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CAREGIVERS' PERCEPTION OF PHYSIOTHERAPY IN THE THERAPEUTIC ITINERARY OF CHILDREN AND ADOLESCENTS WITH BRAIN TUMORS

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Abstract: Physiotherapy, as part of the multidisciplinary team, must act in the therapeutic itinerary of children/adolescents with brain tumors. This professional's contact with families through the main caregiver should be optimized in order to provide, through specific therapeutic strategies and guidance to caregivers, the acquisition of motor skills, prevention of deformities and improvement of quality. The aim of this study is to understand the perception of caregivers about physiotherapy in the therapeutic itinerary of children and adolescents with brain tumors. This is an observational, descriptive field study with a qualitative approach, carried out in September and October 2024 and taking place in the Neurosurgery block of the Albert Sabin Children's Hospital. Six caregivers, of both sexes, who were monitoring the hospitalization of the child/adolescent took part in the study. The results showed that the path to identifying the tumor can be long and arduous for the child/adolescent and their family. Family members' experiences with the disease are full of feelings, from the moment they notice the signs and symptoms to the moment the diagnosis is confirmed (therapeutic itinerary). The purpose of physiotherapy is to offer well-being through therapeutic resources and possible rehabilitation, but it still needs to be optimized within the hospital team. In conclusion, when we delve into the narratives behind this diagnosis, we realize how fragile families are and how physiotherapy can help with its vision of assessment, prevention and treatment of this disease.

Keywords: Physiotherapy, Brain cancer, Child, Analysis of feelings.

INTRODUCTION

Cancer in children and adolescents has a multifactorial etiology, characterized by the rapid proliferation of abnormal cells, which can manifest anywhere in the body. The National Cancer Institute (INCA) reports an increase in the incidence of cancer in Brazil, so that in the three-year period from 2020 to 2022 around 625,000 cases were diagnosed, with estimates of 704,000 new cases of cancer in Brazil between 2023 and 2025. Regarding childhood cancer, in 2017 there were 1,467 deaths of boys and 1,086 of girls (Silva; Ferreira, 2021; INCA, 2023).

Brain tumors (BT) are the second most prevalent type of cancer in children and adolescents. This form of neoplasm varies widely in type and is usually associated with syndromes or genetic inheritance. The most indicated treatments are surgery, radiotherapy and chemotherapy, either alone or in combination (Teixeira, 2022; Oliveira *et al*, 2023).

Costa and Silva (2021) describe that TCs are a major clinical challenge due to their location, their large size and the risk of alterations in the Central Nervous System (CNS), however, they respond well to treatment and have a good prognosis. Both morbidity and treatment represent challenges for patients, due to physical deficits, as well as neuropsychological and neuroendocrine sequelae.

In general, pediatric neoplasms cause a great deal of psychological, social and financial strain, with a profound impact on patients, their families, society and the public health system, so that during the therapeutic itinerary the need for multi-professional care is emphasized, in order to promote the formation of bonds and carry out qualified listening to the needs of the child/adolescent and family, seeking to achieve solutions to the difficulties presented, minimizing long trajectories, with the persistence of complaints or worsening of signs and symptoms, resulting in unfavorable prognoses (Carvalho *et al,* 2020).

Among the multidisciplinary care team, we highlight the physiotherapist who, through specific therapeutic strategies and guidance for caregivers, promotes the acquisition of motor skills, preventing deformities and facilitating the child's/adolescent's participation in the community and family environment. The contact of the physiotherapist in the therapeutic process makes the caregivers understand the clinical condition of the child/adolescent, the importance of the physiotherapist's approach and the relevance of carrying out the therapy at hospital and home level (Conceição *et al*, 2021).

This study was carried out because the researchers are close to the subject and there is little theoretical or scientific basis on the subject, which makes it current and relevant. It is believed that through the results we will be able to know this itinerary, making it possible to use it as an instrument for health promotion, prevention of further problems and early detection of the disease.

The aim of the study is to understand the perception of caregivers about physiotherapy in the therapeutic itinerary of children and adolescents with brain tumors, by characterizing the population studied according to the sociodemographic variables of the caregiver and the clinical variables of the child/adolescent, describing the conduct of caregivers in the therapeutic path of the disease and verifying the perception of the caregiver about the presence of the physiotherapist in the treatment of the patient.

METHODOLOGY

This was a field, observational, descriptive study with a qualitative approach, carried out in the Neurosurgery Block of the Albert Sabin Children's Hospital (HIAS), located at R. Tertuliano Sales, 544 - Vila União, Fortaleza - CE, after approval by the Ethics Committees (CEP) of the Christus University Center (Opinion 6.857.471) and the study hospital (Opinion 7.084.612).

HIAS is the only tertiary children's hospital in the state of Ceará, a reference in child and adolescent care, with a focus on highly complex serious illnesses and recognized as a teaching and research institution. This hospital was first inaugurated on December 26, 1952 as the Fortaleza Children's Hospital (HIF). In 1976, its new headquarters were inaugurated, where it remains today. On July 17, 1977, on the occasion of Dr. Sabin's visit to the hospital, the State Government decreed that it be renamed the Albert Sabin Children's Hospital (Sesa, 2023).

Data collection took place in September and October 2024 and the population consisted of 6 caregivers, of both sexes, who were monitoring children/adolescents (1 to 16 years old) admitted to the HIAS Neurosurgical Unit with a diagnosis of HT. In order to better delimit the population, only caregivers with some degree of kinship with the child and who already accompanied them four or more days a week were included in the study.

All the subjects agreed to take part in the research, were informed about the study and signed the Informed Consent Form (ICF). As research instruments, we used a structured questionnaire that included sociodemographic characteristics of the caregiver; the clinical situation of the child/adolescent and a semi-structured interview script that highlighted the guiding question of the research, which sought to understand the perception of caregivers about physiotherapy in the therapeutic itinerary of children and adolescents with HT.

The interview was divided into three blocks about the diagnosis, hospitalization and the meaning of physiotherapy for the caregiver. The answers were recorded in order to fully record what was said and, as a form of validation, the main points expressed were noted down by one of the researchers and read out at the end of the interview so that the participants could agree with the content, complete it or correct it.

According to Paiva, Oliveira and Hillesheim (2021), in order to carry out a study, planning is important, and one of the most decisive stages is defining the exact techniques for collecting and analyzing the data. According to Minayo (2013), the "content analysis" approach was chosen by the researchers, as it answers particular questions and is concerned, in the social sciences, with a level of reality that cannot be quantified. The steps taken in this analysis were comprehensive reading of the material, exploration of the material and drawing up an interpretative summary.

In order to safeguard the anonymity of the participants and based on the study by Rodrigues, Oliveira and Santos (2021) who describe that qualitative research is "entangled in the subjectivity of the researcher" because the researcher interprets the problem and "explains the phenomena meaningfully and appropriately", we decided to name the caregivers after superheroes from the 1970s and 1980s (Cheetara, Adora (She-ha), Diana (Wonder Woman), Gamora, Adam (He-man) and Lion-O), which reminds us of feelings such as strength, determination, resilience and courage.

In order to carry out this research, all the ethical precepts of research with human beings that govern confidentiality, secrecy, anonymity, autonomy, beneficence, non-maleficence, justice and equity, regulated by Resolution 466/12 of the National Health Council/Ministry of Health/MH (Brazil, 2013), were complied with.

RESULTS

In order to get to know the population to be studied, the sociodemographic characteristics of the caregivers and the clinical characteristics of the children/adolescents were investigated. Six caregivers took part in this study, four of whom were mothers, one father and one uncle, aged between 21 and 33, single, with an average income of between 2 and 3 minimum wages (MW) and schooling that ranged from higher education to complete primary education. Their main occupation was working from home and their house was rented (Table 1).

Table 2 shows that the children whose caregivers took part in the study were mostly male, with an average age of 8.3 years, and were experiencing their second hospitalization due to follow-up or complications related to HT.

Costa and Silva (2021) described in their study that malignant HTs mainly affect white male children and adolescents, rank between first and third in incidence and mortality, have a shorter latency, rapid progression and invasiveness, as seen in the present study.

When we entered the neurosurgery ward, we felt "part of the whole", because although we weren't part of that team, our essence as health professionals made us want to take part in that care. We listened to the stories of six families. The interviews were moving, and we saw how hard it is for the caregivers to become ill, to be hospitalized (some have left their homes in the countryside, leaving their spouse and other children without their care) and the fear of the finitude of life

After analyzing the participants' statements extracted from the interviews, exploring the material and interpreting the content, three thematic axes emerged for the discussion of the study, presented as follows: "The diagnosis: Path of identification of the disease", "Hospitalization: The caregiver in the hospital setting" and "Physiotherapy: the main caregiver's view".

DIAGNOSIS: THE PATH TO IDENTIFYING THE DISEASE

In the first block, we questioned the caregivers about the diagnosis process, which was guided by the following questions: What was the first sign of the disease in your child/adolescent; what service or professional did you seek at that moment and how can you describe the steps you took until the diagnosis, answered in the speeches below, respectively:

Caregivers	Age	Marital status	Income (SM)	Education	Occupation	Type of home
Cheetara	29 a	Consensual union	More than 3 MW	Elementary School Completed	Farmer	Relatives' house
Love it **She-Ra**	29 a	Single	Up to 1 MW	Elementary School Completed	Home	Own home
Diana **Wonder Woman**	33 a	Married	2 to 3 MW	Secondary school incomplete	Home	Rented house
Gamora	25 a	Single	2 to 3 MW	Secondary school incomplete	Home	Rented house
He-Man	21 a	Single	More than 3 MW	Incomplete university degree	Student	Own home
Lion-O	28 a	Married	2 to 3 MW	University degree completed	Secretary	Rented house

TABLE 1: Sociodemographic characteristics of caregivers
Source: Author

Caregivers	Gender	Age	Hospitalization	Reason for current hospitalization
Cheetara	Male	12 years old	Monday	Seizures
Diana	Male	10 years	Third	Tumor treatment
Lion-O	Male	2 years	Monday	Tumor removal
Gamora	Female	5 years	Third	Headache
Love it	Male	5 years	Monday	Pneumonia + EVD
Adam	Female	16 years old	First	Intense Headache

TABLE 2: Clinical characteristics of the children/adolescents
Source: Author

> "From the age of two, he always said he felt dizzy, out of the blue he said he felt dizzy. Then at the health center he was treated for anemia, then it got longer and longer, but every year I took him for a checkup! When this year passed, it got worse and worse, he lost his sight, his hearing and the movement on his left side, then they started treating it as epilepsy, but even taking the epilepsy medication, he kept having seizures, and that's when the doctor ordered an MRI scan which showed a tumor." (Cheetara) .

> "Intense headaches, she'd had them before, but we never thought it was anything more serious, she thought it was just a migraine, so she had a CT scan and a brain mass was found on the left side of her brain, a tumor, right? A neoplasm" (Adam, He-Man).

> "He couldn't walk, his eye was bent, he had a lot of headaches and vomited a lot, so we despaired of this, we started taking him to the doctors and nobody found out, so it was here at Albert Sabin that they discovered his illness" (Diana, Wonder Woman).

Melo (2024) describes that children diagnosed with brain tumors initially manifest vague and non-specific symptoms, common to other conditions, without a high degree of severity, such as: intracranial hypertension, focal neurological deficits, convulsions, ataxia, headaches, weakness, loss of balance and memory problems, making diagnosis more difficult and time-consuming.

> "I went to the UPA and they gave her an IV to take, said it was nothing, (tone of indignation) said it was just a virus so we went home, then the symptoms continued and this girl didn't get better. So I went back to the UPA and asked for an examination of her head, then I went to SOPAI and there she had a CT scan, from SOPAI we went to Peter Pan and she had the valve fitted and she was fine, she ate well, she was smart and then we stayed for her to have another operation here at Sabin." (Gamora) (Gamora)

> "First I went to the health center, the doctor ordered an MRI scan and it was the right thing to go private because to this day his file is there waiting to be called, so I started raising money, I did vakinha and raffle tickets to go private and it worked (sigh) but there came a time when it couldn't work anymore and I came here to Albert Sabin." (Cheetara)

> "In 2020, one day he started vomiting a lot, so I took him to the health center, when I got there they gave him medicine for vomiting because it could be a worm crisis, I did all the treatment with him but he didn't get better, then I took him to the hospital when I got there it was the same thing and he didn't get any better, then a friend of ours said: 'why don't you take him to Albert Sabin?"We hadn't taken him before because we thought that because we were from Maracanaú he wouldn't be seen, but my husband decided to take him, it was the end of November to December, so he stayed from December to February. In December he had the surgery to place the PVD and in January he had the surgery to remove the tumor, he was under observation and in February he went home." (Diana, Wonder Woman)

The search for an explanation for their children's signs and symptoms is not always valued by the health professional and the path to identifying the tumor can be long and arduous for the child/adolescent and their family, leading us to question whether there is a lack of clinical insight and thorough investigation for this type of diagnosis.

The literature describes that when the tumor is discovered early, it increases the effectiveness of the treatment and brings benefits, while the delay in identifying it generates great damage. Passos (2020) and Barros *et al* (2020) state that early diagnosis allows morbidity and mortality rates to be minimized, directly influencing the path taken by the families of children and adolescents with neoplasms, known as the "therapeutic itinerary".

Alves (2015) describes the therapeutic itinerary as one of the central concepts of the journey to diagnosis, i.e. all the activities carried out by individuals in search of treatment for the disease or affliction. Also due to the fact that sometimes the symptoms of the disease are non-specific, according to Ponciano and Moreira (2020) in pediatric oncology, better investigation and differential diagnosis is necessary, which occurs through clinical instruments, such as a complete clinical history, blood count, complete physical examination, imaging tests and clinical family history, thus being able to correctly and effectively conduct treatment

Family members' experience of therapeutic itinerary is full of multiple feelings, such as unrealities, surprises and disappointments related to each stage, from the moment they notice the signs and symptoms to the moment the diagnosis is confirmed.

HOSPITALIZATION: THE CAREGIVER IN THE HOSPITAL SETTING

The second section dealt with the child's/adolescent's hospitalization, with questions about how the family was organized during the hospitalization period and what their feelings were as caregivers in this hospital setting. We observed in the speeches that they are able to abandon everything and "cancel themselves out" in order to provide the best possible treatment for the child/adolescent and that due to the daily routines of treatment, consultations and the high demand for care, they often end up putting aside their obligations at home and caring for their other children in order to dedicate all their time to their sick child.

Feelings of homesickness, worry, fear, insecurity and difficulties in adapting to family life are part of these families' daily lives, as can be seen in the following statements:

> "It gets difficult, right, my wife is in the care home and we get very worried." (Lion-O)
>
> "My daughter stays with her mother, my house is near hers. My husband's other son is already older. And I miss her, I leave my daughter behind." (Gamora)
>
> "My children stay with my mother and my sisters, that's the way it is and I really want to leave, I leave my other children to stay here, but I just want him to leave here well. That's all that matters. (Adora, She-Ra)

> "My daughter stayed with my mother in Tianguá and my husband is at my sister's house so we can take turns at the hospital [...] I have nothing to complain about the hospitalization, but the first time we were admitted on Saturday and they only came to see us on Tuesday, after I went to talk to the social worker. But the girls are super nice and so is the doctor, so the hospitalization is going smoothly." (Cheetara)

> "Everyone is very available, her mother is downstairs, her father came here from the countryside, there's a sister-in-law, there's me, there's a lot of people available. [...] we were worried at first, it's one of the most complicated illnesses to deal with and even more so because of where she was diagnosed, but by coming together, having strength and examining what it is better, asking friends for their opinions and pooling the family's knowledge, we were reassured and that's it." (Adam, He-Man) (Adam, He-Man)

> "My daughter stays with my mother, my mother-in-law, but at the moment she's with my husband because we don't like being bothered, you know? She's being monitored at CAPES, the doctor says she has ADHD and autism, so she's very agitated and not everyone understands the situation. I feel sad, because I didn't want him here. If I could he wouldn't be here, but unfortunately fate has done this to us, but as long as I can take care of him, as long as there's a chance of it working out, I'll be here." (Diana, Wonder Woman)

The diagnosis of cancer in children and adolescents can shake up relationships and family dynamics, as well as causing suffering and fear caused by the assimilation of the discovery, treatment and control of the disease. In the care provided to this patient and their family, one must understand not only the pathology and its treatment, but also the social context so that support for them becomes as humanized as possible (Paula, 2019).

PHYSIOTHERAPY: THE MAIN CAREGIVER'S VIEW

In the third block, we asked caregivers about physiotherapy in their patients' therapeutic itinerary, asking them about their perception of the profession, when it entered the family's itinerary (path) and the importance of this treatment for the child/adolescent, as expressed in the speeches below:

> "Physiotherapy, I think it's treatment for the child to return to a normal life. Because he used to run a lot, play, jump and now he's not doing that anymore because there's no physiotherapy to give him the access he needs, [...] in my town we looked for private physiotherapy, but he started treatment with chemotherapy and radiotherapy. And when we come here I always ask him to stay for physiotherapy." (Diana, Wonder Woman).

> "I know physiotherapy, he used to spend a lot of time doing nothing, so physiotherapy came to work on him [...] then I did his physiotherapy at home myself" (Adora, She-Ra).

> "I know very little about physiotherapy, but my daughter has already been treated a few times [...] since her first hospitalization she has had physiotherapy, at Peter Pan and here at Albert Sabin. Especially when she was in the ICU and now in the PICU." (Gamora)

Of the 6 caregivers interviewed, 2 reported that they did not know about physiotherapy and 1 said that he did, but that up until the moment of the interview physiotherapy had not been part of his child's therapeutic itinerary. These reports show that despite the literature's evidence of the benefits of physiotherapy for patients diagnosed with HT, physiotherapy is not prescribed/included in the care process for these children/adolescents, perhaps due to the lack of an ideal quantitative dimension or because the medical professionals responsible don't really understand its importance.

In view of the professional areas in the multidisciplinary team, Silva (2021) highlights physiotherapy, which can participate in primary, secondary and tertiary prevention and rehabilitation, and therefore has the skills to act at all stages of life, in order to assist the multidisciplinary team in controlling symptoms, reducing complications of the disease and treatment, providing quality of life for patients, in addition to offering well-being through therapeutic resources and rehabilitation with a view to optimizing assessment, prevention and treatment.

> “Physiotherapy is very important, especially when it comes to surgery on the brain, I think it can affect motor coordination a lot and physiotherapy tries to adjust and adapt the best for him. I think it’s not just important, it’s essential.” (Adam, He-Man).
>
> “It’s very good to get his movements back, so that he doesn’t have too many sequelae, whether he wants it or not, he needs physiotherapy to re-establish his body. It’s also good for the psyche because the physiotherapists talk to the children, sometimes he doesn’t like it very much because it affects him, but he agrees to do it.” (Adora, She-Ra)

According to Rios (2014), physiotherapy aims to maintain or increase the patient’s independence and quality of life, accompany the return or evolution of the pathology, with the help of behaviors that stimulate and rehabilitate the patient, and also support the child’s caregiver in dealing with the uncontrolled development of the illness, with the aim of reducing the patient’s time in hospital and prolonging time with family and friends.

To conclude the interview, we asked the caregivers to define “what physiotherapy is” in one word or phrase, and the result shows that they understand the importance of physiotherapy and see the need to maintain physiotherapeutic care as a necessity, bringing hope of a return to the child’s/adolescent’s activities of daily living.

> “Hope.” (Diana, Wonder Woman)
>
> “Physiotherapy is very necessary for all children, because they lie down for a long time and lose strength.” (Adora, She-Ra)
>
> ‘’Need, physiotherapy is of great importance on a daily basis, especially for the elderly, post-surgery, those who have a lot of instabilities, a lot of vulnerabilities” (Adam, He-Man).

The Regional Council for Physiotherapy and Occupational Therapy (CREFITO) states that physiotherapy is a science that studies human movement, all its forms of expression and its capabilities, both in pathological alterations and in functional kinetic diagnosis. It can act in the prescription, analysis, diagnosis, planning and assessment of patients in different areas.

CONCLUSION

The interviewees’ accounts were of great importance in getting to know the reality experienced by each family and the participation of the physiotherapist as part of the multidisciplinary team caring for children/adolescents with brain tumors. By delving into the narratives involved, we realized how fragile the families are after the diagnosis and how physiotherapy can help them along this path.

However, despite the consensus among the authors that physiotherapy provides these patients with a better quality of life by maintaining their physical and cognitive integrity, it was seen that this professional is still “unknown” to some families, so we suggest that more studies be carried out on the subject in order to scientifically strengthen this profession and its ideal application.

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