.36), and most children were in the treatment maintenance phase (61.5%). Chemotherapy treatment, including intravenous and oral, was used in almost the entire sample (80%). According to family caregivers, the reasons for children's hospitalizations during treatment were complications (31.2%), followed by diagnosis (25%) and medication (18.8%). It was found that the children had, on average, 2.64 (SD = 2.66) occurrences of hospitalization throughout the treatment, totaling an average of 44.45 days hospitalization in the Onco-hematology ward of the hospital.

### Instruments

The data reviewed were obtained from the application of the Hospitalization Coping Scale (COPE-H) (Garioli, 2016; Garioli, Machado, et al., 2016). This is the adaptation to the scaled version of the Assessment of Hospitalization Coping Strategies (AEH), developed by Motta and Enumo (2004, 2010). The AEH is a self-report instrument that includes the survey on each child's response, in order to classify them into coping strategies and families, through content analysis based on the CMT. In COPE-H, the construction of the scale items considered the coping components proposed by the CMT.

In more detail, the COPE-H is composed of 17 boards, with colored drawings (boy and girl versions), which represent the child's responses (what the child does, thinks or feels) regarding the stressor, such as playing, talking, seeking information, crying, be sad, discouraged, among others. The child should inform how much the drawing represents what he/she does, thinks or feels (behaviors or instances of coping) to face hospitalization. At a higher level of analysis, the boards representing the coping instances are shown again, but accompanied by an item that presents its functionality, covering a coping strategy. Thus, when informing that they play to face hospitalization, children must answer the items that deal with the functionality of playing, such as "I play to pass the time". In both situations (coping instances and coping strategies), the response is given using a Likert-type scale, where 0 = never, 1 = a little, 2 = sometimes, 3 = almost always, 4 = always).

The instrument validation study in a sample of children hospitalized for different causes found three factors for the scale (Garioli, 2016). Factor 1 – Hospital Maladaptive Coping contains coping responses that are mostly involuntary and often hamper the process of adaptation to the hospital setting. This factor is made up of 27 items that represent the six coping families associated with perceived threat to basic psychological needs, such as Submission, Opposition, Helplessness, Escape, Isolation and Delegation. As an example of items in this factor, there are item 10- I cry because I believe this will never end; and item 51- I am afraid and I just keep thinking that I won't leave this place (Garioli, 2016). Factor 2 – Hospital Adaptive Coping contains voluntary coping responses, which represent the six coping families that generally lead to an adaptive outcome in the medium and long term: Negotiation, Accommodation, Self-confidence, Seeking Support, Problem Solving, and Seeking Information , divided into 27 items, such as item 40- I seek someone to talk with, to feel more confident and item 65- I try to know more about my problem and the treatment to be aware of what I can do to improve (Garioli, 2016). Factor 3 – Involuntary and Voluntary Disengagement Coping, with 11 items that characterizes involuntary (8 items) and voluntary (3 items) coping responses. Such responses have the motivational orientation of moving away from the stressor, which occurs through strategies commonly related to a maladaptive outcome, such as Escape, Helplessness, Submission and Delegation; and also by emotional regulation responses, in the sense of moving away from the negative affect represented by the stressor. Examples of this factor items are: item 35- I dream in running away from the hospital to get away from the injections; and item 60- When they give me medicine, I feel like pushing off the nurse (Garioli, 2016).

The study by Garioli (2016) found evidence of the COPE-H validity, with satisfactory internal consistency indicators for the factors: Factor 1- Hospital Maladaptive Coping (Cronbach's alpha = 0.98); Factor 2- Hospital Adaptive Coping (Cronbach's alpha = 0.73) and Factor 3- Involuntary and Voluntary Hospital Disengagement Coping (Cronbach's alpha = 0.69).

For this study, we used the digitized version of the COPE-H Scale, called the Hospital Coping Scale: digitized version [COPE-HD] (Garioli et al., 2020). It is a version adapted to a digitized application format, presented as an application, to be used on mobile devices, such as tablets. This

format preserved the playful and interactive aspect of the instrument, and maintained the theoretical and methodological structure of the manual version.

Data on quality of life were obtained by applying the Pediatric Quality of Life (PedsQL™) Cancer Module (PedsQL) (Varni, Seid, et al., 2002). This instrument is based on the World Health Organization (WHO) definition of quality of life (Varni et al., 2001). According to the WHO, this concept has been defined as "[...] an individual's perception of their position in life in connection with the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHOQOL Group, 1994, p. 41). According to the WHO, instruments that assess quality of life should include the physical dimensions (individual's perception of their physical condition); psychological (individual's perception of their affective and cognitive condition) and social (individual's perception of social relationships and social roles adopted in life) (The WHOQOL Group, 1995; Varni et al., 2001). Quality of life is classified in a more generic perspective as well as related to health, thus being more specific. In this connection, the PedsQL™ instrument integrates generic basic scales as well as disease-specific scales (Varni et al., 2001). PedsQL™ scales were developed by Dr. James W. Varni, to measure the quality of life in healthy children and adolescents, as well as those with acute and chronic diseases, including cancer. In general, the scales are a sensitive measure of the child's cognitive development and, therefore, include the patients' self-report, and the caregiver's hetero-report can also be obtained (Varni, Burwinkle, et al., 2002). In this study, the PedsQLTM version for cancer based on the child's self-report was used.

The PedsQLTM Cancer Module (PedsQL) is intended to assess the impact of disease and treatment on the quality of life in children and adolescents with cancer (Varni, Seid, et al., 2002). The instrument consists of 27 items distributed in 8 subscales: pain (2 items) – Example: "I feel a lot of pain"; nausea (5 items) – Example: "I get sick when I receive medical treatment"; anxiety about the procedures (3 items) – Example: "I am afraid of getting pricked by needles"; anxiety about treatment (3 items) – Example: "I am afraid when I am waiting to be seen by the doctor"; concerns (3 items) – Example: "I worry that my cancer may come back"; reasoning problems (5 items) – Example: "I have trouble paying attention to things"; perception of physical appearance (3 items) – Example: "I don't like other people to see my scars"; and communication (3 items) – Example: "I have trouble telling doctors and nurses how I feel".

The answer is provided on a five-point Likert-type scale that corresponds to 0 - never; 1 - almost never; 2 - sometimes; 3 - often; and 4 - almost always. For children aged 5-7 years, there is an adaptation for 3 answers, namely: 0 – never; 2 - sometimes; and 4 - almost always. In this case, a Face Scale is also used; it is composed of three figures of facial expressions ranging from a smiling face to a very sad face corresponding, respectively, to the answers "never"; "sometimes"; and "almost always". It is important to mention that in PedsQL, the score comprises the values of the responses inversely transformed on a scale from 0 to 100; that is, 0 = 100; 1 = 75; 2 = 50; 3 = 25 and 4 = 0; and, for children aged 5-7 years, 0 = 100; 2 = 50 and 4 = 0. Regarding the interpretation of the scale, higher scores indicate lower levels of difficulties associated with the disease and/or treatment, that is, better perception of quality of life. The information presented was based on the instrument manual.

## Procedures

Data collection took place between February and March 2020, it was interrupted because of the COVID-19 pandemic. The study began after approval by the Institution's Research Ethics Committee, in accordance with Norm nº 196/96 of the National Research Ethics

Commission – Conep/National Health Council/Ministry of Health, under the number of Certificate of Submission for Ethical Review (CAAE 07747518.6.0000.5542, protocol 3.295.064).

After selection of the participants to compose the sample, the Free and Informed Consent Form was presented to family members/caregivers, and the Free and Informed Assent Form to the children, through which the objectives of the study were explained, the conditions of confidentiality and respect for their well-being were explained, as well as the voluntary nature of their participation. After agreeing and expressing their will to participate in the study, the terms of the free and informed consent and the assent form were signed.

The application of the survey instruments took place in several places in the onco-hematology sector of the hospital, such as the toy library, research room and wards. At first, sociodemographic data and clinical data of the participants were collected from family members'/caregivers, through an interview. In cases where the characteristics of the disease and treatment were unknown, information was collected from the child's medical records.

Prior to the application of the instruments, the investigator sought to establish rapport with the child, through playful verbal interaction, in order to provide a relationship of trust between them. Then, the Hospitalization Coping Scale (COPE-HD) was applied – to measure coping, with duration of around 45 minutes. The application was carried out on a tablet manipulated by the child himself, who was instructed to click in the field that represented their response to the item and then on the field that allowed them to proceed to the next screen. This response process was monitored by the investigator, who read the items to the child. After the application of the COPE-HD, the child responded to the Pediatric Quality of Life (PedsQL™) Cancer Module (PedsQL) to measure quality of life. The application lasted about 20 minutes, with each item being read by the investigator, who also recorded the child's response.

## Data Analysis

The data collected through the instruments were processed and reviewed according to the instructions of their own manuals, standards and/or authorial indication, as informed in their description. Thereafter a data descriptive statistical analysis was performed through summary measures (mean, standard deviation, minimum, median, maximum, frequency and percentage). Correlation analyses were used to answer the main objective which was to verify the relationship between coping and quality of life. More specifically, the Spearman correlation coefficient was used. Spearman's correlation coefficient can vary from -1 to 1, with values closer to zero indicating absence of correlation between the variables. Whereas 0.7 to 0.9, positive or negative, indicates a strong correlation; 0.5 to 0.7 positive or negative a moderate correlation and 0.3 to 0.5 positive or negative a weak correlation, it is worth noting that: no strong correlations were found between the variables associated, but two possible moderate correlations were found with adaptive coping. Thus, the classification from moderate (r value equal to or greater than 0.50) was used to suggest a possible correlation between the variables (Shaughnessy et al., 2012), since the small sample size did not allow to test the null hypothesis that the correlation coefficient is equal to zero.

## Results

Data on coping were obtained from the children, who responded to the COPE-HD scale, allowing the understanding of the most frequent coping behaviors, as well as the coping factors that characterized the study sample. The coping behaviors that scored the highest averages were:

talking (*M* = 3.2); playing (*M* = 3.1), taking medicine (*M* = 3.1), crying (*M* = 2.9), watching TV (*M* = 2.5) and feeling courageous (*M* = 2.5). The lowest averages were observed in hiding (*M* = 0.8), feeling guilty (*M* = 0.9), feeling scared (*M* = 1.6), seeking information (*M* = 1.8) and thinking about running away (*M* = 1.8). It appears that Adaptive Coping (*M* = 71.70; *SD* = 15.50) presented a higher average in relation to the other factors that presented an average equal to 45.40 *(SD* = 17.30) for Maladaptive Coping and average 21.10 (*SD* = 6.49) for Involuntary and Voluntary Disengagement Coping. The table below shows the frequency of coping behaviors used by children (Table 2).

**Table 2**
*Coping behaviors of hospitalized children with cancer, from the Hospitalization Coping Scale*

| Coping behaviors | Frequency | | | | | *M* | *SD* |
| --- | --- | --- | --- | --- | --- | --- | --- |
| | No | A little | Some-times | Often | Always | | |
| To talk | 0 | 1 | 2 | 3 | 7 | 3.2 | 1,0 |
| To play | 1 | 1 | 2 | 1 | 8 | 3.1 | 1.4 |
| Take medicine | 1 | 1 | 2 | 1 | 8 | 3.1 | 1.4 |
| To cry | 1 | 1 | 2 | 3 | 6 | 2.9 | 1.3 |
| Feel courage | 3 | 0 | 2 | 3 | 5 | 2.5 | 1.6 |
| Watch TV | 0 | 5 | 1 | 2 | 5 | 2.5 | 1.4 |
| Feel angry | 3 | 1 | 1 | 4 | 4 | 2.4 | 1.6 |
| Pray | 3 | 2 | 1 | 2 | 5 | 2.3 | 1.7 |
| Listen to music | 3 | 2 | 1 | 3 | 4 | 2.2 | 1.6 |
| Feel sad | 2 | 3 | 2 | 2 | 4 | 2.2 | 1.5 |
| Make a deal | 5 | 1 | 0 | 2 | 5 | 2.1 | 1.9 |
| Feel discouraged | 4 | 1 | 3 | 2 | 3 | 1.9 | 1.6 |
| Searching information | 5 | 1 | 1 | 3 | 3 | 1.8 | 1.7 |
| Think about running away | 6 | 1 | 1 | 0 | 5 | 1.8 | 1.9 |
| Feel scared | 4 | 1 | 5 | 2 | 1 | 1.6 | 1.3 |
| Feel guilty | 8 | 0 | 4 | 0 | 1 | 0.9 | 1.3 |
| Hide | 9 | 1 | 1 | 0 | 2 | 0.8 | 1.5 |

The children also provided data on quality of life, responding to the PedsQL, which made it possible to know the domains of cancer-related quality of life perceived as being more preserved (higher score) and those perceived as disease-related difficulties (lower score). The quality of life measure showed that the domains with the highest scores in the children's perception were: Anxiety about the procedures (*M* = 74.36) and Anxiety about the treatments (*M* = 69.87), meaning less difficulties in these aspects, that is, better perception of quality of life. The analysis of the items that make up these domains shows that the items "I'm afraid of taking blood tests" (*M* = 84.62) and "I'm afraid of visiting the doctor" (*M* = 80.77), respectively, had higher means, representing less difficulty for the children in the study. The quality of life domain with the lowest score was Nausea (*M* = 43.46), meaning greater difficulties in this area, that is, worse perception of quality of life. Consistent with these data, this domain included the items with the lowest means: "Treatments make me too sick to be able to eat" (*M* = 28.85) and "Some foods and smells make me sick" (*M* = 38.46); that is, those are the items that represent the greatest difficulties for children. In addition to the items already mentioned in the Nausea domain, the item "I worry that my cancer may come back", in the Worry domain, presented an average of 40.38, indicating a greater problem in this aspect.

Using the Spearman correlation test, the results suggest a potential positive correlation (*p* = 0.63) between adaptive coping and quality of life in the anxiety domain in relation to the

treatments (Table 3). This means that the greater the amount of adaptive coping behaviors presented by children, the less children feel anxiety related to the treatments to which they have to undergo. The results also indicated a possible negative correlation ( $p$ = -0.64) between adaptive coping and quality of life in nausea domain; this means that the more adaptive coping children have, the lower their perception of quality of life – the more they feel bad – about their nausea.

**Table 3**
*Values of the Spearman Correlation Coefficient between the Scores Obtained by the Hospitalization Coping Scale (Coping) and by the Pediatric Quality of Life 3.0 (Quality of Life) (N = 13)*

| Quality of Life | COPE-HD Maladaptive | COPE-HD Adaptive | COPE-HD Involuntary and voluntary disengagement |
|---|---|---|---|
| Total score | -0.352 | 0.055 | -0.238 |
| Pain | -0.117 | 0.214 | 0.048 |
| Nausea | -0.028 | -0.635 | -0.057 |
| Anxiety about procedures | -0.304 | -0.109 | -0.182 |
| Anxiety about treatments | -0.359 | 0.628 | -0.100 |
| Worry | -0.435 | -0.258 | -0.339 |
| reasoning problems | -0.214 | 0.199 | -0.093 |
| Physical appearance perception | 0.098 | 0.204 | -0.065 |
| Communication | -0.363 | -0.185 | -0.401 |

Note: COPE-HD: Hospitalization Coping Scale; PedsQL: Pediatric Quality of Life 3.0.

## Discussion

This study assessed the relationship between coping and quality of life in children hospitalized with cancer and corroborated the hypothesis that the coping strategies that children use to face the stress arising from the disease and its treatment affect their quality of life. Regarding the coping of hospitalization by children, it was observed that the highest averages are in behaviors that facilitate a more adaptive outcome, among them: playing, talking and taking medicine, corroborating other studies in the area (Caprini & Motta, 2017;  Hostert et al., 2015; Motta et al., 2015; Padovani et al., 2021).

Regarding the behavior of playing in the context of hospitalization, there is an immediate therapeutic effect for children, thus promoting well-being (Motta & Enumo, 2002). In addition, playing can be an effective tool for children to allow them to deal with the characteristic idleness of the hospitalization period, especially when they need to stay connected to drug infusion pumps (Sposito et al., 2018). With reference to the Motivational Theory of Coping, playing behavior may have features related to distraction that are associated with the ability to make adjustments, reconciling the children's preferences and the options available in the environment, which is part of a coping family called accommodation (Skinner et al., 2003).

Adaptive outcomes may also be favored by conversational behavior, which may have the functionality of seeking support, comfort or help (Skinner et al., 2003). Studies that evaluated coping in children with cancer also indicated the presence of talking behavior (Caprini & Motta, 2017; Hostert et al., 2015; Motta et al., 2015; Padovani et al., 2021). The support-seeking functionality attributed to the behavior of talking to another child is based on the theoretical model used (Skinner et al., 2003). Despite this, the content of the conversation may include information about the disease, treatment and hospitalization, which would add information search functionality to the conversation behavior. In COPE-H and earlier versions of the instrument, such as the AEH, the search

for information functionality is measured by the child's conversation with the health professional and is often among the least mentioned behaviors (Caprini & Motta, 2017; Garioli, 2016).

The children in this study also tend not to seek information in the hospital context, which corroborates the findings of a literature review study (Azevêdo et al., 2017). The authors point out that children are commonly excluded from the communications established between doctors and family members, and the intrafamily communication is the main source of information for the child. These findings are important for directing psychological intervention with hospitalized children, as shown in the study by Vicente (2017). The author found a low frequency of information search using COPE-H before the psychological intervention that used a psychoeducational material, focusing on expanding the behavioral repertoire related to adaptive coping. As an example, the material used presented the functionality of some behaviors, such as "asking", which allows obtaining information about hospitalization, treatment and illness, from the health team. After the intervention, children reported more information seeking, demonstrating possible effects on the child's autonomy in communication with the health team (Vicente, 2017).

The behavior of taking medicine was also present in studies on children with cancer (Caprini & Motta, 2017; Hostert et al., 2015; Padovani et al., 2021) as well as in other hospitalization contexts (Silveira et al., 2018). Based on the theoretical model adopted in the study, this behavior is characterized as an instrumental action that allows children to adjust their actions to be more effective in the setting, which comprises the functionality of the coping family of problem solving (Skinner et al., 2003). This coping family seems to solidify on a developmental basis, given the cognitive resources available to children during school age, in which they are increasingly able to coordinate their personal efforts with those of others and with the environment (Skinner & Zimmer-Gembeck, 2015).

It is interesting to note that among the most mentioned coping behaviors "crying" is included. In this connection, even if the child engages in distracting behaviors, such as playing and watching TV, the hospitalization stressors can acquire a magnitude that limits their action. This limit of action on the children can lead to helplessness, in a perception of threat to their need for competence (Skinner & Wellborn, 1994). On the other hand, crying tends to be a possible reaction to the stressor, which can even be adaptive due to the possibility of emotional expression. This point highlights the complexity of understanding some behaviors in the illness and hospitalization process, because even considering the emotional relief that can be observed as a result of crying, it is a behavior that deserves attention.

Regarding the coping factors, the study showed that adaptive coping scored higher. This finding is consistent with the one obtained in the COPE-H validation study, despite using a different sample (Garioli, 2016). In addition, since the adaptive coping factor consists of coping strategies related to the families: accommodation, search for support, problem solving, self-confidence, negotiation and information search, we can assess that it is in line with studies with the AEH that showed the predominance of this type of coping families (Caprini & Motta, 2017; Hostert et al., 2015).

Regarding quality of life, the interpretation of the instrument suggests that a higher score means a better perception of quality of life or less difficulty in the domains assessed. In this connection, the children in the study did not show difficulties in most domains, especially anxiety regarding procedures and anxiety in connection with treatments. However, they had difficulties with nausea. Similar findings were also found in studies that used the PedsQLTM 3.0 Cancer Module (Batalha et al., 2015; Dupuis et al., 2016).

In a US study, children undergoing cancer treatment experienced a reduction in treatment-related anxiety, procedure-related anxiety, and pain during the first year of treatment.

However, the worsening of nausea after 6 months of treatment was highlighted (Dupuis et al., 2016). Similarly, in a Portuguese study, the children did not present difficulties regarding anxiety treatments, but both children and their parents scored low quality of life related to the nausea domain (Batalha et al., 2015). In the present study, the data also indicated the children's difficulty to cope with nausea caused by food and medical treatments. It appears that, even if the child can count on antiemetics, available in the hospital setting and provided for in the treatment protocols for antiemetic prophylaxis, nausea is one of the most reported untoward effects of chemotherapy treatment (Marsilio et al., 2014). Despite the efforts of doctors with pharmacological interventions in connection with the treatment of nausea and vomiting, pediatric patients still have to deal with this symptom (Hooke & Linder, 2019).

In the same analysis direction, the perception of quality of life associated with nausea was associated with adaptive coping. The relationship was negative, so that the greater the adaptive coping, the lower the perception of quality of life. Adaptive coping includes strategies related to problem solving, information seeking, negotiation, for example. However, in managing nausea responses, they may not be enough. Even with the advancement of medicine, which introduced antiemetics for the management of nausea in cancer patients, these responses are still present. Depending on the antineoplastic used by the treatment protocols, the emetogenic potential may vary, so that symptom control and the appropriate combination of drugs are necessary (Santos et al., 2015). This is a necessity in children's health care, since nausea and vomiting are still the side effects that generate a lot of anguish and scare in pediatric cancer patients (Perwitasari et al., 2011; Santos et al., 2015). These data suggests a limitation of the study, with regard to the investigation of clinical variables related to the treatment, such as the administration of antiemetics and even the presence of symptoms such as nausea and vomiting, which could contribute to a better understanding of the outcome regarding quality of life in the nausea domain.

In another domain of quality of life, the presence of adaptive coping showed a positive correlation, indicating fewer difficulties in that area. This is the treatment-related anxiety domain. This domain addresses the child's perception of fear responses in going to the hospital, as well as in waiting to be seen by the doctor. In this connection, the children in the study more often mentioned coping behaviors (playing and watching TV, for example), which are associated with adaptive coping strategies and families, which make up the adaptive coping factor of COPE-H (Garioli, 2016) and also its digitized version (COPE-HD).

In the case of the most mentioned behaviors, one of the features is distraction, from the accommodation coping family, which includes flexible adjustments to the situation (Skinner et al., 2003). Such adjustments are possible when the environment is structured to offer options that meet the individual's preferences. This is what happens in the hospital, when children can wait for a medical appointment in playful environments, such as the toy library, or even at the reception, when recreational activities are offered, through an itinerant toy library, for example. Such actions can favor the use of adaptive coping and dampen the emotional reactions of scare associated with the hospital context and the medical visit.

Studies demonstrate the use of distraction coping strategies, such as playing and watching TV by hospitalized children to adapt to the context, as in cases of sickle cell disease (Dias et al., 2019; Garioli et al., 2019), of childhood cancer (Caprini & Motta, 2017) and of different causes for hospitalization (Garioli, 2016; Silveira et al., 2018). Playful spaces can also contribute to the resignification of the hospital environment, associating it with family and playful elements, typical of the child's development environment.

# Conclusion

This survey sought to understand the relationships between variables associated with coping and quality of life in children with cancer. It was assessed that the use of adaptive coping can be an indicator of quality of life for children. It is known that adaptive coping is associated with a positive outcome, highlighting in this study the use of family accommodation strategies, which allowed distraction through behaviors of playing and watching TV. Furthermore, in the presence of adaptive coping, the analysis suggested lower anxiety regarding cancer treatment, that is, a better quality of life. However, it was not enough to manage nausea responses, one of the factors that affected most the participants' quality of life.

Despite the study findings, limitations were observed, such as the small sample size, which did not allow testing the null hypothesis that the correlation coefficient is equal to zero. For this reason, the results were described in terms of possible relationships. The composition of larger samples in the hospital environment can be a challenge, especially when the aim is to obtain data from the children themselves, since their clinical conditions must be taken into account in the investigator's approach.

On the other hand, obtaining data from the child himself is characterized as a relevant point of the study. The quality of life and coping measures used are specific to the child and are based on the particularity of the cancer illness and the hospitalization that the treatment imposes. The findings of the study suggest that such measures can compose the resources for psychological assistance in Pediatric Oncology, by monitoring well-being indicators and directing the intervention focused on coping with stressors associated with the disease and treatment, which includes hospitalization.

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## Contributors

J. R MATOS contributed to the concept and design; analysis and interpretation of data; review and approval of the final version of the article. A. B. MOTTA contributed to the concept and design; data analysis and interpretation; review and approval of the final version of the article. A. P. M. COUTINHO and A. L. M. GONÇALVES contributed to the data analysis and interpretation.