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IMPACT OF INFORMAL CAREGIVER OVERBURDEN ON CARE FOR FAMILY MEMBERS WITH CANCER

IMPACTO DA SOBRECARGA DO CUIDADOR INFORMAL NO CUIDADO AO FAMILIAR COM CÂNCER

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ABSTRACT: The act of caring involves a burden on the caregiver, causing impacts on social and family dynamics, as well as on the quality of care. This research aimed to understand the burden and the daily care provided by informal caregivers of people with cancer. This is a descriptive qualitative study, with the participation of 12 informal caregivers of pacient cancer. Data collection was carried out through the application of a socioeconomic questionnaire, associated with semi-structured interviews, with the aim of exploring the experiences related to care. Data analysis allowed the identification of three units of meaning: emotions, conflicting experiences, and coping strategies adopted. The results showed negative impacts on the health of caregivers, as well as wear and tear on interpersonal relationships. However, it was observed that these adversities did not change the way caregivers perform their activities, demonstrating resilience in the context of care.

KEYWORDS: Caregivers. Cancer. Caregiver burnout. Empathy. Health.

RESUMO: O ato de cuidar implica uma sobrecarga ao cuidador, ocasionando impactos na dinâmica social e familiar, bem como na qualidade do cuidado. Esta pesquisa teve como objetivo compreender a sobrecarga e o cotidiano do cuidado realizado por cuidadores informais de pessoas com câncer. Trata-se de um estudo qualitativo descritivo, com a participação de 12 cuidadores informais de pacientes oncológicos assistidos em uma instituição filantrópica. A coleta de dados foi realizada por meio da aplicação de um questionário socioeconômico, associado a entrevistas semiestruturadas, com o intuito de explorar as vivências relacionadas ao cuidado. A análise dos dados permitiu identificar três unidades de sentido: emoções, experiências conflituosas e estratégias de enfrentamento adotadas. Os resultados evidenciaram impactos negativos na saúde dos cuidadores, bem como desgastes nas relações interpessoais. No entanto, observou-se que essas adversidades não alteraram a forma como os cuidadores desempenham suas atividades, demonstrando resiliência no contexto do cuidado.

PALAVRAS-CHAVE: Câncer. Cuidadores. Desgaste do cuidador. Empatia. Saúde.

INTRODUCTION

Cancer is a term used to designate a group of more than 200 diseases characterized by the disordered (malignant) growth of cells that invade tissues and organs, potentially spreading, in the form of metastases, to other regions of the body. Cancer cells divide rapidly and tend to be highly aggressive and uncontrollable, leading to the formation of tumors or malignant neoplasms[1].

Cancer is undoubtedly one of the most significant public health challenges in Brazil and worldwide among chronic non-communicable diseases. Between 2014 and 2015, more than 500,000 new cases of cancer were recorded, placing Brazil among the countries with the highest incidence rates globally[2]. In this context, cancer has caused substantial psychological and social impacts, leading to a reduced quality of life, the onset of disabilities, and significant economic burdens for society and healthcare systems[3].

Another aspect to be considered is the impact of a positive diagnosis of cancer or any chronic disease on the family, which can cause the patient and his/her family group to suffer an emotional and psychological impact, especially the primary caregiver[3]. Adaptation to this process of illness is necessary.

It is necessary to adapt to this process of illness, which can present instability and uncertainty, with the need for comprehensive care for the patient, at the cost of overloading the most diverse aspects of their life, thus generating a risk group that can develop psychological symptoms, as well as chronic illnesses[4].

According to sociologist Émile Durkheim, society can be compared to a biological body, since it is composed of parts that interact with each other[5]. Thus, characterizing the family nucleus as a society, its members will have a unique way of relating to each other, based on their perceptions, beliefs and needs. Each member of the family will react in their own and unique way to the various events, including the illness of a family member. This can trigger impacts on the structure and roles that each individual holds within this social nucleus[4].

With the increase in life expectancy and scientific advances in the health area for the treatment of diseases, the importance of the role of the caregiver becomes evident. The informal caregiver classification is for any and all relatives, partners or friends who have an emotional relationship and provide assistance (physical, social and/or psychological) to a person with a serious or incurable illness[6]. Thus, the experience of caring for a sick family member can represent a great burden for the caregiver, leading to deprivation and changes in social and family dynamics[3].

The presence of numerous clinical, emotional and psychological complications triggered by this overload is well-known, and can cause strain on the mental and physical health of the caregiver, which compromises essential areas of life, such as self-care, work and leisure. These implications occur due to the time demands that caring for a cancer patient requires, and consequences such as depressive symptoms and stress, both physical and emotional, are perceived by caregivers[3].

The exhausting routine of medical appointments, chemotherapy and radiotherapy treatments, nutritional support, and emotional support, for months or even years. This routine brings, in addition to the emotional burden attributed to the disease, the physical and health burden for those who become responsible for the care. Thus, the experience of caring for a sick family member can represent an emotional, physical and financial burden, which affects the lives of caregivers, demanding time and dedication. This burden is generally accompanied by states of physical and mental fatigue, stress, depression, anxiety, lack of social support and a worse quality of life for caregivers.

According to studies, the prevalence of depression among caregivers is high, reaching approximately 42% globally, with higher rates among women, which highlights the vulnerability of this population to mental health problems[8]. In addition, caregivers often experience symptoms of anxiety and psychological distress, especially when exposed to diagnoses of diseases in advanced stages, due to high mortality rates and limited prognosis, exacerbating the emotional and social impact on the family context[9].

Additionally, caregivers deal with unmet needs, such as a lack of psychological support and specific training to manage critical situations, including the clinical and emotional aspects of care. Many report difficulties in accessing clear information, especially in health systems, which increases feelings of helplessness and frustration[10.] These demands, combined with a lack of preparation and social isolation, become aggravating factors that increase the negative impact on the health of these individuals. Interventions aimed at psychosocial support, effective communication, and reducing the subjective burden of suffering can significantly improve both the resilience and quality of life of caregivers, contributing to more humanized and sustainable care[8-9.]

In this context, the study is relevant in the current scenario, since cancer is one of the most complex public health problems facing the Brazilian health system. It is estimated that approximately one third of new cancer cases could be prevented[11]. The care actions for cancer patients have undergone exponential evolution in their diagnostic and therapeutic techniques, contributing to greater survival and quality of life for this population. This evolution is occurring due to the greater search for information in clinical protocols and effective interventions to the real needs of cancer patients, aiming at personalized care for their patients[12].

Reflecting on this issue can bring greater visibility to those who are the extension of assistance to the person with cancer, which is the care for those who care. With this study, we seek to gain greater knowledge regarding the influence of the burden of informal caregivers of cancer patients on the care provided by them. We seek to bring a critical analysis to interested parties and to the caregivers themselves, enabling this scenario to change positively. Thus, the main objective of the work was to understand the daily care provided by informal caregivers of people with cancer assisted by a philanthropic institution, and the self-reported burden.

METHODOLOGY

This qualitative and descriptive study was conducted with informal caregivers of cancer patients treated by the Casa de Apoio Entidade Ecumênica Amor ao Próximo. Family or informal caregivers who accompany cancer patients were included in the study, and those who had specific professional or technical training as caregivers were excluded.

To identify the participants, the institution's coordination was asked for a list containing the names of the informal caregivers linked to the patients treated, with the aim of selecting those who met the inclusion criteria. After this survey, eligible caregivers were invited to participate in the study through a face-to-face meeting at the philanthropic organization.

The study included the participation of 12 primary caregivers of cancer patients. The participants were approached in the waiting room of the Casa de Apoio while they were waiting for the family members being treated. The study included caregivers with a direct family connection to the patient, who were over 18 years old, and who declared themselves as the primary caregivers.

No predefined number of participants was established for the study. Data collection was completed when theoretical saturation was reached, that is, when the information obtained was sufficient to meet the research objectives and the responses began to show recurrence.

The interviews were conducted between January and June 2023, at the Casa de Apoio. This choice was due to the fact that most of the institution's attendees live outside the city of Maringá, which made it impossible to conduct the interviews in the caregivers' homes.

The interviews were conducted in person at the support unit, strictly following local COVID-19 prevention standards. Each interview was carefully scheduled, aiming for the greatest possible relevance to the context and needs of the participants. Before the interviews began, the caregivers were duly informed about the study's objectives and procedures. They also formalized their agreement by signing the Free and Informed Consent Form (FICF), ensuring the confidentiality and secrecy of the information provided.

The study used semi-structured interviews as the main data collection instrument. Initially, caregivers' identification data were recorded in order to understand their family context, occupation, time dedicated to care activities and aspects of their routine. In addition, the interviews addressed the caregivers' relationship with their family members, changes implemented in care, impacts on daily life resulting from this activity, history of illnesses, use of medications, financial status, time dedicated to leisure and self-reported quality of life.

The semi-structured interview was then continued with the application of the Zarit Scale[13], which aimed to assess the caregivers' burden in aspects related to availability, stress, relationships, fatigue and health. Since this was a qualitative study, each question on the scale was followed by the following question: “Could you explain the reason for your answer?” This approach allowed the questions to be asked in an open-ended manner, allowing new questions to be added based on the answers provided by the participants, which enabled a more in-depth investigation into possible influences of the answers on the care provided to the family member with cancer.

After the questions were completed, the information recorded using a voice recorder was fully transcribed. This process enabled the analysis of the answers using the thematic content analysis technique, which is structured in three stages: pre-analysis, exploration of the material and treatment and interpretation of the results[14]. In the pre-analysis, the set of documents to be analyzed was organized, the data of interest were identified, and indicators that would support the final interpretation were developed. The material exploration stage consisted of processes of decomposition, classification, grouping, and enumeration, aiming to identify information that responded to the study objectives.

The processing of the results involved the interpretation of the data obtained, relating them to the initial hypotheses, the research objectives, and the general findings. To ensure the anonymity of the participants, the coding “CDR” (referring to “caregiver”) was established, followed by sequential numbering according to the order in which the interviews were conducted. Thus, the first participant was identified as “CDR 1”, the second as “CDR 2”, and so on.

The research followed all national and international ethical precepts regarding studies with human beings. The project was initially submitted and approved by the management of the Casa de Apoio Entidade Ecumênica, Amor ao Próximo and then forwarded to the Research Ethics Committee (CEP) of UNICESUMAR, where it was duly assessed and approved (CAAE: 53736821.0.0000.5539). All the steps described were initiated only after obtaining the necessary authorizations.

RESULTS

Of the 12 family caregivers who participated in the study, eight were female and four were male, with ages ranging from 18 to 76 years. Regarding education, five participants had incomplete elementary education, three had completed elementary education, three had completed high school, and one had completed higher education. Regarding the degree of kinship, nine caregivers were children, one grandson, one sister, and one daughter-in-law.

With regard to occupation, four of the interviewees were housewives, four were retired, two were self-employed, one was a student, and one was a bricklayer. The average family salary reported among the interviewees was four minimum wages. Regarding the coexistence with the sick family member, 8 of the 12 caregivers reported living in the same residence. Regarding the length of care, a duration of one month to three years was reported since they assumed this role.

Regarding the type of care provided, there was a variability in the level of dependency on the part of the patients, ranging from those who required assistance with personal hygiene, eating, moving around and administering medication, which were five of the family members assisted; to those who were able to perform several activities alone, that is, who presented a lower level of dependency, which were seven of the family members assisted.

DISCUSSION

After a detailed analysis of the participants' statements, three main thematic categories emerged: empathy and the secondary benefit of the disease in care; Complexities involved in care: challenges and obstacles; and Experiences of the care process: overload and conflicting relationships. These categories were structured based on the similarity of the information collected, enabling a coherent organization of the analyzed data.

Even with the various courses before learning about the state of each condition, the diagnosis of cancer, performed by a professional, is one of the stages that can generate great concern for all family members and those who are monitoring the health condition [15].

Care, from the perspective of the study collaborators, was then permeated by emotions, experiences and strategies adopted by each caregiver to overcome the long and uncertain journey of cancer treatment.

> The doctor told us about the cancer, we had only gone for a follow-up, so no one was expecting it, everyone was shocked, so I left there very worried and shaken. (CDR3)
>
> I realized that my husband (cancer patient) was just like me, very shaken, because of the diagnosis. [...] Oh, his routine has changed a lot. Because all his food is blended, so it's something that requires a lot of care. I worry a lot about his health, and there are days when it seems like he doesn't eat, because everything is liquid (CDR4).

However, it is clear that although this concern is a constant for those who care for and live with a family member with cancer, it is still possible to find comfort and support from friends and family. Furthermore, testimonies were also collected that demonstrate greater tranquility when faced with the condition of illness.

> During chemotherapy, she (girlfriend with cancer) became weak, but we are always close, right? So her daughter and I help her with things, because I think we always have to be close in difficult times. Her daughter and her friends also helped a lot during that time. But after it was over, I feel calmer (CDR5).

> I don't have as much time to see my friends and the rest of my family anymore, but that hasn't changed my relationship with my family and friends. I have received a lot of support, and that has helped me a lot with all the suffering since the death of my son and now with my husband (relative with cancer) (CDR2).

> It's only at the beginning of the treatment that we get more worried and stressed. But now I think the worst is over (CDR6).

The concerns of each interviewee were expressed differently, but most reported greater concern when the condition was undergoing more intensive monitoring, since this is a stage that may require radical changes in the daily routine to adapt to the treatment routine. However, when patients were finishing treatment or in phases that require less medical intervention, the concern reported was less.

There are many difficulties faced by caregivers and cancer patients. Changes in family life and activities are common with the diagnosis, where caregivers have had to adapt to a new reality full of tensions and concerns[16.] It is believed that seeking information, together with spiritual, physical and emotional support, helps to minimize doubts, anxieties and concerns and contributes to a better quality of life for the caregiver and patient[17].

Another point addressed was the different experiences faced with the beginning and course of care and treatment for a family member with cancer, which directly affect the daily lives of the patient and caregiver.

> She didn't want treatment for a year, complaining of pain, crying that she couldn't eat. Then, after encouraging her so much, I managed to get her to start treatment (CDR7.

> I was more affectionate in taking care of her because before she was fine, and after she discovered the disease we have more dedicated attention (CDR8).

> At home, I'm the one who cleans, makes the meals she likes and once a month I accompany her to the doctor, but I do all this with great pleasure to help my sister (cancer patient) (CDR9).

> Sometimes he fights with me over nothing. […] but in the end I manage to reconcile with him. He lives next door to me and is with us 24 hours a day (CDR1).

Caregivers reported feeling indignant about behavioral changes, physical exhaustion, and the need to divert much of their attention to the family member they are caring for. Sometimes, caring for a family member with cancer can cause deprivation of social life and freedom, which implies changes in the lives and activities of those who are caring for them. In turn, these people may experience changes in their routines, which begin to be organized around the sick person, forgetting about self-care[18].

To support the changes generated by the diagnosis and treatment of the family member with cancer, strategies adopted to help them experience this phase were discussed.

> I think it was peaceful. Because God gives strength, knows everything and knows who has to go through each thing. Then we pray and everything is at peace and we hand it over to Him (CDR6).

> I always remember that this is just a phase and God will enlighten him (husband with cancer). Then I have more energy to continue taking care of him (CDR3).

In this sense, there are studies that reveal the religious appeal on the part of several caregivers, demonstrating this support as a source of support necessary to continue accompanying the patient. In addition to the support generated by spirituality, it also helps to minimize suffering, worries and difficulties in adapting to the treatment routine[19].

Another fact that was often observed was the empathy of the caregiver for the sick family member, who put themselves in the patient's shoes and sought the best way to help him/her during this period of treatment.

> But I cried a lot, but then I stopped to think, if I wasn't sick, I was already tired, I stayed in bed for three days. Imagine him, who is sick, and how his mental state is. There were days when he was so tired, that when he was waiting for an appointment and there was no place to sit, he would sit on the stairs and sleep. […] Because imagine, he's a man who has nothing, and the next day he has cancer. […] Then I started to see his side, he would fight, he would tell me not to raise his voice, that we would try to resolve it, but I never, ever fought with him. There were times when he would yell at me really loudly and I would say in a louder tone: "Wow, what's going on?" To see if he would realize what he was doing (CDR1).

> We never argued, we never fought. There are times when she is quite rude, right? But then I understand that it's because of the problem. Because you go to eat, you can't, there's that pain. So, you're not always in a good mood, but I'm not always in a good mood, I take it as a joke and that's it. […] I eat what she eats. Because if I made rice, beans, meat for myself, I wouldn't like it, knowing that she won't be able to eat it. So I prefer to make a soup that she can eat too, the way I'm eating it. I think she'll be offended, so I make the same food and eat the same thing with her (CDR7).

The role of the caregiver is essential to increasing success and generating greater adherence to various types of treatments. The companion is dedicated to meeting the patient's demands and limitations, providing attention, affection and empathy. For this to occur effectively, the caregiver is subject to increased overload, stress and a worsening of quality of life[20].

Another frequent report during the interviews was the previous experience of one or more cases of cancer in the family in the vast majority of participants. There were cases in which the treatment was completed in a short space of time and the patient managed to overcome the cancer, however the vast majority had negative experiences with the course of each condition, with the greatest fear being the patient's death.

> I lost a sister, who will be three years old now, in May, and I lost a son, both of them because of cancer. And last Saturday he would have turned 35 (CDR2).

> So, my grandmother and my two aunts have already died of cancer. My grandmother had leukemia, one of my aunts had uterine cancer and another had breast cancer (CDR12).

> I took care of my sister first and then my daughter got it. We feel sad and worried about that (CDR6).

> I have a brother who died five years ago from cancer that spread from the waist up. And in his family, he has a nephew who had stomach and esophageal cancer. In my brother's case, it happened suddenly, he got sick, then no one found out anything, and when they did, he did some tests and he died the next day (CDR4).

> As you can see, the person is undergoing treatment, and I've already lost five members of my family, I know what I've been through, right? Because imagine the doctor coming and telling you this diagnosis, it's going to change your life completely (CDR7).

> I live with this fear of losing my husband (a cancer patient) because, as I said, I've already lost my sister and my son to cancer. […] I feel very distressed and afraid that he'll die because of it cancer (CDR2).

During the conversations about past experiences with relatives with cancer, several signs of sadness were presented, marked by pauses in conversation and crying, which demonstrated concern about the occurrence of a possible negative situation with the family member who is currently being cared for. The concern, mostly, was caused by the rapid and uncertain evolution of each case, directly affecting the thoughts of each caregiver and each family member who is witnessing the process, such as the fear and constant worry about losing the family member to cancer. The fact that this recurrence of conditions is explained by the multifactorial and genetic nature of cancers, increasing the predisposition to the occurrence of a similar condition in close family members[21]. Recurrent living with the disease can generate diverse feelings, such as habitualness, but also frustration and sadness, due to the potential lethality that the disease imposes on people's lives[22].

However, in the face of several negative reports, there were also interviewees claiming that the care process was in some way favorable for them, where they mentioned obtaining secondary gains from caring for the cancer patient.

> I met her, started helping her, and I think it was good for me. It's taking up my time. I've had a lot of loss since the beginning of last year, it was the whole year, that loss, so I was locked up at home every day because of COVID. Then when I started taking care of her, things developed, I started leaving the house more, coming to Maringá, and everything. […] before I was very closed off. So, when she came asking for my help, I started leaving to come here, I'm going somewhere I want, right? So I thought it was even good, to start taking care of her (CDR7).

> Now our relationship is better than before. Because before he (husband with cancer) didn't call much, didn't talk much, now he's more attentive and is talking to me more (CDR4).

> Everything has been very good and I'm always in touch with my sister, who I hadn't had for a long time. It hasn't negatively affected my relationship with my family or friends, except that I see them less because of the distance, because they live in São Paulo (CDR9).

The statements about secondary gain involved the expression of antagonistic feelings, such as sadness caused by the uncertain care process and happiness with the benefit obtained. Nevertheless, the act of caring can generate secondary gains, such as greater attention and time with the patient. However, he also states that this process can generate several limitations that end up interfering in this relationship between caregiver and patient, such as the deprivation of some activity due to the treatment[23].

COMPLEXITIES INVOLVED IN THE CARE PROCESS: MAIN CHALLENGES AND OBSTACLES

The act of caring has an impact on the caregiver's life, and can lead to significant changes in areas such as self-care, health, and interpersonal relationships with other family members[24]. However, despite all these challenges, caregivers remained motivated to continue caring for their sick family member.

The complexity of the act of caring is evident, and in view of this, it is extremely important for caregivers to maintain self-care throughout this process. However, during the interview period, it became clear that this self-care was not maintained, especially in relation to the sleep routine. The emotional factor was also mentioned as having a significant influence, as well as difficulty in maintaining physical exercise and a healthy diet, which led to the deterioration of their health.

> To tell you the truth, my health is terrible. I can't sleep, right? I'm taking sleeping pills every other day. I can't eat properly, because every time he goes to eat, he can't swallow, so I see that he hasn't eaten and I don't eat either, and so on, right? (CDR2).
>
> Ahh, I used to take better care of my health. Before, I could take better care of my diet, with fruits and vegetables, I would go for walks and diets, because I wanted to lose weight, right? So I would eat fruits and vegetables, but now I don't have time anymore. Now, with the support home, they help a lot. But before, there were times when I would go almost the whole day without eating, then during my father-in-law's treatment I lost about 10 kg (CDR1).
>
> I don't have any time anymore, I don't even have time to prepare food, so I end up eating more snacks, salty snacks, soda, and stuff like that. I don't have time anymore to go for walks, which I always liked to do before so I could take care of myself (CDR1).

The interviewees reported several challenges faced while caring for a sick family member, such as difficulty sleeping, inadequate nutrition and lack of time to perform physical activities. These changes in routine are corroborated by a study[1], which indicates that such changes can negatively affect the physical, psychological and social conditions of the caregiver.

The overload generated by the care process contributes to a daily routine full of responsibilities, which requires adaptations in the caregiver's life and routine, which directly affects their quality of life, especially with regard to self-care. Changes in sleep and physical activity, associated with a decrease in emotional well-being, are frequently observed[12]. Another factor addressed in the interview was the long wait in line for treatment, which increases the level of stress and anxiety in the caregiver's life.

> Since I worked at night, there were times when I would sleep for two hours a night, so I could bring him and stay here all day. So, like, everything in your life changes a lot and my health got worse with it (CDR1).
>
> My health has deteriorated a lot, stress has increased, and we don't sleep the same way we used to, everything changes (CDR11).
>
> My mental health has gotten a lot worse during this time. Like, now that he stopped coming every day, we've been able to get a little more excited, right? But I've felt like giving up, I just didn't give up because of him. I've spent three days in bed, because there were so many days of treatment, every day. So we had to come, wait too long, and when they called, the appointment only lasted 15 minutes doing the radio (CDR4).

The exhausting routine of caring for a sick family member directly impacts the caregiver's health, generating a significant increase in physical and mental stress. Pain, often reported by caregivers, arises as a manifestation of this stress, possibly associated with the activities performed, such as bathing, helping with mobility and performing household tasks, such as cleaning, organizing and preparing meals[1].

The constant physical effort required in caregiving, combined with insufficient time for rest, are determining factors in the deterioration of the caregiver's physical health. Studies that assess the vitality and quality of life of caregivers of family members with cancer show that, regardless of age group, it is common to report a decline in these aspects, evidencing the emotional distress experienced[1]. In this context, it is essential that a multidisciplinary team offers support not only to the sick family member, but also to the caregiver².

In addition to the impact on health, another challenge faced by caregivers involves changes in interpersonal relationships with other family members. These changes have an impact on both the caregiver's life and that of other family members. Reports of feelings such as sadness, worry and stress are common, reflecting the emotional complexity of the caregiver.

> I told my daughter: Daughter, school is going to start again and you can go play with your friends (at that moment she held back tears) and my daughter said she didn't want to go, she wanted to stay with me, and the school staff called me into a small room to talk, and asked me what was happening because their daughter wasn't used to crying before, and at the time my daughter answered: “it's because my mother doesn't have time to take care of me anymore (at that moment the interviewee apologized and started to cry), because my mother goes to Maringá every day with my grandfather” (CDR1).
>
> Contact with my husband is being very complicated, because he works away from home and I always have to come to Maringá during the week, and that ends up keeping us apart (shows concern), and I end up leaving my children alone, my chores end up falling behind (feeling sad), and I end up getting a little depressed (CDR3).
>
> It affects my daughter because I get stressed and end up taking it out on her (she gave the awkward smile again from before) (CDR8).

Due to the overload of activities during the process of caring for a sick family member, the caregiver ends up neglecting other areas of life, especially interactions with other family members, thus generating significant wear and tear on the interpersonal relationships of this caregiver. In this sense, it is common to find obstacles in the caregiver's attempt to maintain the life they had before starting their role as primary caregiver, causing the caregiver's personal wishes to be nullified[29].

Despite these negative impacts, the constant presence of the possibility of losing a loved one and the implications for the family become motivating factors in continuing to provide care, even in the face of numerous challenges. The reports generally demonstrated that caregivers seek to perform their duties in the best possible way, expressing dedication and appreciation for their family members.

> I'm feeling physically, psychologically and spiritually exhausted. But how could I not help someone my husband loves? How could I see someone like him, a wonderful person, suffering with the possibility of losing his father at any moment and not wanting to help (CDR1).
>
> But despite the stress and exhaustion, I never changed the way I take care of him. Because he's my husband, he's the one who's been with me my whole life and he could have surgery at any moment and I might never see him again (CDR2).
>
> I would never regret taking care of her, because she's my mother, right? I have a lot of respect for her, and I think taking care of her is an obligation that I have to do (CDR12).
>
> I have a feeling that I'm doing something to help him (grandfather with cancer), because I know he helped me a lot and unfortunately, as I said, his children aren't reciprocating, right? So, as his granddaughter, I'm helping, but as a way of giving back (CDR10).

> I feel tired during this whole process, but I'm happy to be able to help my mother, she has done so much for me and now I'm trying to give back (CDR3).

The interviews revealed several significant impacts on the lives of caregivers, resulting in changes such as increased stress levels, health problems and weakened relationships with other family members. However, despite the numerous negative aspects that directly and indirectly affect their lives, caregivers demonstrate resilience and remain dedicated to fulfilling their responsibilities. This attitude is largely driven by the intention to reciprocate the care received throughout their careers, as a form of gratitude and recognition. Furthermore, the feeling of satisfaction in providing assistance to those who, at other times, were responsible for caring for them stands out[30].

EXPERIENCES OF THE CARE PROCESS: OVERLOAD AND CONFLICTING RELATIONSHIPS

The organization of the service was something that was often reported by caregivers, who mentioned that among the factors that end up making the process of caring for a cancer patient very tiring are the long waiting times before a medical procedure or simple consultation is performed.

> Here, it takes a long time for everything to happen, my friend. If your appointment is scheduled for 1:00 p.m. today, you'll be seen at 3:00 p.m. What's tiring is not the treatment, but the long waiting time (CDR1).

> What's really tiring is having to come here, because the appointments take a long time, there are a lot of people in the place, there aren't enough chairs, that's the problem (CDR10).

> We feel really exhausted, we have to wake up at 3:30 a.m. and leave at 4:30 a.m. So there's no time to get home, because sometimes it takes a long time to call for the appointment and then there's the travel time to get back home (CDR4).

Since none of the interviewees were from the city where the medical procedure were performed, the travel time added to the waiting time ended up resulting in several hours during the day of monitoring, causing dissatisfaction and fatigue on the part of the caregivers. Another factor linked to this longer waiting time is the use of vans to go to the hospital and return home, subject to the schedules established by the transportation provider. However, there were reports in which the family member undergoing treatment ended up negatively influencing the caregiver's mood, because they were discouraged with the progress of their case or even exhausted by the delay in treatment.

> I've been very irritated, you know, because my mother (cancer patient) is very stubborn, she doesn't help us, even though I just want to help (CDR8).

> And my mother has been very discouraged and this ends up making me more tired, because when you see that the person is trying, is fighting, it gives you the motivation to continue the care, and sometimes I get discouraged because it seems like she doesn't even want to try anymore (CDR3).

The complex path of cancer treatment can give rise to different and contradictory feelings, which can even disrupt the relationship between the caregiver and the family member being cared for. However, the support of people or relatives helps both parties to better cope with the adversities generated by the illness and improves the course of care[18].

Another difficulty presented during the dialogues is related to the lack of help with care. Although some interviewees stated that care tasks were shared with more people and did not generate a significant burden, the other participants stated that the care process created a burden on their routines, which was even more evident in cases of single caregivers or those without any support.

> In short, he has 10 children, five from one wife and five from the other, but I am the only one who takes care of my father-in-law. Only my husband has this concern, but then he stays home working and I take care of him. […] My husband's family didn't come together after the diagnosis and doesn't even try to help. It ends up that I get very overwhelmed and if there were more people helping, my routine wouldn't have changed so much (CDR1).

> Just today, I got a huge scolding from the doctor, because I told her to bring the medication and she didn't. She lives with my stepfather who is also sick, who is another stubborn old man and doesn't want to come to the city to help, and I also have to take care of my granddaughter. So, there's no way I can provide assistance every day (CDR8).

> Yes, there are five of us siblings, but I'm the only one who comes to accompany her during treatment. […] If a sister came along, it might be easier. But today, it's just me, who comes with her, so it's a bit overwhelming (CDR12).

> Because he has two children, and they could be helping. One is my father, who works and has a lot of problems and stuff, and one is my aunt, who is a drug user. So it's up to me, who's the oldest granddaughter (CDR10).

> I'm the only one who's been taking care of my mother, and all this treatment has affected my mental health because of the worry, and I also have two children to take care of, both of whom have a rare disease. So, it's a lot of worry for one person to handle (CDR3).

The statements regarding care expressed signs of indignation and disappointment at the same time, since they deal with caregivers who are spending several hours of the day just to care for sick family members, and in most cases, they have no support whatsoever, not even the recognition of the patient who is being cared for. Carrying out solitary care sometimes has negative repercussions on the caregiver's life for several reasons. Caregivers may feel a lack of support and indignation because this is work not performed by other family members, impacting their physical and mental health[31].

Another relevant aspect was that some interviewees reported that the long treatment process ended up triggering great stress in the caregiver and in the patient undergoing treatment. Therefore, there were reports in which the caregiver-patient relationship was becoming increasingly troubled and ended up being yet another difficulty in this process

> There was even a time when the treatment was too much, he became a bit upset. And he got stressed and changed his tone of voice with two of his daughters who helped take care of him, and then the daughters gave up taking care of him. […] I couldn’t do it anymore, he changed his voice with me, he spoke loudly to me, he yelled at me, he swore at me and I said to him: You can go in the back of the van and I’ll go in front, you don’t even have to pretend to know me, but I’m not going to abandon him. Because there’s no way, the person is already not well. […] But when he argues, we feel useless, because we say: “My God, I’m giving up my life to take care of him”. […] People say: “But he’s just your father-in-law, right?” But he’s also my husband’s father (CDR1).

> There are times when he gets on my nerves because he's ignorant, he doesn't like talking to me, so I keep asking questions and he doesn't answer and that's why I get really angry. […] I maintained the same care with him, but sometimes I feel hurt for doing so much for him and still being treated rudely (CDR2).

During our study, it became clear that conflicts were triggered within the family, especially between the caregiver and the sick family member, due to the significant increase in stress and the care routine. Thus, it is an interesting aspect to be considered, when not only caregivers of cancer patients report this fact, but also caregivers of family members with sequelae or high care demands, originating from other chronic morbidities[32].

In this context, studies that addressed family caregivers of people who require monitoring due to chronic diseases highlighted changes mainly in marriage, where these relationships have undergone radical changes imposed by the disease, leading them to feel dissatisfied with their marriages, increasing friction within the family[27-28]. Furthermore, the indignation on the part of the family caregiver, often due to not receiving recognition for their work, demonstrated that the caregiver is resentful towards the sick family member, which was also verified in these same studies[32-33].

Therefore, it became clear that the caregiving process is full of surprises for both the patient and the caregiver. The need for monitoring can trigger several physical, mental and social changes in the caregiver. Thus, the environment in which the caregiver is inserted directly affects the intensity of the overload generated by the process, making it clear that the support of family and friends during this phase for the caregiver and the patient is important.

PRACTICAL IMPLICATIONS OF THE STUDY AND THE PROMOTION OF CAREGIVERS' HEALTH

Informal care for cancer patients is essential, but it presents significant challenges for those who perform this role. This study reveals, in some cases, a gap in caregivers' knowledge regarding patient management. Therefore, it is necessary to develop public intervention practices with the aim of training caregivers, such as training programs that address patient management, techniques, and support. Such programs can assist and improve care, reducing errors and reducing the insecurity of those who provide this care[34].

Based on the interviews presented, caregivers demonstrated neglect of their own well-being due to the demands of care. In view of this, the possibility of implementing campaigns and programs that encourage self-care, including physical exercise, healthy eating, relaxation techniques and rest routines can help prevent physical and emotional exhaustion, improving the quality of life of caregivers[35].

Emotional stress and feelings of isolation are frequent challenges for caregivers, as reported in the study. The creation of support groups and individual or group therapies can provide a safe space to share experiences. Integrating these caregivers into support networks, such as community organizations or specific groups, can minimize the emotional impact and provide a more welcoming and supportive environment[36].

The need to improve access to health services, which often present logistical barriers, such as long waiting times and transportation difficulties. Creating more accessible services adapted to the needs of caregivers, such as dedicated transportation and priority care, can significantly reduce logistical and emotional stress[37].

Another essential aspect revealed by the study is that the lack of recognition and family support are factors that intensify caregiver burden. Therefore, valuing the role of informal caregivers through public policies and awareness campaigns can help reduce this feeling of neglect[36].

In this context, family relationships can suffer negative impacts during the care process, generating conflicts and emotional distress. Educational programs aimed at improving communication and conflict management can strengthen family ties and create a more collaborative environment in care. These integrated strategies have the potential to improve not only the quality of life of caregivers, but also the effectiveness of care provided to cancer patients[38]. Therefore, it becomes possible to construct relevant social and political aspects for promoting the health of caregivers of cancer patients.

CONCLUSION

It was concluded that acting as a caregiver for a family member with cancer brings about profound changes in physical and mental health and family dynamics. A significant increase in physical and emotional exhaustion was observed, caused mainly by changes in sleep quality, the exhausting routine of caring for the sick family member and the high level of emotional stress throughout the process. However, despite these adversities, a genuine feeling of gratitude was identified in the caregivers, who see this experience as an opportunity to reciprocate the care received, evidencing a reversal of roles in their relationships, as they take on the role of caring for those who have done so much for them.

Another relevant aspect is the need for support from a multidisciplinary health team, considering that this period is marked by uncertainty and conflict, in which the caregiver can often feel helpless, exhausted and vulnerable. Thus, it is clear that the physical and psychosocial challenges faced by caregivers require greater attention, with effective interventions that promote the integral well-being of caregivers and their families, going beyond conventional clinical treatment.

During data collection and interviews, it became clear that there is a lack of research in the medical field that addresses this current and relevant topic. It is necessary to expand studies on the subject in order to assist doctors and caregivers throughout the patient's treatment process. This approach will make it possible to treat cancer holistically, and not just as a clinical comorbidity, favoring interventions that benefit both the patient and the family caregiver.

REFERENCES

1. Toledo MO, Ballarin MLGS. O cotidiano de cuidadores informais de pacientes em tratamento quimioterápico. Caderno Brasileiro de Terapia Ocupacional (São Carlos). 2013;29(1):75-81. http://dx.doi.org/10.4322/cto.2013.011
2. Panis C, Kawasaki ACB, Pascotto CR, Justina EYD, Vicentini GE, Lucio LC, Prates RTC. Revisão crítica da mortalidade por câncer usando registros hospitalares e anos potenciais de vida perdidos. Jpurnal Einstein (São Paulo) 2018;16(1): eAO4018. https://journal.einstein.br/pt-br/article/revisao-critica-da-mortalidade-por-cancer-usando-registros-hospitalares-e-anos-potenciais-de-vida-perdidos/ (accessed November 12, 2023)
3. Machado BM, Dahdah DF, Kebbe LM. Cuidadores de familiares com doenças crônicas: estratégias de enfrentamento utilizadas no cotidiano. Caderno Brasileiro de Terapia Ocupacional (São Carlos). 2018; 26(2):299-313. https://doi.org/10.4322/2526-8910.ctoAO1188
4. Pereira BS. Saúde mental de pacientes com doença renal crônica e cuidadores e sua associação com alterações clínicas [dissertação] Juiz de Fora: Universidade Federal de Juiz de Fora; 2016. Available from: https://repositorio.ufjf.br/jspui/handle/ufjf/2350 (accessed October 12, 2023)
5. Durkheim É. Da divisão do trabalho social. 2ª ed. São Paulo: Livraria Martin Fontes Editora Ltda.; 1999.

6. Delalibera M, Barbosa A, Leal I. Circunstâncias e consequências do cuidar: caracterização do cuidador familiar em cuidados paliativos. Ciência & Saúde Coletiva (São Paulo). 2018; 23(4):1105-1117. https://doi.org/10.1590/1413-81232018234.12902016
7. Delalibera M, Presa J, Barbosa A, Lela I. Sobrecarga no cuidar e suas repercussões nos cuidadores de pacientes em fim de vida: revisão sistemática da literatura. Ciência & Saúde Coletiva (São Paulo). 2015; 20(9):2731-2747. https://doi.org/10.1590/1413-81232015209.09562014
8. Bedaso A, Dejenu G, Duko B. Depression among caregivers of cancer patients: Updated systematic review and meta-analysis. Psycho-Oncology. 2022;31:1809–20. https://doi.org/10.1002/pon.6045
9. Chong E, Crowe L, Mentor K, Pandanaboyana S, Sharp L. Systematic review of caregiver burden, unmet needs and quality-of-life among informal caregivers of patients with pancreatic cancer. Support Care Cancer. 2023;31:74. https://doi.org/10.1007/s00520-022-07468-7
10. Mollaei F, Nia HS, Pouralizadeh M, Karkhah S, Javadi-Pashaki N, Ghorbani Vajargah P. Resilience and related factors in caregivers of adult cancer patients: a systematic review. Ann Med Surg (Londres). 2024;86:3451–3459. https://doi.org/10.1097/MS9.0000000000001469
11. Instituto Nacional de Câncer. ABC do câncer: abordagens básicas para o controle do câncer. 5ª edição. Rio de Janeiro: INCA, 2019.
12. Lopes-Júnior LC, Lima RAG. Cuidado ao câncer e a prática interdisciplinar. Caderno de Saúde Pública (Rio de Janeiro). 2019;35(1):e00193218. https://doi.org/10.1590/0102-311X00193218
13. Brasil. Ministério da Saúde. Secretaria de Atenção à Saúde. Departamento de Atenção Básica. Caderno de atenção domiciliar - Volume 1. Brasília: Ministério da Saúde. 2013.
14. Cardoso MRG, Oliveira GS, Ghelli KGM. Análise de conteúdo: uma metodologia de pesquisa qualitativa. Caderno da UniFucamp (Minas Gerais). 2021; 20(43):98-111. https://revistas.fucamp.edu.br/index.php/cadernos/article/view/2347 (accessed October 23, 2024)
15. Silva Júnior RF, Santos MA, Oliveira TR, Souza GF, Lima RA. Comunicação do diagnóstico de câncer colorretal à pessoa e família e/ou cuidador. J Health NPEPS (Mato Grosso). 2020;5(1):1-15. https://periodicos.unemat.br/index.php/jhnpeps/article/view/4585/3837 (accessed December 18, 2023)
16. Figueiredo T, SILVA AP, Silva RMR, Silva JJ, Silva CSO; Alcântara DDF, Souza LPS, Souza AAM. Como posso ajudar? Sentimentos e experiências do familiar cuidador de pacientes oncológicos. Abcs Health Sci (São Paulo). 2017; 42(1):34-39. http://dx.doi.org/10.7322/abcshs.v42i1.947
17. Oliveira MBP, Souza NR, Bushatsky M, Dâmaso BFR, Bezerra DM, Brito JA. Atendimento domiciliar oncológico: percepção de familiares/cuidadores sobre cuidados paliativos. Escola Anna Nery (Rio de Janeiro). 2017; 21(2):e20170030. https://doi.org/10.5935/1414-8145.20170030
18. Chesani FH, Andrade MGC, Kerkoski E. Vulnerabilidade e empatia de cuidadores/familiares de pacientes hospitalizados como sentimento reflexo à equipe assistencial. Rev. Univap (São José dos Campos). 2019; 25(48):149-159. https://doi.org/10.18066/revistaunivap.v25i48.2215
19. Oliveira J de Silva, Cunha D de O, Santos CS, Morais RLGL. Repercussões na vida de cuidadores de crianças e adolescentes com doença oncológica. Cogitare Enfermagem (Paráná).2018; 23(2): e51589. https://doi.org/10.5380/ce.v23i2.51589
20. Oliveira AC, Pilon JK, Santos QS dos, Pereira DA, Rocha AC, Luz GA, Monteiro I do N, Vale ES do, Teixeira ACS, Amorin IFC. Qualidade de vida e espiritualidade dos cuidadores informais de pacientes oncológicos: uma revisão narrativa. Revista Eletrônica Acervo Saúde (São Paulo). 2022; 15(2):1-7. https://doi.org/10.25248/reas.e9835.2022
21. Andrade RO, Goldfarb AMA, Waisse S. Estudos sobre o câncer no século XIX e sua construção como um problema médico no início do século XX no Brasil. Revista Brasileira de História da Ciência (Rio de Janeiro) 2017; 10(2):154-168. https://rbhciencia.emnuvens.com.br/revista/article/view/130/96 (accessed November 29, 2023)

22. Prado E do, Sales CA, Girardon-Perlini NMO, Matsuda LM, Benedetti GM dos S, Marcon SS. Vivência de pessoas com câncer em estágio avançado ante a impossibilidade de cura: análise fenomenológica. Escola Anna Nery (Rio de Janeiro). 2020;24(2):1-8, 2020. https://doi.org/10.1590/2177-9465-EAN-2019-0113
23. Kohlsdorf M, Costa Junior ÁL da. Dificuldades relatadas por cuidadores de crianças e adolescentes com leucemia: alterações comportamentais e familiares. Interação em Psicologia (Curitiba). 2010; 14(1):1-12. https://pesquisa.bvsalud.org/gim/resource/en,au:%22Martins%20Neto,%20Viviana%22/lil-575850 (accessed November 15, 2023)
24. Mattos EBT, Oliveira JP, Novelli MMP. As demandas de cuidado e autocuidado na perspectiva do cuidador familiar da pessoa idosa com demência. Revista Brasileira de Geriatria e Gerontologia (Rio de Janeiro). 2020;23(3):e200189. https://doi.org/10.1590/1981-22562020023.200189
25. Eugenio APL, Savaris LE. A vivência de cuidadores/as de doentes de câncer: impactos, desafios e estratégias de enfrentamento. Revista de Saúde Pública (Paraná). 2021; 4(3):115-131. https://doi.org/10.32811/25954482-2021v4n3p115
26. Rocha RAPL, Rocha E de M, Machado ME, Souza A, Schuch FB. Sobrecarga do cuidador de pacientes oncológicos em cuidados paliativos. Revista de Enfermagem UFPE Online (Pernambuco). 2020;14:e244165. https://doi.org/10.5205/1981-8963.2020.244165
27. Kalinke LP. Qualidade de Vida em Oncologia. Campo Grande: Life Editora, 2019.
28. Monteiro FLR, Queiroz J da C, Couto ACA, Oliveira LG, Pinto BF, Fagundes LCM, Pinheiro FP, Gama PL da, Barbosa JS, Ribeiro AT do R, Nascimento FS, Assunção AF, Maciel AF, Souza RCN de. Atuação da equipe multiprofissional em cuidados paliativos oncológicos na assistência domiciliar ao paciente e seus familiares. Brazilian Journal of Development (Paraná). 2020;6(5):31203-31216. https://doi.org/10.34117/bjdv6n5-542
29. Ferreira MLSM, Mutro ME, Conde CR, Marin MJS, Meneguin S, Mazzetto FMC. Ser cuidador de familiar com câncer. Ciencia Y Enfermaria (Chile). 2018;24(1):1-11. http://dx.doi.org/10.4067/s0717-95532018000100206
30. Ferreira TSG, Siqueira CA, Rodrigues RC, Melo J dos S. Um olhar fenomenológico sobre o cuidador familiar e os cuidados paliativos ao paciente oncológico. Revista Arquivos Científicos (Macapá). 2019; 2(1): 43-48. Available from: https://arqcientificosimmes.emnuvens.com.br/abi/article/view/77/70 (accessed December 10, 2023)
31. Mello J de, Oliveira DA de, Hildebrandt LM, Jantsch LB, Begnini D, Leite MT. Vivências de cuidadores ante o processo de adoecimento por câncer de seu familiar. Revista de Enfermagem da UFSM (Rio Grande do Sul). 2021; 11(17): 1-21. https://doi.org/10.5902/2179769244116
32. Bocchi SCM. Vivenciando a sobrecarga ao vir-a-ser um cuidador familiar de pessoa com acidente vascular cerebral (AVC): análise do conhecimento. Revista Latino-Americana de Enfermagem (Ribeirão Preto). 2004; 12(1): 115-121. https://www.scielo.br/j/rlae/a/9kZRDymWn5pNqLyDbP6LgdG/?format=pdf&lang=pt (accessed December 21, 2023)
33. Fonseca N da R; Penha AFG, Soares MPG. Ser cuidador familiar: um estudo sobre as conseqüências de assumir este papel. Physis: Revista de Saúde Coletiva (Rio de Janeiro).2008; 18(4):727-743. https://doi.org/10.1590/S0103-73312008000400007
34. Godinho MIM, Canais EMDP, Saruga SMP. Capacitar o cuidador informal no decorrer da prestação de cuidados no domicílio. Rev Ibero-Americana de Saúde e Envelhecimento (Portugal). 2022;8(2):241-257. http://dx.doi.org/10.24902/r.riase.2022.8(2).544.241-257
35. Silva JV, Dias BVB, Nascimento MC, Melo JLL, Francisco R, Fava SMCL, Reis RD. Características sociodemográficas, estado de saúde e capacidades de autocuidado de cuidadores familiares primários de pessoas idosas. Enfermagem Brasil (São Paulo). 2022;21(4):400-412. https://doi.org/10.33233/eb.v21i4.5032

36. Nascimento EMA, Rodrigues MSD, Evangelista CB, Cruz RAO, Lordão AV, Batista PSS. Estresse emocional entre cuidadores informais de pacientes em cuidados paliativos. Revista de Enfermagem UERJ (Rio de Janeiro). 2021;29:e61132. https://doi.org/10.12957/reuerj.2021.61132
37. Graboyes EM, Chaiyachati KH, Gall JS, Johnson W, Krishnan JA, McManus SS, et al. Addressing transportation insecurity among patients with cancer. Journal of The National Cancer Instute (Reino Unido). 2022;114(12):1593-1600. https://doi.org/10.1093/jnci/djac134
38. Camargos MGD, Paiva BSR, Oliveira MA, Ferreira PS, Almeida VTN, Cadamuro SA, Fereira, PS, Almeida, CSL, Paiva, CE. An explorative analysis of the differences in levels of happiness between cancer patients, informal caregivers and the general population. BMC Palliative Care (Nova York). 2020;19(106):1-13. https://doi.org/10.1186/s12904-020-00594-1