

Caregiver profile during the process of illness in children and adolescents with cancer

Perfil do acompanhante durante o adoecimento de crianças e adolescentes com câncer

Perfil del cuidador durante el proceso de enfermedad de niños y adolescentes con cáncer

Hellen Francine Bruno Bulcão¹ 

Jayne Matos de Alcântara² 

Layse Matos Rebouças Mota³ 

Larissa de Oliveira Barbosa⁴ 

Priscila Correia da Silva Ferraz⁵ 

¹⁻³Centro Universitário UniFTC (Salvador). Bahia, Brazil. hellen_fbb@hotmail.com, jaynematos@outlook.com.br, matos_layse@hotmail.com

⁴Grupo de Apoio à Criança com Câncer (Salvador). Bahia, Brazil. larissaoliveirabfisiogmail.com

⁵Corresponding author. Centro Universitário UniFTC (Salvador). Bahia, Brazil. pris_correia@hotmail.com

ABSTRACT | INTRODUCTION: Parental care for a child or adolescent under antineoplastic treatment exposes parents or guardians to greater responsibilities required by this. These changes affect family relationships, personal life, work, and even the relationship of parents and children. **OBJECTIVES:** To describe the profile and participation of the family caregiver of children and adolescents with cancer in a support home. **METHODS:** This is a cross-sectional study with a quantitative/qualitative approach of a descriptive type. Caregivers of both sexes, over the age of 18 (eighteen) years, were included in the study, and caregivers who demonstrated some cognitive, language, and/or difficulty in understanding were excluded. Data collection was carried out using a questionnaire with the caregivers from October 2019 to January 2020. **RESULTS:** The study sample consisted of 12 caregivers, 11 of whom were female, mean age 36.33 ± 24.95 years, of whom 8 (67%) were single, reported being the parents of the children/adolescents, have other children and at least one of them lives with them, most of them 25% have more than 3 children, 17% have 2 children and 8% only 1 child. **CONCLUSION:** With the need to leave the job to take care of the child, most caregivers do not perform any occupation. As they live far from the care unit, the opportunity to stay in a support home facilitates access to treatment.

KEYWORDS: Oncology. Pediatrics. Caregivers. Care.

RESUMO | INTRODUÇÃO: O cuidado parental de uma criança ou adolescente em tratamento antineoplásico expõe os pais ou responsáveis a maiores responsabilidades. Essas alterações afetam as relações familiares, da vida pessoal, do trabalho e até mesmo na própria relação de pais e filhos. **OBJETIVOS:** Descrever o perfil e a participação do acompanhante de crianças e adolescentes com câncer em uma casa de apoio. **MATERIAIS E MÉTODOS:** Trata-se de um estudo transversal com abordagem quanti/qualitativa do tipo descritivo. Foram incluídos no estudo acompanhantes de ambos os sexos, com idade superior a 18 (dezoito) anos e excluídos os acompanhantes que demonstraram apresentar algum déficit cognitivo, de linguagem e/ou dificuldade de compreensão. A coleta de dados foi realizada através do uso de um questionário com os acompanhantes no período de outubro de 2019 a janeiro de 2020. **RESULTADOS:** A amostra do estudo foi constituída por 12 acompanhantes, sendo 11 do sexo feminino, idade média de 36,33 ± 24,95 anos, dos quais 8 (67%) eram solteiros, relataram serem os pais das crianças/adolescentes, possuírem outros filhos e pelo menos um destes residirem com eles, a maioria deles, 25%, possui mais de 3 filhos, 17% possuem 2 filhos e 8% apenas 1 filho. **CONCLUSÃO:** Com a necessidade de deixar o emprego para cuidar da criança, a maioria dos acompanhantes não desempenha nenhum tipo de ocupação. Como residem distante da unidade de atendimento, a oportunidade de permanecer numa casa de apoio facilita o acesso ao tratamento.

PALAVRAS-CHAVE: Oncologia. Pediatria. Acompanhantes. Cuidado.

RESUMEN | INTRODUCCIÓN: El cuidado parental de un niño o adolescente en tratamiento contra el cáncer expone a los padres o tutores a mayores responsabilidades que este requiere. Estos cambios afectan las relaciones familiares, la vida personal, laboral e incluso la relación entre padres e hijos. **OBJETIVOS:** Describir el perfil y participación de acompañantes de niños y adolescentes con cáncer en un hogar de apoyo. **MATERIALES Y MÉTODOS:** Se trata de un estudio transversal con un enfoque descriptivo cuantitativo / cualitativo. Se incluyó en el estudio a acompañantes de ambos sexos, mayores de 18 (dieciocho) años, y se excluyó a los acompañantes que demostraran algún déficit cognitivo, de lenguaje y / o dificultad de comprensión. La recolección de datos se realizó mediante el uso de un cuestionario con acompañantes desde octubre de 2019 a enero de 2020. **RESULTADOS:** La muestra de estudio estuvo conformada por 12 acompañantes, 11 mujeres, edad media 36,33 ±: 24,95 años, de los cuales 8 (67%) eran solteros, reportaron ser padres de niños / adolescentes, tener otros hijos y al menos uno de ellos viviendo con ellos, la mayoría de ellos 25% tiene más de 3 hijos, 17% tiene 2 hijos y 8% solo 1 hijo. **CONCLUSIÓN:** Ante la necesidad de dejar el trabajo para cuidar al niño, la mayoría de los cuidadores no tienen ningún tipo de ocupación. Como viven lejos de la unidad de servicio, la oportunidad de permanecer en un hogar de apoyo le facilita el acceso al tratamiento.

PALABRAS CLAVE: Oncología. Pediatría. Cuidador. Cuidado.

Introduction

Childhood cancer corresponds to a group of several diseases that have in common the uncontrolled proliferation of abnormal cells that can occur anywhere in the body, having characteristics that differ from cancer in adults (Duarte et al., 2012). Among them, we have the origin, predominantly, of embryonic cells, short latency period, and, in general, fast growth. The main tumors in pediatric patients are hematological (leukemias and lymphomas) and solid ones such as the central nervous system, bone and abdominal tumors, and soft tissue tumors (Ministério da Saúde, 2019).

The incidence rate of cancer in children and adolescents has progressively increased over time. In Brazil, for 2018, the National Cancer Institute estimated 12,500 new cases of childhood cancer and 2,704 deaths. Worldwide, according to the International Agency for Research on Cancer (IARC), it is estimated that 215,000 cases are diagnosed every year in children under 15 years of age and about 85,000 in adolescents aged between 15 and 19 years (Instituto Nacional de Câncer, 2021).

Cancer in children and adolescents has non-specific signs and symptoms, which in most cases are confused with common childhood diseases, leading to a delay in its diagnosis. Chemotherapy treatment offers the possibility of cure or even palliative action. However, it causes the patient to suffer several side effects that cause discomfort, the most frequent being apathy, loss of appetite, weight loss, alopecia, bruises, nausea, vomiting, and diarrhea (Cicogna et al., 2010). These situations require the child/adolescent and their caregivers, who are most often the family themselves, to change habits that adapt their routine to coping with problems, thus minimizing the effects of the disease and treatment (Ministério da Saúde, 2019).

The parental care of a child or adolescent undergoing anticancer treatment exposes parents or guardians to greater responsibilities required by it, such as administration of medication, hospitalizations, complications, up to outpatient returns and follow-up in consultations and invasive tests, where, in most cases, it is the mothers who are responsible for the countless cares. Therefore, when they perceive themselves in front of a sick member, it can be seen that many changes occur in the family structure (Kohlsdorf & Costa, 2011). These changes affect family relationships, personal life, work, and even the relationship of parents and children, as they are experiencing a new phase of discoveries and insecurities, where the main focus is the preservation of life (Duarte et al., 2012).

Brazil has philanthropic entities with the objective of offering support to cancer patients and their families. An example of a philanthropic entity is the Support Centers for Children with Cancer, which offers specialized treatment when the patient does not need to be hospitalized, featuring outpatient therapy. The possibility of staying in a support home facilitates the child's access to treatment, as, in many cases, families cannot afford travel and hospitalization (França et al., 2017).

The participation of caregivers during the illness process, despite being debated in several articles, lacks greater exposure in pediatric oncology. Yet, knowing the participation of the caregivers of these children can bring significant contributions to adjustments and/or strengthening of public policies for them and their families, who, in their vast majority, come from conditions of great economic and social vulnerability, bringing health professionals and family members to a greater extent—clarity as to the importance of this participation in the service. Given the above, this work aims to describe the profile and participation of caregivers of children and adolescents with cancer during the illness process in a support home.

Materials and methods

This is a cross-sectional study with a quantitative/qualitative descriptive approach. The target audience was composed of family caregivers of children and adolescents hosted and assisted in the support group for children with cancer (GACC-BA), where the daily population is represented by an average of 40 people, adding caregivers and patients. The ethical aspects being respected, following Resolution No. 466/12 of the National Health Council (CNS), all individuals were invited to participate in the research voluntarily and signed the Free and Informed Consent Term (TCLE).

The GACC-BA is a non-profit, philanthropic civil association that assists children and adolescents from families with an unfavorable economic, educational and cultural situation, most of them from the state's interior. This assistance is provided through a multidisciplinary team composed of social workers, physiotherapists, nutritionists, psychologists, dentists, and volunteers. The GACC-BA also has leisure areas, such as a toy library, music, and computer room, thus seeking to provide the necessary conditions for these children and adolescents to be submitted to adequate treatment in the fight against cancer and, at the same time, guaranteeing the quality of life.

The sample was defined as a probabilistic stratified type for gender grouping. The study included 12 caregivers of both sexes, aged over 18 (eighteen) years old and who agreed to participate in the research. As an exclusion criterion, caregivers who demonstrated some cognitive and language deficits and/or difficulty understanding were used.

The instrument used in the research was a semi-structured questionnaire prepared by the authors, containing 23 questions. 14 objective and 9 subjective, organized into three guiding axes: identification of the caregiver, knowledge about cancer, and participation of the caregivers in the treatment. And to calibrate the instrument, a pilot study was carried out in September 2019 with the participation of 3 caregivers, providing adjustments in the structure of two questions and adding another one due to the interviewees' difficulty in understanding. In addition, it was possible to observe the best way to approach this companion during the interview and facilitate their understanding.

The collection began in October and concluded in January 2020, being carried out through an interview at the GACC-BA, under the supervision of the physiotherapist responsible for the sector, in the patients' rooms (it is noteworthy that the room is individual to the patient and their caregivers, thus providing confidentiality in the information that was passed on and so that the interviewee feels more at ease), by only one of the researchers, with an average duration of 20 (twenty) minutes in the morning and afternoon shifts.

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The interview proceeded as follows: the TCLE and the questionnaire were read before starting; only the physiotherapist, the interviewer, and the caregivers remained in the room, being named father or mother and identified by the name of flowers to preserve their identity. The interview was audio-recorded throughout the collection, using the iPhone 6 cell phone, and later transcribed by the researchers.

Categorical variables were presented as absolute and relative frequency, and numerical variables as mean and standard deviation. And, the data, stored in Microsoft Excel 2007 software and analyzed using SPSS software (Statistical Package for the Social Sciences) for Windows (version 22).

Data were transcribed considering oral and non-oral communication, according to the analysis of a French philosopher: For Pêcheux, the unsaid can only be reached through what he calls "specific exterior", which he later calls Discourse Production Conditions. For this author, the unsaid is the definition of a specific absence of what is present elsewhere (Gomes, 2015, p. 149).

Results

The study sample consisted of 12 caregivers, 11 female and 1 male, mean age 36.33 ± 24.95 years, of which 8 (67%) were single, reported being the parents of the children /teenagers, have other children and at least one of them lives with them, most of them 25% have more than 3 children, 17% have 2 children and 8% only 1 child.

Table 1. Variables of caregivers in relation to education, occupation and income. Salvador-BA, 2020

Variables	f	f(%)
education		
incomplete elementary school	7	58%
Complete high school	3	25%
Incomplete high school	2	17%
Occupation		
Working	2	17%
Not working	10	83%
Family income		
No income declared	2	17%
≤ 1 SM	7	58%
> 1 MW	3	25%
	n=12	100%

Caption: f = absolute frequency; f (%) = relative frequency;

SM: Minimum wage

Source: Prepared by the authors themselves, 2020.

Source: The authors (2020).

Cancer treatment requires financial expenses, and the caregiver directly involved needs to leave their job to care for the child. As identified in this study, 83% of the caregivers are not working at this time, and consequently, 58% of the participants have a family income of less than or equal to 1 minimum wage. When considering the educational level of the caregivers, most of them have not completed elementary school (58%), (25%) have completed high school, and (17%) have not completed high school.

Taking as a reference the distance between the city they live in and the support house located in the city of Salvador, it was observed that the closest city was 56 km and was in the metropolitan region of Salvador and the farthest, 886 km, in the extreme west of Bahia with an average distance of 474.42 ± 849.08 km. The length of stay in the foster home was at least two months and a maximum of 3 years, of which 8 (67%) reported that it was the first time they had stayed in the foster home, and 4 (33%) were unable to quantify the number of times.

Regarding the treatment phase, 3 (25%) children undergo maintenance chemotherapy, 7 (58%) are undergoing high-dose chemotherapy, and of these, 1 undergoes associated radiotherapy, and 2 (17%) are in palliative care. Regarding the location of the tumors, the predominance is in the Central Nervous System where 4 (33%) cases were identified, 1 (8.33%) liver, 1 (8.33%) pelvis, 1 (8.33%) bladder and prostate, 2 (17%) lung, 1 (8.33%) chest, 1 (8.33%) lumbosacral region and 1 (8.33%) neck.

When asked about the meaning that the word cancer reveals, it was possible to verify the feelings that arise when accompanying these children/adolescents and the difficulty in understanding what will happen after the diagnosis. Fear, sadness, and pain were the feelings most frequently verbalized, in addition to demonstrating behaviorally through frowning, intertwining fingers, and crying.

In the beginning, it was difficult, right, to understand what cancer was. So, at first, it was difficult to accept and know, right? Until I understood what cancer was, it was difficult, but after... So, cancer for me is a strong word that until I understood what cancer was, knowing the meaning was difficult. (Sunflower)

When revealing the diagnosis of childhood cancer, the fear of death and rapid loss of the child was present in Girassol's speech. Furthermore, it is possible to see that the caregivers end up denying this possibility of death for themselves and their children.

Boy, I think cancer itself, I think it's very devastating, it's a destroyer of family homes, I think that. Oh, like, he tries to kill people's hopes, right, he changes a family, like he changes the human being's life, you live now for the treatment of your child. (Anise)

Sad, I can't accept it and I don't think I'm going to win. I think I will, that I will give up... It's not giving up, but it gives a little discouragement from time to time because there are many, many fights and we see other people losing and we look at it and ask: what will be the next one? So it gives a little discouragement. (Camellia)

An important role of the caregiver is to maintain the social bond, a connection with life beyond the illness. The participants highlighted that they got closer to these children/adolescents after the diagnosis, and when asked about how this relationship was before

and currently, we found statements pointing to positive changes resulting in the relationship between them.

Before, I was very far from her, I worked in São Paulo and she stayed with my parents. After she got sick, I'm with her now all the time... So, our proximity was very far, now that we're well together, but before it was very far, little contact. (Camélia)

Well... Before the disease, it was like that, we were not so attached as we are today. But now that she's like this, we just stay together, you know, because I'm the only one who takes care of her. At home, I also stay with her because I don't work anymore, so I stay at home all day with her. Then it's like the disease brought us closer together, you know? (Flor de Lis)

Through the reports of parents of children and adolescents with cancer, it is possible to understand how they reacted throughout the illness process. After the impact of receiving the diagnosis, these caregivers feel the need to react and try to be strong in order to adapt to this new reality, demonstrating conformism even though they do not accept the disease and thus start to dedicate care and effort to their children, always trying to do their best to face this situation in the least painful way possible ([Instituto Nacional de Câncer, 2020b](#)).

Yes, it was a very big shock for me when I found out he had this disease, but now I'm more relieved, but when I remember the beginning it gives me chills, but I'm very relieved now. (Lily)

Many also mentioned using the belief in God as a way to overcome the difficulties encountered during treatment. Faith, for caregivers, plays an important role in emotional balance and acceptance of the disease, providing strength to keep fighting ([Duarte et al., 2012](#)). However, due to the adversities that some caregivers are exposed to, at a certain moment, they end up hesitating about their faith and feel, in a way, wronged. As we can see in this report:

My daughter, right at the time it was desperate, you know, I broke up, I destroyed myself, I lamented, I cried, I even cursed God. But then I asked God for forgiveness, because I said that God didn't exist, I talked a lot of nonsense... And I'm there fighting for my daughter's life, which is getting harder every day, but I'm firm and strong. (Fleur de Lis)

Diagnosis and initiation of treatment are the most difficult moments, as the initial contact with the disease causes parents to fear the unknown, followed by intense suffering and pain. Fortunately, thanks to scientific advances in recent decades, the possibility of disease remission arises (Alves et al., 2016). Parents who experience this hopeful possibility report feeling elated and blessed. We noticed in some reports that the saddest moment during treatment was receiving the diagnosis and the happiest, after receiving the news of the cancer remission:

The saddest moment was when I found out she was sick, because it was difficult... for us to know that she was going to get out of this. Because every day the doctors said that she wouldn't survive and that I don't know what. But today for me she's being happy because I'm seeing that she was healed thanks to God! And today she's there, living proof for those who don't believe. (Sunflower)

The saddest thing was when I found out he had cancer. And the happiest when you find out he was cured right? He's already done the CSF test and the doctor said he doesn't have anything else. (Pink)

The routine and participation of caregivers in treating childhood cancer are usually very hostile and exhausting, as taking care of a child with cancer requires time and dedication. It is interesting to note that the vast majority of caregivers interviewed are women. Based on the historical assumption that the mother is responsible for the integral care of her children, they believe that they must participate in the treatment, as we can see in the participants' statements the obligation to assume such a role (Quintana et al., 2011). On the other hand, although in the minority, some parents are also dedicated to the treatment of their children, as we can see in the following reports:

As a mother, it's good for him, he's safer. I think he has more support with his mother than with the others, he doesn't want to stay with his aunts, with his aunt or cousin, or even with his father he doesn't want to stay. (Orchid)

Ah, I describe it as well as my obligation you know? My obligation as a mother, and I will fight for her and with her until the end. (Fleur de Lis)

People even say they've never seen a father like me, but first of all, right, it's God himself who gives us strength and because I'm the father we have to do everything until the last second of our life but we have to do everything possible to fight to see the child sane. So, then I take him to the Hospital every day of consultation, all exams... (Blackhead)

Physical therapy treatment is essential for children and adolescents with cancer, both to improve symptoms and quality of life, with the main objectives of preserving, maintaining, and restoring the kinetic-functional integrity of organs and systems and preventing the disturbances caused by the treatment of the disease. In addition to physical therapy treatment, motor stimulation is necessary to obtain a better prognosis (Silva, Cardoso, et al., 2019). Understanding this, most caregivers reported participating in the physical therapy treatment of their children, maintaining a motor stimulation routine in the support house, and how much they feel satisfied with it.

I do the exercises with her during the shower, when she wakes up, before she goes to sleep, I do some things with her too that she does in physiotherapy. I encourage her to even "wash" right? Move your arms washing on one side and the other side, got it? her feet I ask her to try to put her hand where she can, like in the shower. On the bed I put her to sit, I sit down and place her feet on the floor, I do the steps and I encourage her. (Daisy)
On the first day I came, right, talk about what I needed, do the file and I came to bring him here and he is well received and for me it's wonderful because if I were to leave here for myself another place to do physiotherapy it wasn't easy. Not here, here I go from the second floor to the fourth floor, I'm at home. (Clove)

When asked about the changes that occurred in their lives after becoming caregivers of a child undergoing oncopediatric treatment, it appears that the illness of the child or adolescent leads to several changes in the family routine, such as the abandonment of professional activity, living with family members, due to prolonged hospitalization in a support home and, in most cases, concomitant with separation from other children. Distance from home should also be considered, as this affects caregivers not only because of the emotional attachment to family members who remain far away or for the comfort of their homes

that they had to give up, but also because of the new reality that imposes itself in their lives, adapting to the new city and abandoning their belongings, customs and daily life (Wakiuchi et al., 2017).

Everything. Routine, changed environment, this displacement, right? It's been a year since we've been here, actually and everything has changed, the way of thinking, our vision has changed, everything has changed. (Daisy)

The healthy brother realizes that the diagnosis of cancer causes countless changes in the family, limiting the meetings and participation of everyone together during the treatment, which is only rewarded in the end with cure and family reorganization.

Many... many, like leaving the other children at home alone, without me, call me saying you miss me too, your heart aches. (Orchid)

My life stopped everything, I couldn't educate my daughter anymore, I couldn't participate in her growth during these two years. No, I don't have a house anymore, I don't have a bed anymore, I'm either on the bus or I'm here or I'm in the hospital. Sorry I cried, but it's hard. (Tulip)

The family is the first most important social group in an individual's life, and it is also the first that, faced with an individual need of its members, turns to meet their needs (Duarte et al., 2012).

Here at the support house, I just have to say thanks, I just have to say thank you, I just have to thank everyone here... In physiotherapy, we really like the team, from the heart... Everyone serves us well, I just have to thank, first of all, God and this house here that not only for me but for everyone who is undergoing this treatment here with their children... (Carnation)

Regarding the quality of life of these caregivers in the psychological aspect, it was observed in this study that some of the participants stated that they did not enjoy life or enjoy it very little. Participants in this study stated that there were changes in their routine, referring that they came from the effort to take care of the different areas of life that are affected.

Everything. I had to leave my life behind to live hers, so everything. What I used to do...dating, partying,

having my life, like, my own life, working, I don't have it anymore... This is all behind us because we don't have time. When we go home, it's two days and come back, so there's no more dating, there's nothing, few friendships because only the real one remains and it's over. (Camélia)

Everything. Everything changed in my life, because I live only for him, I don't have time for myself. Then after he got better, I started to get ready, take better care of myself, but I never made an appointment again; an exam... We don't have time for us anymore; we only live for the son, he goes from the hospital to the GACC and sometimes in the hospital directly, I've spent 3 months with him only in the hospital, there's no time for us! It's difficult. (Lily)

Discussion

Among the family members, usually, are the mothers who accompany the child/adolescent's treatment process (Cheron & Pettengill, 2011), as they generally prioritize care and care, organize themselves, make internal arrangements, fail to carry out other activities, request help, in general, take control of the daily care of their children, especially in cases of illness.

Regarding the average age of caregivers and marital status, it was possible to observe in the study by Benedetti et al. (2015) that most participants were married, aged between 21 and 74 years. On the other hand, in the study by Silva, Barros, et al., (2011), the same information was proven, where most participants were married with an average age of 33 years, adverse with the current study's findings.

The support house is of great importance, as without them, many children would not have adequate access to treatment due to the financial condition of the families and the absence of a local health care network where they live (Sélos et al., 2014). Furthermore, according to Ferreira et al. (2015), they expressed that hosting at the support house helps cope with the treatment or even alleviates the difficult reality experienced, which provides quality of life for the hosted subject. That is due to the achievement of other essential characteristics for individuals, such as family support, an adequate nutritional diet, mastery of emotions, tranquility, respect for its principles and history, among other aspects.

[Sélos](#) et al. (2014) indicated that living in a support home during their child's treatment implies living with different people, who came from different places, with unique customs and ways of living, and these differences are not always seen as a positive factor.

In the literature, a study was found ([Kohlsdorf](#) & Costa, 2008) that describes the burden on the caregiver's life, related to the need to move from one city to another for cancer treatment, as well as the diversion of resources that would be used before for family expense. Adapting to this new situation is a challenge for the caregiver and can cause physical, emotional, psychological, and financial stress as the sick child becomes the center of their life ([Almico](#) & Faro, 2014). In this way, the child's illness and hospitalization change the family dynamics, leading to different feelings and emotions, such as fear, impotence, and guilt, where the person who accompanies the child in the hospital often has to face the difficulty alone ([Instituto Nacional de Câncer](#), 2020b).

The confirmation of a cancer diagnosis drastically changes the person's life with the disease and their families. Not just for the news but mainly for the implications arising from the treatment. In addition, doubts and questions that arise about cancer can be, in a way, a barrier, taking into account that some caregivers have little or no prior knowledge about the disease ([Farinhas](#) et al., 2013). Among the main factors related to delayed diagnosis is the level of parental education. It is noteworthy that the delay in diagnosis contributes to an increase in the period between the onset of the disease and its correct treatment, which may reflect on the evolution of the disease ([Fermo](#) et al., 2014) (Table 1).

Given the studies [Duarte](#) et al. (2012) and [Ferreira](#) et al. (2015), it is possible to observe that leukemia is among the most common types of cancer in children/adolescents and, in sequence, the central nervous system and soft tissue tumors.

Cancer treatment generates unpleasant side effects in the child/adolescent, causing them suffering and exhaustion ([Instituto Nacional de Câncer](#), 2020b). Aiming to reach malignant cells, prevent their multiplication by mitosis, and/or determine cell death, chemotherapy and radiotherapy are the forms of treatment. Antineoplastic chemotherapy is widely used in cancer treatment. It consists of the

use of chemical substances, alone or in combination, whereas radiotherapy is the therapeutic modality that uses ionizing radiation to combat neoplastic agents, which can be combined to enhance their effects ([Instituto Nacional de Câncer](#), 2020a).

The greater the information and involvement of mothers in the child's therapeutic plan, clarifying the risks/benefits, the greater the understanding, security, and tranquility for adherence to the proposed treatment ([Farinhas](#) et al., 2013). In addition, parents' understanding of the disease enables greater involvement in care, treatment monitoring, anxiety reduction, and cooperation with the team ([Sales](#) et al., 2012).

To face cancer, caregivers seek strength and courage in religiosity, in which they try to find an explanation/meaning for their child's illness and, at the same time, the hope of obtaining a cure. In the study by [Almico](#) and Faro (2014), it was mentioned that when the family does not lose faith and manages to move on, even in the face of suffering, they seek to have religion as an ally in the fight against a serious disease. Finally, considering the importance of faith as an element of emotional support for caregivers in situations of illness of their children, it is believed that it is essential to understand this experience in its particular and unique sense in an attempt to develop healthier ways of dealing with the suffering triggered for treatment ([Instituto Nacional de Câncer](#), 2020b).

The relationship between physical therapist and patient is a fundamental factor for the success of rehabilitation and being a key part of the adherence process. In the case of physical therapists, factors related to the quality of the relationship and the therapist's social skills appear as priorities, including concerning technical skills. It is very important to establish bonds between the professional and the family, and the bond built between these individuals must be permeated by attention, comfort, and affection ([Schwertner](#) et al., 2021). It is essential for these caregivers to feel motivated to take their children to physical therapy.

The patient who undergoes treatment far from their home is often in a situation of dependence to achieve day-to-day satisfaction due to the demands of the treatment, so this support offered by the home has immeasurable value for these individuals who

receive it (Dossena & Perez, 2017). Humanized care that includes affection, attention, and conversation becomes a fundamental tool in dealing with the disease. The study by Silva et al. (2011) confirms that there were changes in the routine of these family members, as many caregivers stopped working, studying, giving up their leisure, and caring for their own health by dedicating themselves fully to the health care of their children.

Emotional problems frequently occur both in cancer patients and their families due to the difficulty in dealing with the diagnosis. It is not uncommon for psychological disorders such as depression and anxiety to be diagnosed in patients and their families at all stages of treatment (Silva et al., 2011). At times, childhood cancer's social and psychological consequences can be more debilitating than the physical illness itself. For family members to fully assume the position of caregivers of the child, they need to enjoy good conditions that enable them to get involved in coping with the disease. However, family members are often faced with the situation of trying to save the child, burdening themselves with psychological suffering that reverberates throughout the family organization (Alves et al., 2016).

Final considerations

Research participants were mostly female, single, having other children, and the mothers were the main caregiver during the treatment. With the need to leave their job to take care of the child, most caregivers do not have any occupation. As they live far from the service unit, the opportunity to stay in a support home facilitates access to treatment, as in many cases, families do not have the financial means to spend on travel and hospitalizations.

In such a delicate moment, faith is a valuable element for the emotional support of caregivers to develop healthier ways of dealing with the suffering triggered by the treatment. Due to the hospital routine required to carry out the treatment of patients, the limitation found in this study was to reconcile the presence of caregivers in the support house with the interviews. However, given the emotional suffering identified in the caregivers' statements, adequate multidisciplinary follow-up is suggested so that they can expose their anxieties, fears, and difficulties. Thus,

we emphasize the value of this study in contributing to the dissemination of scientific knowledge in the areas of pediatric physiotherapy, oncology, and care for caregivers during the process of illness.

Authors' contributions

Bulcão HFB, Alcântara JM and Mota LMR prepared the initial project, which was reviewed by Ferraz PCS. Bulcão HFB participated in the writing, formatting of the article, interpretation of results, statistical analysis, and text revision. Alcântara JM was responsible for writing, data collection, interpretation of results, statistical analysis, and text revision. Barbosa LO participated in writing, supervising data collection, and reviewing the text. Mota LMR participated in the writing, translation of the manuscript, interpretation of results, statistical analysis, and text review. Ferraz PCS was responsible for the writing, critical intellectual review of the manuscript, statistical analysis, text review, and supervised the work. All authors read and approved the final version of the manuscript.

Conflicts of interest

No financial, legal, or political conflicts involving third parties (government, corporations and private foundations, etc.) have been declared for any aspect of the submitted work (including, but not limited to grants and funding, advisory board membership, study design, preparation manuscript, statistical analysis, etc.).

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