

# IMPACT OF CARING FOR CHILDREN AND ADOLESCENTS WITH CANCER ON THE QUALITY OF LIFE OF CAREGIVERS

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**ABSTRACT: Objective:** to describe the impacts of caring for children and adolescents with cancer on the lives of caregivers. **Method:** Descriptive study with a qualitative approach conducted from May to June 2015. Fifteen (15) caregivers of children and adolescents from an institution that provides support to children with cancer in a municipality in the southern region of Bahia. The data were collected through semi-structured interviews and analyzed according to the technique of content analysis, thematic modality. **Results:** Changes in family routine and financial problems were identified as negative aspects faced by caregivers, and the support obtained was identified as a positive aspect. The main feelings experienced by them were discouragement, sadness, loss, revolt, victory, death and faith. **Conclusion:** It can be concluded that follow up by a multidisciplinary team is necessary to provide emotional support to caregivers, in order to prepare them to cope with the stressful events associated with the care process.

**KEYWORDS:** Neoplasias; Caregivers; Children; Adolescents.

## REPERCUSSÕES NA VIDA DE CUIDADORES DE CRIANÇAS E ADOLESCENTES COM DOENÇA ONCOLÓGICA

**RESUMO: Objetivo:** descrever as repercussões que ocorreram na vida de cuidadores de crianças e adolescentes com doença oncológica. **Método:** estudo descritivo com abordagem qualitativa, realizado entre maio e junho de 2015, com 15 cuidadores de crianças e adolescentes, em uma instituição de apoio a crianças com câncer de um município da região sul da Bahia. Os dados foram coletados através de entrevistas semiestruturadas e analisados conforme a técnica de análise de conteúdo, modalidade temática. **Resultados:** identificou-se como dificuldades para as cuidadoras as mudanças da rotina familiar e os problemas financeiros, e como facilidade o apoio encontrado. Os principais sentimentos vivenciados pelas mesmas foram desânimo, tristeza, perda, revolta, vitória, morte e fé. **Conclusão:** dessa forma, faz-se necessário acompanhamento com equipe multidisciplinar, a fim de fornecer o suporte emocional para as cuidadoras poderem vivenciar as repercussões que o processo de cuidar lhes impõe.

**DESCRIPTORES:** Neoplasias; Cuidadores; Crianças; Adolescentes.

## REPERCUSIONES EN LA VIDA DE CUIDADORES DE NIÑOS Y ADOLESCENTES CON ENFERMEDAD ONCOLÓGICA

**RESUMEN: Objetivo:** describir las repercusiones que ocurrieron en la vida de cuidadores de niños y adolescentes con enfermedad oncológica. **Método:** estudio descriptivo con abordaje cualitativo, hecho entre mayo y junio de 2015, con 15 cuidadores de niños y adolescentes, en una institución de apoyo a niños con cáncer de un municipio de la región sur de Bahia. Se obtuvieron los datos por medio de entrevistas semi estructuradas y se los analizaron conforme la técnica de análisis de contenido, modalidad temática. **Resultados:** se identificaron como dificultades para las cuidadoras los cambios de la rutina familiar y los problemas financieros, y como facilidad el apoyo encontrado. Los principales sentimientos presentes fueron desánimo, tristeza, pérdida, indignación, victoria, muerte y fe. **Conclusión:** es necesario acompañamiento con el equipo multidisciplinar, con fines de fornecer el soporte emocional para que las cuidadoras puedan vivir las repercusiones que el proceso de cuidar les impone.

**DESCRIPTORES:** Neoplasias; Cuidadores; Niños; Adolescentes.

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## ● INTRODUCTION

The National Cancer Institute - INCA defines cancer as a “set of more than 100 diseases that have in common the disordered growth of cells that invade neighboring tissues and organs”<sup>(1:17)</sup>. Due to the high morbidity and mortality rates of individuals with cancer, confirmation of this diagnosis is usually associated with death<sup>(2)</sup>, making it difficult to manage and treat the disease.

Cancer should be diagnosed at an early stage of the disease to reduce the burden of therapy and the risk of future sequelae and for the implementation of the most appropriate intervention. The stage of cancer progression and the tissue pattern are key factors for relapse and mortality. The most relevant unfavorable points are advanced stage and anomalies of cells or tissues, particularly when chemotherapy is no longer effective<sup>(3)</sup>.

The disease is painful not only for diagnosed cancer patients, but also for family members and/or caregivers who experience the illness process. In children/ adolescents, this approach is even more complex due to the prolonged and frequent periods of hospitalization, which may affect routine activities.

Cancer has several impacts on patients' lives. It is believed that a successful treatment requires acceptance, and the family is the primary network of social support of sick children/adolescents, because such support is essential in this stressful situation <sup>(4)</sup>. Personal care is a difficult task for caregivers, who will need support to cope with the changes imposed by the diagnosis of cancer.

Family caregivers of cancer patients need support and help to be able to provide the care needed by these patients<sup>(5)</sup>.

The importance of the participation of caregivers in the follow-up and treatment of children/adolescents with cancer is well known. However, there are few studies focused on the identification of the daily difficulties encountered by these individuals.

The complexity of the care provided to cancer patients has stimulated the development of the present study. It is aimed to describe the impact of caregiving on the lives of caregivers of children and adolescents with cancer.

## ● METHOD

The present study is a descriptive and qualitative research. The study design contemplates the object, since it concerns experiences, feelings and influences experienced by the respondents<sup>(6)</sup>.

This study was carried out in an institution that provides support to children with cancer located in the city of Itabuna, in the southern region of Bahia, in May-June 2015. The participants were 15 caregivers of children and adolescents diagnosed with cancer.

The eligibility criteria for the study were: caregivers of children/adolescents with cancer; caregivers working in the institution at the time of data collection. The caregivers who were not found in the institution after three attempts were excluded from the study. For data collection, semi-structured interviews were used. The data obtained was recorded to assure the reliability of the information and transcribed in full, with subsequent verification of the faithfulness of the transcript.

Thematic content analysis was used to analyze the data. It comprised the following stages: pre-analysis, exploration of the material, choice of the registration units, classification and aggregation of thematic categories<sup>(7)</sup>.

The study complied with the requirements of Resolution n. 466/2012, which establishes the Guidelines and Regulatory Norms in Research with Humans<sup>(8)</sup>, and was submitted to the Research Ethics

## ● RESULTS

The eligible sample of the study consisted of 15 female caregivers of children and adolescents who were aged 27-63 years and had children. Seven (46.6%) were in a stable union; 12 (80%) were housewives and had a family income between BRL 120,00 and BRL 788,00.

Two main categories of research emerged from the analysis of the statements: "Facilitating and complicating factors experienced by caregivers" and "Feelings experienced by the caregivers".

### Category 1 – Facilitating and Complicating factors experienced by the caregivers

Several factors may impact the care provided to children and adolescents with cancer and the lives of their caregivers. Thus, this category includes units of analysis that report a facilitator point mentioned in the study of the disease. However, there were several complicating factors e.g. related to financial issues and family relationships.

The only facilitating factor reported was support. It is well known that support is essential so help patients and caregivers face this new stage in their lives

*The doctors gave me advice, which made me feel more comfortable.* (E. 11)

*My relatives helped a lot... we had a lot of support.* (E. 14)0

On the other hand, several complicating factors were mentioned by the participants of this study. It can be seen that the impact of diagnosis of cancer may cause a disruption in family routine, and the sickness results in changes in the daily routine of those who are close to the patient.

*[...] My routine has changed a lot.... because she is here... I must stop doing other things because and spend all my time taking care of her; sometimes I say this: Gee, I should take better care of myself* (E. 12)

Another condition imposed on caregivers by the process of illness was the need to leave the family to provide care to the patients.

*It's hard for me to leave my husband behind, leave my house, but I chose to take care of my son.* (E. 04)

*[...] experiencing all this and far without having my family by my side, this was the hardest thing for me... I had to change everything, leave everything behind, leave home, leave husband, leave family, leave work.* (E. 05)

*I stopped working to take care of him, I also left my house.* (E. 07)

Another complicating factor mentioned was lack of family support and the marital relationship

*I don't even like to talk about it [cry] ... I didn't have support from the family...my relatives moved away ... and I ended up alone, I was alone with her ...* (E. 02)

Lack of leisure was another complicating factor identified from the units of analysis, since the caregivers no longer have free leisure time or no longer engage in leisure occupations as often as before.

*[...] I don't feel like going out anymore, I spend all my time at home and only get out when I have to take her to the doctor.* (E. 02)

*I used to go out often, used to go to my aunt's house, to my mother's house... she lives in the countryside, but I don't do this anymore.* (E. 03)

Financial problems emerge as an important factor experienced by some caregivers.

*The problem at home is that he [my husband] could not work and send me money ... (E. 03)*

*[...] we could not afford to come here.. she was hospitalized awaiting to be discharged from home care, because she could not just leave the hospital and come here. (E. 15)*

In addition to the difficult financial situation, dependence on municipal transportation was another problem reported by the caregivers,

*[...] there is also the problem of transportation: sometimes the car is available; sometimes not, and we have to stay here. (E. 01)*

## Category 2 – Feelings experienced by the caregivers

When questioned about the feelings that emerged at the time of the discovery of the diagnosis, caregivers reported several such as death, discouragement, sadness, revolt, questioning, victory, and there was always emphasis on religious and spiritual issues.

Death was a frequent concern mentioned by the caregivers

*I was very sorry, I cried too much, I thought that at that moment I was going to lose him ... (E. 04)*

*I felt the floor disappear beneath my feet, nothing else made sense to me; we think about death, we don't think about the cure... at first we believe that it is the end, he/she is going to die. (E. 05)*

Feelings such as sadness, guilt, despair, fear, insecurity, anguish and anger were also mentioned by the caregivers because they were experiencing this painful moment of caring for someone with cancer.

*I felt very sad ... I felt cold inside, I was scared, and all I could was crying ... (E. 10)*

*I was sad and angry at me, because there were times when he complained of pain and I thought it was silly. (E. 13)*

Feelings such as hope, faith and spirituality were frequently described by the caregivers.

*I also prayed, asking God to give me strength to succeed and then, more or less six months later, I calmed down... that crowd of people... they were praying (E. 02)*

*Thank God, I got over it. (E. 07)*

*I experienced a difficult moment, and only God could help us ... (E. 08)*

Several feelings are experienced by caregivers of children/adolescents with cancer. Thus, monitoring by a multidisciplinary team is necessary to help them cope with this situation.

## ● DISCUSSION

This study found that all the caregivers of children and adolescents in cancer treatment were women, who usually play caregiving roles. A study with female caregivers showed that low-income mothers with seriously ill children at home have trouble getting a job or keeping a job<sup>(9-10)</sup>.

The support provided by the multidisciplinary team of the institution made it possible for the caregivers to adapt and cope with the diagnosis of cancer of their children, making sound decisions about the treatment. These results are similar to those of a study carried out in Goiânia<sup>(4)</sup> Thus, the nursing team and the multidisciplinary team play a key role in facilitating the inclusion and participation of family members in caregiving<sup>(11)</sup>, as well as in the understanding of the modifications of the daily routine that occur in the caregivers' lives<sup>(9)</sup>.

The hospitalization of their family members and the suffering generated by separation impacts the routine of many individuals, with disruption of the family lifestyle<sup>(12)</sup>. Getting sick is a difficult process that imposes several changes on the patient due to the severity of the condition, loss or withdrawal from daily routines, which sometimes generate conflicts in the family environment<sup>(4,13-14)</sup>. In this study, the participants reported that as soon as the diagnosis of cancer was revealed their family has been impacted, and there were changes in their structure, e.g. the fact that the sick persons had to be hospitalized and deprived of contact with the other family members.

Corroborating the findings of this study, it should be noted that changes in caregivers' lives can be perceived in the reduced social interaction, less leisure activities with families, friends, and other networks, such as church, school and neighbors<sup>(4, 13)</sup>. However, it is known that leisure and recreation is essential for people's mental and physical health.

Moreover, caring for someone going through cancer treatment can be very demanding: caregivers often spend a great deal of time with the patients and have to adapt to this new situation. Many of them experience a conflict when they leave their homes, particularly when they have children and a companion.

The feeling of abandonment is recurrent, and besides feeling lonely and helpless, they blame themselves for leaving their homes, husbands and other children<sup>(4)</sup>. In general, illness changes the pattern of family functioning. However, mothers often feel responsible for providing full care to their sick children<sup>(11)</sup>. The study found that the caregivers were willing to provide full care to their sick children, regardless of its possible impact on family structure.

The importance of family support to ensure better recovery of children/ adolescents with cancer is well known, as shown in the statements of the respondents who mentioned dedication, time, financial resources, changes in daily routine, among other factors. Therefore, all the family members must participate in the decision-making process to solve the conflicts, in order to meet the mutual needs of those involved.

Although some caregivers said they had received support after diagnosis and during cancer treatment, this was not observed in most of the units of this study. The relationships in the family are very complex, and sometimes the family members were unwilling to get involved in the process of cancer treatment.

Many caregivers who participated in this study devoted themselves entirely to the care of their sick children. Their partners apparently did not understand why they moved away from home and no longer performed their household chores.

Studies have reported changes in marital relationships because of the lack of attention paid to the partner. They were also less likely to have sex, and some couples who could not deal with the situation split up<sup>(9-12)</sup>.

Corroborating the statements of the participants, some authors argue that most caregivers lost their jobs because they did not have support from their families in their caregiving and household tasks, which worsened the financial problems<sup>(5, 10)</sup>. There is still the need to reorganize routine situations, such as changes in the economic situation and in the family dynamics<sup>(15)</sup>.

Thus, financial difficulties emerge as an important factor experienced by some caregivers of this research, since many of them had to quit paying jobs to care for their children or adolescents with cancer. Thus, their survival depended on funding/help from the government, or help from their families, friends and the community.

However, despite this difficulty, caregivers are fully aware of the need to care for their sick children, even if it means giving up their personal lives. The partners of the caregivers also had to change their routines.

Transportation was another challenge because the patients and their caregivers needed to move to another city to obtain the treatment that was unavailable in the municipalities where they lived, which also lacked regular transportation.

According to Ordinance no. 55 of February 24, 1999, of the Ministry of Health, the municipalities/states must bear the costs of the medical treatment of individuals who cannot afford it<sup>(16)</sup>. In the present study, it was found that such right was not fully assured for this population in the referred municipality.

In addition, the various responsibilities of caregivers impact their lives in all their aspects: personal, family and work environment as well as in the social sphere, which can lead to conflicts that reduce the quality of life<sup>(5)</sup>. Despite such difficulties, the caregivers do their best to cope with the new situation, seeking to overcome the barriers imposed by the disease.

Corroborating the findings of this study regarding the feelings experienced by caregivers, other studies reported the presence of death as one of the main concerns experienced by caregivers during cancer treatment. Various emotions are aroused by the imminence of death<sup>(4, 17-18)</sup>.

Despair is a feeling present in the coping process which begins with the diagnosis of cancer, especially when there are several negative reports about the pathology marked by sadness, loneliness and a sense of failure<sup>(18)</sup>.

During the process of coping with cancer, the most common feelings experienced by the family members are shock, despair, fear, revolt and anxiety, which result in changes in the lives of caregivers of cancer patients<sup>(4,18)</sup>.

However, the spiritual experiences concern the search for answers to the suffering and existential questions about cancer. Therefore, they encourage the caregiver and the child to focus on hope, to be able to cope with the pathology-related issues<sup>(12)</sup>.

In this study, the caregivers reported several difficulties and experienced different feelings and emotions such as sadness, pain, etc. but they found in spirituality the necessary support to provide the best possible care to ensure the recovery of their sick relatives. Spirituality provides strength and gives courage to overcome barriers, minimizes suffering, and increases adherence to treatment<sup>(19)</sup>.

Thus, local support assured by the state/municipality, through a multidisciplinary team, is necessary both for the patient diagnosed with cancer and for caregivers who experience changes in their routines, especially for those who have been performing caregiving activities for a longer period.

One limitation of this study is the unavailability of information on the length of time spent by the participants in caregiving activities, since such data could interfere in the burden experienced by them.

## ● CONCLUSION

In view of the above, it can be concluded that cancer has a significant impact on the quality of life of caregivers. Continuous follow-up is necessary during the treatment and rehabilitation process, since the weaknesses and insecurities of caregivers impact the treatment of children and adolescents.

Also, there was a change in the routine and daily life habits of caregivers. In order to overcome the suffering imposed by the illness, they often turn to spiritual and religious issues.

It is believed that this study can contribute to increase the knowledge of health professionals about the emotions experienced by caregivers, demonstrating the need to monitor these individuals, given their crucial role in the treatment of the referred population.

Therefore, a multidisciplinary approach is necessary to ensure emotional support for caregivers, so that they are able to experience the different feelings and impacts imposed by cancer. Caregivers must be inserted in a social context and seen as whole human beings with their fears, doubts and other emotions.



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