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Experiences of caregivers in the face of their relative's cancer illness process

Vivências de cuidadores ante o processo de adoecimento por câncer de seu familiar

Experiencias de los cuidadores ante la enfermedad de cáncer de su pariente

Jonata de Mello[I], Dionatan Almeida de Oliveira[II], Leila Mariza Hildebrandt[III], Leonardo Bigolin Jantsch[IV], Danusa Begnini[V], Marinês Tambara Leite[VI]

Abstract: **Objective:** to understand the experiences of family caregivers of people with cancer during the illness process. **Method:** qualitative and descriptive study, conducted in a city in the Northwest of Rio Grande do Sul, with nine family caregivers of people with cancer. The data produced through semi-structured interviews were submitted to thematic analysis, originating three themes. Data were collected between February and June 2019. **Results:** after a family member's illness with cancer, it became necessary to elect a primary caregiver, designated by the other relatives, by the patient or by the caregiver's own desire. There were changes in the daily dynamics of the family caregiver, highlighted by the abandonment of the job and his/her personal life tasks, entailing overloads. Several conditions experienced by the family caregivers were identified: fear, despair, crying, powerlessness, concern and depressive symptoms. **Conclusion:** the act of caring for a relative with cancer changes the caregiver's daily life and has the potential to transform the family structure.

Descriptors: Neoplasms; Caregivers; Family; Nursing; Home Care

Resumo: **Objetivo:** compreender as vivências de cuidadores familiares de pessoas com câncer durante o processo de adoecimento. **Método:** estudo qualitativo, descritivo, realizado em um município do Noroeste do Rio Grande do Sul, com nove cuidadores familiares de pessoas com câncer. Os dados produzidos mediante entrevistas semiestruturadas foram submetidos à análise temática, originando três temas. Os dados foram coletados entre fevereiro e junho de 2019. **Resultados:** após o adoecimento por câncer de um membro da família fez-se necessário

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[I] Nurse, Resident from the Multiprofessional Residency Program in Cancer Care, University of Passo Fundo, Passo Fundo, RS, Brazil. E-mail: jonataenfermagem@gmail.com. Orcid: https://orcid.org/0000-0001-6386-4701.

[II] Undergraduate Nursing Student, Federal University of Santa Maria/Palmeira das Missões Campus, Palmeira das Missões, RS, Brazil. E-mail: dionatan190@gmail.com. Orcid: https://orcid.org/0000-0002-7377-6112.

[III] Nurse, PhD in Sciences, Adjunct Professor, Department of Health Sciences, Federal University of Santa Maria/Palmeira das Missões Campus. Palmeira das Missões, RS, Brazil. E-mail: leilahildebrandt@yahoo.com.br. Orcid: http://orcid.org/0000-0003-0504-6166.

[IV] Nurse, PhD in Nursing, Adjunct Professor, Department of Health Sciences, Federal University of Santa Maria/Palmeira das Missões Campus. Palmeira das Missões, RS, Brazil. E-mail: leo_jantsch@hotmail.com. Orcid: http://orcid.org/0000-0002-4571-183X.

[V] Nurse, PhD Student in Nursing, Federal University of Rio Grande do Sul. Porto Alegre, RS, Brazil. E-mail: danusabegnini@hotmail.com. Orcid: http://orcid.org/0000-0002-4713-946X.

[VI] Nurse, PhD in Biomedical Gerontology, Associated Professor, Department of Health Sciences, Federal University of Santa Maria/Palmeira das Missões Campus. Palmeira das Missões, RS. Brazil. E-mail: tambaraleite@yahoo.com.br. Orcid: https://orcid.org/0000-0003-3280-337X.

eleger um cuidador principal, designado pelos demais familiares, pelo doente ou por desejo do próprio cuidador. Houve mudanças na dinâmica cotidiana do cuidador familiar, evidenciadas pelo abandono do emprego e de seus afazeres da vida pessoal, acarretando sobrecargas. Identificaram-se diversas condições vivenciadas pelos cuidadores familiares: medo, desespero, choro, impotência, preocupação e sintomas depressivos. **Conclusão:** cuidar de um familiar com câncer modifica o cotidiano do cuidador e tem potencial para alterar a estrutura familiar.

Descritores: Neoplasias; Cuidadores; Família; Enfermagem; Assistência Domiciliar

Resumen: **Objetivo:** comprender las experiencias de los parientes que brindan atención a personas con cáncer durante el proceso de la enfermedad. **Método:** estudio cualitativo y descriptivo efectuado en una ciudad del Noroeste de Rio Grande do Sul, con nueve parientes cuidadores de personas con cáncer. Los datos producidos mediante entrevistas semiestructuradas se sometieron al análisis temático, generando tres tópicos. Los datos se recopilaron entre febrero y junio de 2019. **Resultados:** después de que un miembro de la familia se enfermara de cáncer, era necesario elegir un cuidador principal, designado por los otros parientes, por el paciente o por el deseo del propio cuidador. Hubo cambios en la dinámica diaria del cuidador familiar, señaladas por el abandono del trabajo y de las tareas de su vida personal, lo que condujo a sobrecargas. Se identificaron diversas condiciones que experimentan los cuidadores familiares: miedo, desesperanza, llanto, impotencia, preocupación y síntomas depresivos. **Conclusión:** la atención de un pariente con cáncer modifica la vida diaria del cuidador y tiene el potencial de cambiar la estructura familiar.

Descriptores: Neoplasia; Cuidadores; Familia; Enfermería; Atención Domiciliaria

Introduction

Cancer is a public health problem and is among the four leading causes of death in most countries. A study on cancer incidence shows that in 2018, there were 18 million new cases of cancer and 9.6 million deaths worldwide. Lung cancer is the most incident in the world, followed by breast cancer, both with about 2.1 million cases each. The colorectal cancer covers 1.8 million cases, while the prostate cancer covers 1.3 million. Mortality is higher in men (53% of cases) than in women (47%).[1]

In Brazil, the estimate for the period from 2020 to 2022 is 625,000 new cases annually.[1] The highest incidence will be that of non-melanoma skin cancer, followed by breast and prostate, colon and rectum, lung and stomach cancers. In men, with the exception of non-melanoma skin cancer, prostate, colon and rectum, lung, stomach and oral cavity will be the most frequent. Breast, colon and rectum, cervix, lung and thyroid cancers will be the most frequent in women, except for non-melanoma skin.[1]

Considering this context, it is signaled that there is the possibility that many Brazilian families will face cancer illness. Family is understood as an open and permeable system, made up of parents, spouses, children, and can also be made up of who the members of this group name as part of it.[2] Every day, after the diagnosis of cancer of a member of the family group, the family experiences several changes in its dynamics, such as, for example, the dismissal from work of the person with cancer and the caregiver, economic difficulties due to expenses arising from treatment and anxiety permeating daily life by the expectations regarding the prognosis.[3]

The demands for care of those who fall ill with cancer involve follow-up in hospital admissions and medical appointments, trips to radiotherapy and/or chemotherapy sessions, as well as care procedures in the home space, including assistance in hygiene, food, medication administration, among others. In this perspective, the changes in the family setting are triggered, starting with the indication of a main caregiver, who will be responsible for exercising the activities and care actions that involve the person with cancer.[4]

Mostly, this role is exercised by women and, in the family sphere, most of the caregivers are daughters, sisters and wives. One reason for the low number of male family caregivers could be that they have difficulty leaving their formal work because they are responsible for the financial contribution and, generally, assume the role of home’s financial providers.[5] Accordingly, when glimpsing the complex management and practice of the care required of him/her, the family member goes through an adaptive phase for the exercise of his/her new function, occasion in which situations of physical and emotional discomfort, such as anxiety, stress and fear, can be unleashed, until the moment of getting involved with the care and showing solicitude in the task of caring for.[4,6]

Usually, family caregivers are unprepared to perform this function.[7] It is common for them to find themselves unsure about how to provide care in the home or for never having taken care of people with cancer, and also for responsibility in making decisions. Feelings such as fear, anguish and guilt can also be present in this process and, generally, result in damage to the quality of life of both the caregiver and the sick relative.[8-9]

Many times, when assuming the care and responsibilities for the patient alone, without the help of someone else, the caregiver may suffer stress, making him/her vulnerable in this process.[8] In addition, it is worth emphasizing that the family member, when playing the role of caregiver, experiences feelings and emotions similar to those experienced by people with cancer, whether of joy or sadness.[6] Knowing these demands, it is essential that the patient-caregiver-professional health triad has mutual bond and responsibility for exercising this care.[10]

In view of these factors linked to the challenge of performing care in the home environment, which often does not provide the resources to do so, family caregivers also lack attention from the health team. Thus, this study has a local justification, since, in the study setting, part of the primary health care teams still lacks strategies and systematization of care for people in oncologic treatment and their families. Giving a voice to family caregivers of people with cancer is a powerful mechanism that allows the exposure of their experiences and, based on this, the establishment of care according to their demands, including nursing interventions, and the creation of an articulated network for these families, in order to define priorities and public policies with respect to health.

Facing the possibility of the function of family caregiver being exercised by one or more people that make up the family group and considering the changes and possible effects of the process of becoming ill with cancer for the caregiver, this research was guided by the following research question: "what are the experiences of family caregivers of a person with cancer during the process of becoming ill?" In order to respond to this question, the objective of this article was to understand the experiences of family caregivers of people with cancer during the illness process.

Method

This is a qualitative and descriptive research,[11] conducted in a municipality located in the Northwest region of Rio Grande do Sul, where 01 medium-sized general hospital and 10 Primary Health Care Units with Family Health Strategy (FHS) are installed. This location was chosen because of the ease of access to the families by the researchers. Moreover, because patients need to travel to other municipalities, which have oncology services, to undergo a treatment, which usually requires the accompaniment of a family member. In the study setting, the incidence of cases is approximately 100 diagnostic people annually.[12] There are no official records of the number of people with oncologic diagnosis and undergoing treatment (curative or palliative).

In order to define the study participants, initially, contact was made with the FHS nurses, who indicated the families, in their area of coverage, who had a member with cancer diagnosis. Each nurse indicated two families that had a member with cancer. Subsequently, a draw was made with all the families indicated by the FHS teams to define the order of the invitation and data collection. From the definition of the families, they were contacted through a home visit, accompanied by the Community Health Worker (CHW).

The interviews were conducted soon after the approach, at home, according to the decision and availability of the interviewee. Thus, there were a total of nine family caregivers interviewed, who met the following inclusion criteria: being 18 years of age or older; calling yourself the primary caregiver of the person with cancer (criteria such as time of diagnosis, therapy or type of cancer were not defined). Exclusion criteria: having been a family member of the caregiver of the person who has already died; being a caregiver for the person with cancer but not part of the family (recognized by family members);[2] not having cognitive conditions to participate in the interview. None of the invited family members refused to participate in the investigation, and the definition of the number of participants was delimited by means of theoretical data saturation. It was understood that none of the participants' speech was the same as the other, but common elements and similar syntheses were found, which defined the closure of data collection.[13]

Data collection took place from February to June 2019, through a semi-structured interview, containing questions that sought information related to the participants' characterization and also with a view to apprehending the experiences of the caregiver during the illness process of the person with cancer, such as: How did you receive the cancer diagnosis from your relative? How is it for you to take care of your relative with cancer? What care actions do you give to your relative with cancer? Who are or were your support networks during the illness and care process of your relative? The interview script was empirically oriented by the pertinent literature.[14]

For the interviews, conducted by one of the researchers, in the family home, in a reserved environment and time chosen by the participants, a digital recorder was used and its duration was approximately 30 minutes each. Subsequently, they were transcribed, respecting the trustworthiness of the participants' reports. The collected data were submitted to thematic analysis,[11] with construction of three categories. The Consolidated Criteria for Reporting Qualitative Research (COREQ) was used to support the accuracy and credibility of the research by describing aspects such as study design and data analysis, throughout the detailing of the research method.[15]

In the presentation of the results, the anonymity of the participants was preserved through the identification with the letter E (initial letter of *entrevistado*, interviewee translated into Portuguese language), followed by an Arabic number, obeying the order in which the interviews were held (E1, E2, E3....). This research was approved by the Institutional Research Ethics Committee under the CAAE number: 03728118.2.0000.5346 and Consubstantiated Opinion nº 3.106.576, whose approval date was January 04th, 2019, being conducted based on ethical precepts relating to research with human beings, according to Resolution 466/12.

Results

Of the family caregivers who participated, eight were female and one male, aged between 38 and 74 years. With regard to schooling, four participants had completed higher education, followed by three with incomplete elementary school and two with high school. In addition, six family members were married, one in a stable union, one divorced and one widower. Regarding the degree of kinship with the person with cancer, six caregivers were children, two spouses and one brother.

Concerning the profession of the interviewed caregivers, three were teachers, one civil servant, one nursing technician, one housekeeper, one human resources manager, one farmer and one retired. Of these, five were not in the formal labor market at the time of data collection. With respect to the religion of family caregivers, six professed the Catholic religion and three the Evangelical religion. Of the interviewees, five reported that the care procedures took place at the relative's home with cancer and four informed that it was held at the caregiver's home. The time of care ranged from 1 month to 10 years.

Regarding the physical condition of the person with cancer, according to the interviewees, five were partially dependent on care, whose physical conditions required assistance for hygiene, food, locomotion and administration of medicines, followed by four people who needed only supervision for such activities. About the type of cancer that affected the people cared for by their relatives, two had stomach cancer, two had breast cancer, one had bone cancer, one had throat cancer, one had lung cancer, one had brain cancer and one had pancreas cancer. The time of diagnosis of cancer ranged from 1 month to 10 years.

The information derived from the participants' testimonies was grouped in three categories: How I care for: care actions performed by caregivers; My concerns and experiences during the care procedures; and How I feel providing care. The construction of the analytical categories was based on the similarity of the information.

How I care for: care actions performed by caregivers

This category includes testimonials that reflect the relative's care actions towards the cancer patient at home. After the confirmation of the cancer diagnosis of a family member, the choice of the primary caregiver was made, who performed various types of care that involved physical aspects and primary care, such as, for example, assistance with food and hygiene, as well as control of visits, limiting access to people who could exacerbate negative feelings in the sick person.

> *At home, I prepare the food for him, he is skinny, skinny. I have to put him to lie down to sleep; when it’s cold, I have to pick up his sweats and wrap him. Look! It’s not easy.* (E4)
>
> *At the beginning of the surgery, he was more dependent on everything, food in his mouth, bathing, lifting him to get him out of bed, dressing him, he didn’t move anything. From there, about 15 or 20 days, we went to put him in a wheelchair, and then we pushed to make the things easier.* (E6)
>
> *Another thing I also avoided was the visit, not that we didn’t want the visit, but we had to think of her [...] when I saw that there was a person who was very downhearted, I told her that she was not there, she was resting, in order to avoid, because that person who is low astral, she ends up passing it, so leave her aside.* (E2)

There was also mention of the concern to offer space for listening by the family caregiver. This can be highlighted in the report of one participant.

> *Then she would pick up, sit in the shade and I’d say to her: “Look! I’m going to stay here quiet and, if you want to talk a little, I’m here, just call me”.* (E2)

The interviewees reported that the tasks cover innumerable activities and that, commonly, they happen at home and outside, which has changed their way of living. At home, washing clothes and preparing food are some of the actions developed by the caregivers and, among the external attributions to the residence, those related to the purchase of inputs in markets and drugstores were included.

> *I prepare her food, I wash her clothes, I do her matinho* [mate tea]*, I give her coffee, and then I go to do my job.* (E1)
> *If you need to go to the market to buy things, it's up to me, go to the drugstore to buy a remedy, it's up to me, send a request for medication, via public defenders, for him, it's up to me too, all by myself.* (E8)

There was concern of the caregivers in the sense of keeping the person with cancer well physically and minimize the organic symptoms. The participants' testimonies indicate these aspects.

> *I know if I don't stay close to my father, they don't know how to take care of my father, not even to serve him, give a bath. Yesterday, he didn't want to eat, but I arrived and said to him: "Look, you're going to eat or you're going to the doctor", and then he ate!* (E7)
>
> *We get very worried, nervous about trying to make her eat. At the beginning of the first chemo session, she spent several days without sleeping, and therefore the care was hard, we tried to do everything to make her eat. We did everything we could to try to soften; let's say, the care so that she wouldn't have a fever.* (E9)

The concern during the execution of the care procedures to the relative with cancer in the perspective of preserving its physical and psychicological integrity were indicated by the familiar caregivers. Moreover, tasks performed in order to maintain the organization of the home space and provide necessary inputs for the sick person and other family members were also listed by these caregivers.

My concerns and experiences during the care procedures

This category addresses the concerns and experiences of caregivers from the perspective of caring for the relative with cancer. The interviewees reported a series of feelings exacerbated by the illness of a family member. Among them, they cited discouragement, difficulty in accepting the diagnosis and concern about the prognosis, crying, sadness and feeling of powerlessness in the face of the clinical picture of their sick relatives.

> *It's no use saying that I'm fine, I'm not nervous or I'm going well because I'm not fine at all, one day I'm nervous, the next day I'm felled.* (E3)
> *For me, the most difficult is the emotional aspect, there is no way, I'm not being able to accept his illness, I really can't. When I found out, I got into a depression, it was something very serious. Thus, I needed help, it wasn't easy and it's not easy until today. I'm afraid of him one day staying on a bed just suffering.* (E5)

The E2's testimony refers to the fear and anguish of losing her relative to cancer. This is due to the fact that she experienced a painful situation in the recent past with the death of her mother-in-law for the same reason.

> *We become very fragile, very down* [...] *sometimes, I felt, at the same time, a sadness and, at the same time I said: "My God! Am I going to have to go through this again?" And then I was already feeling something bad.* (E2)

Another experience reported by the caregivers concerns the uncertainties regarding the future, especially in relation to the prognosis. The participants' perspective is that, as time goes by, the loss of tranquility and wear and tear tend to worsen.

> *The care actions have to be always available, since there is no more tranquility to say that you'll go to bed and sleep.* (E9)
>
> *It's from home to my work, from my work to home and so we're dealing with this situation, cause the trend, you know, only tends to get worse, has nothing to improve.* (E7)

In addition, the experiences pointed out in this research by family caregivers are related to some daily changes. Regarding this aspect, they emphasized the abdication of the job and restriction of social life.

> *Working, was very good when I was working because there, besides being working, I was distracting myself. Now, I stay alone at home.* (E3)
>
> *My life has changed! As for my jobs on the outside, I don't do anymore.* (E7)

> *We don't live anymore, we live only because of him, I don't go out anymore, I don't go anywhere; since I get up in the morning, it's because of him.* (E8)

The caregivers reported a series of concerns and feelings in the process of becoming ill with cancer of their relatives. Among them, it should be cited expectation in relation to the prognosis, fear of the loss of her/his loved one, sadness and powerlessness. The participants also reported daily changes during the process of becoming ill with cancer of their family members, which involved leaving their formal work and loss of peace of mind.

How I feel providing care

This category introduces and discusses how family caregivers felt about care routines. Feeling alone during the activities was pointed out by the participants in the following speeches:

> *Nobody has asked me if I'm okay! The only person who asked me about myself today, in all this time I've been there, two years and little taking care of my dad, was you [interviewer], nobody even asked me if I'm okay, if I'm sad, if I need anything, nobody, just charges. I have a brother who does almost nothing to help me, if he can hide, he hides.* (E7)
>
> *My nephews? They could give me a hand, none of them will do it. There's no one in the family to help me, they don't even care, nobody, but nobody really care, they'd be only interested if they received in return. A nephew wanted to charge R$ 700 (Brazilian reais) to stay with her in the hospital.* (E1)

In the caregivers' voice, the care process of a person with cancer entails physical and emotional wear and tear, as well as compromising his/her well-being and financial condition, due to the increase in treatment expenses and daily and social demands. In addition, it limits the caregiver's exit from home.

> *Look! It's very hard, he doesn't want me to leave his side, he's afraid of being alone. I only leave when I need to do something, because it's all up to me.* (E4)

> *I had to take over everything, I'm responsible for my father today, I'm responsible for the household too. I have to buy the things, I can't let anything missing and still have to take care of him. I'm very overloaded, very overloaded, a lot of things, a lot of task and, therefore, I have to share still with my personal life. There's lot of things, a lot of pressure, but I have to work, I have my bills, my life.* (E7)
>
> *We keep feeling the load, you know, I'm already getting a health problem, the mother, who also helps to take care of this relative, is already having a health problem, everything has got too hard, everything left for me, which made me overloaded.* (E8)

During the care actions, the participants felt alone, physically and emotionally worn out. Moreover, they exposed limitations to social life, commitment to their well-being and also financial difficulties.

Discussion

Most of the family members accompanying people with cancer were women. This data is in line with a study conducted in Havana/Cuba, with informal caregivers, mostly family members of people with head and neck cancers, which highlights that female caregivers predominated in families that had one of their members with cancer. They usually had emotional ties and carried out the care procedures, even without having the knowledge required to develop them, a fact that may overload their lives.[16]

After the cancer diagnosis of a member of the family group, different types of care were provided by the caregivers, which involved hygiene, food, visit control and provision of listening space. Associated with this, activities outside the home space were also performed by them. The care actions related to the physical well-being of the person with cancer, carried out by the family caregivers, are targeted at mitigating the person's suffering and meeting his/her basic needs, including the care with his/her body hygiene and diet.[17]

Besides the basic/physiological care directed to the physical aspects of the cancer patient, those directed to his/her psychological elements deserve to be highlighted, such as love, affection, attention and listening, with the purpose of enabling the expression of the experiences of those who deal with cancer.[17] There are different ways to care for and make the care easier; and, in order to enable it, there was the reference to the caregivers in terms of reducing the number of visits and driving away people who could cause discouragement in the person with cancer. The disease process is experienced in a milder way when the patient feels accompanied and served by a caregiver who expresses affection, respect and closeness.[18]

During the investigation, the required adaptation of the caregiver to the new function was identified by remaining involved with needs that went beyond the direct care of the sick person. To fully deposit the time to perform care actions is an attribution commonly found in caregivers and, through this condition, they show concern, abdicate their period of rest and wait for the demands and needs that the sick person may come to show.[19] In this configuration of activities that include the act of caring for, there are demands in several areas and these reveal a progressive character, where the know-how takes over greater importance at an early stage of the process.[4]

According to the caregivers' viewpoint, the concern with the execution of the care actions to the relative with cancer, the preservation of his/her integrity and the provision of good health conditions are basic designations of the role of a caregiver. Therefore, the responsibility for maintaining the physical and psychological well-being of these patients has become a goal for the caregivers, in order to avoid the worsening of their clinical picture, which could lead to new complications and hospital admissions. A study conducted with family caregivers of people with metastatic cancer showed that care attitudes and concern are justified in the sense that, if the patient is psychologically well, the physical and emotional wear and tear of the caregiver also reduces and, consequently, the demands for care actions can be minimized.[20]

The interviewees expressed various feelings during the process of caring for the person with cancer that changed their physical and emotional state, which can transform their daily lives and compromise their well-being. A study conducted in the Northeast region of Brazil with family caregivers of patients in palliative care identified that their experiences were pointed out as negative situations in the provision of care. Crying, sadness, anguish and powerlessness in the care of the sick person were present in the care process.[17] There is also the difficulty in accepting the health situation of the sick relative and the effects on the life style of the caregiver, which has some difficulties in reconciling his/her personal life with the care of the sick person.[20]

As the cancer progresses, within the family context, difficulties emerge and are glimpsed in different ways by the caregivers. Permeated by the sense of finitude, death becomes a palpable and possible situation, given the cultural stigma that cancer carries with it. In this sense, a study that sought to understand the social representations about cancer among relatives of patients undergoing oncologic treatment, in a hospital in Maranhão/Brazil, identified that the word cancer still produces negative feelings, such as fear, sadness, pain and despair, as well as the relationship of the disease with death.[21]

Situations involving a chronic illness, such as cancer, cause changes in daily routine and family dynamics. These occurrences include changes in personal, professional and social life, all referring to uncertainties regarding the future.[22] Commonly, these changes produce suffering, but it is possible that, over time, caregivers develop coping mechanisms characterized by adaptations that promote the reduction of emotional responses to stressful events, i.e., the development of skills to deal with the illness process.[23] Accordingly, research points out some strategies to family caregivers in terms of coping with cancer, such as avoiding focusing on the disease or using licit substances, such as anxiolytics, tobacco and herbal medicines to relieve stress and anxiety, seeking support in family group and friends and, also, requesting religious support.[7]

The changes that happened in the caregivers' lives are intimately related to the imposition of abandonment of activities previously developed so that the new demands of care are met.[23] Studies show that, usually, while women prioritize the care of sick men, they renounce themselves and their basic needs. Similarly, men are willing to offer care to the sick relative, although they have difficulties in perceiving their own weaknesses.[24-25] Such facts denounce the need for psychosocial support, sensitizing the caregivers not only to physical care, but also to pay attention to the other aspects of the sick person, looking at him/her in an integral way, in order to allow the exercise of health care activities of their relatives in a comprehensive and healthy way.

The execution of the care procedures in a solitary way causes repercussions, sometimes negative, in the caregiver's life, since he/she feels abandoned and, associated with this, receives criticism from other relatives. Caregivers may feel a lack of support, leading them to experience feelings of suffering when they realize that the care could be performed by more family members,[17] which is similar to the experiences of the participants of the study analyzed herein. The difficulties are exacerbated by emotional suffering associated with the incessant daily demands, where the caregiver has no condition to withdraw.

Issues related to economic difficulties experienced by the caregivers, from the process of becoming ill with cancer of a member of the family group were identified in this study. Similar data were also emphasized in other surveys, highlighting an increase in expenses due to the illness itself, acquisition of medications, trips to hospital institutions and decreased family income, due to the removal of the caregiver from his/her formal work, besides the fact that many families already have low purchasing power.[26-27]

The function of caring for is, generally, exercised by a single family member and, sometimes, he or she has no support from other family members to execute it, which causes wear and tear because it is a task that requires time and dedication. This fact is in line with the study that addresses the quality of life of family caregivers of people undergoing treatment against cancer.[9]

The work and emotional overload of the caregivers is related to the clinical situation of the patient. As the illness worsens, the demand for care increases. In this context, the tasks related to caring for may entail overloads and cause health damage, thus affecting physical, psychological and social well-being, which generates pain, suffering and even the caregiver's illness.[28-29]

Associated with this, it is considered that the affective bond between the caregiver and the person who receives the care is a fundamental element for the execution of health care actions. Moreover, it is worth mentioning that the changes in the life of the family caregiver due to the fact of exercising this care-related activity, without the help of other family members, may trigger mental disorders, such as depression.[30] Accordingly, the study participants experienced emotional, physical, financial and social overloads.

It is important to highlight that this study has limitations because it was held in a certain reality, in a medium-sized municipality, whose family caregivers were accompanying the person with cancer in the home environment. In this perspective, in order to apprehend the experience of the family group that accompanies the person with cancer, other investigations may contribute to making us understand the family dynamics.

Conclusion

The care actions held by family caregivers to the benefit of people with cancer included being close to them and accompanying them in the procedures related to treatment, preparation of food and help at mealtimes, thus helping in the accomplishment of personal hygiene, offering moments of listening and mitigating emotional wear and tear. Different experiences of the family caregivers of a person with cancer were pointed out during this study, such as denial, stress, fear, concern, change in daily routine and abdication of work. These situations generated physical, emotional, financial and social overloads. Moreover, there were reports that indicated the presence of depressive symptoms arising from the excessive loads.

In light of the foregoing, the role of the health team, including the nurse, in addressing and caring for the sick person and the caregiver should be highlighted. Such actions include technical interventions and attention to emotional aspects. Moreover, the act of clarifying doubts and advising in relation to the necessary care procedures are actions that can collaborate in the confrontation of the cancer illness process, both to the sick person and to his/her caregiver.

Finally, it is considered that the results of this study may contribute to producing discussions about the experiences of family caregivers of people with cancer, with the possibility of drawing up care plans, and therefore reducing their overloads and facilitating the management of daily life, where there is a person of the family group affected by cancer. The fact that most of the surveyed caregivers are women suffering from overload of activities can collaborate to guide care strategies focused on this public.

References

1. Instituto Nacional do Câncer (INCA). Estimativa 2020: incidência de câncer no Brasil. Rio de Janeiro: INCA; 2019.

2. Wright LM, Leahey M. Enfermeiras e famílias: guia para avaliação e intervenção na família. 5ª ed. São Paulo: Roca; 2012.

3. Blanc LO, Silveira LMOB, Pinto SP. Compreendendo as experiências vividas pelos familiares cuidadores frente ao paciente oncológico. Pensando Fam [Internet]. 2016 [acesso 2020 jul 29]; 20(2):132-48. Disponível em: http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1679-494X2016000200010&lng=pt&nrm=iso

4. Fernandes CS, Angelo M. Family caregivers: what do they need? an integrative review. Rev Esc Enferm USP. 2016;50(4):675-82. doi: https://doi.org/10.1590/S0080-623420160000500019

5. Fetsch CFM, Portella MP, Kirchner RM, Gomes JS, Benett ERR, Stumm EMF. Estratégias de coping entre familiares de pacientes oncológicos. Rev Bras Cancerol. 2016;62(1):17-25. doi: https://doi.org/10.32635/2176-9745.RBC.2016v62n1.175

6. Marchi JA, Paula CC, Girardon-Perlini NM, Sales CA. Significado de ser-cuidador de familiar com câncer e dependente: contribuições para a paliação. Texto Contexto Enferm. 2016;25(1):e0760014. doi: http://dx.doi.org/10.1590/0104-07072016007600014

7. Mattos K, Blomer TH, Campos ACBF, Silvério MR. Cancer coping strategies adopted by families individuals for cancer treatment. Rev Psicol Saúde. 2016;8(1):1-6. doi: http://dx.doi.org/10.20435/2177093X2016101

8. Anjos ACY, Zago MMF. Ressignification of life of caregivers of elderly patients with cancer. Rev Bras Enferm. 2014; 67(5):752-8. doi: http://dx.doi.org/10.1590/0034-7167.2014670512

9. Pedraza HMP. Quality of life in family caregivers of people in cancer treatment. Rev Cuid (Bucaramanga 2010). 2015;6(2):1029-40. doi: http://dx.doi.org/10.15649/cuidarte.v6i2.154

10. Ministério da Saúde (BR). Plano de Ações Estratégicas para o enfrentamento das Doenças Crônicas Não Transmissíveis (DCNT) no Brasil: 2011-2020 [Internet]. Brasília (DF): Ministério da Saúde; 2011 [acesso 2020 abr 10]. Disponível em: https://bvsms.saude.gov.br/bvs/publicacoes/plano_acoes_enfrent_dcnt_2011.pdf

11. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 14ª ed. São Paulo: Hucitec; 2014.

12. Sistema Nacional de Regulação. Pacientes em acompanhamento oncológico de Palmeira das Missões em hospital referência no ano de 2019. SISREG; 2020.

13 Fontanella BJB, Ricas J, Turato EB. Saturation sampling in qualitative health research: theoretical contributions. Cad Saúde Pública. 2008;24(1):17-27. doi: https://doi.org/10.1590/S0102-311X2008000100003

14. Leonidou C, Giannousi Z. Experiences of caregivers of patients with metastatic cancer: what can we learn from them to better support them? Eur J Oncol Nurs. 2018;32:25-32. doi: 10.1016/j.ejon.2017.11.002

15. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349-57. doi: 10.1093/intqhc/mzm042

16. Debs LM, Ruiz AL, Abreu MCL. Carga del cuidador en cuidadores informales primarios de pacientes con cáncer de cabeza y cuello. Rev Habanera Cienc Médi [Internet]. 2018 [citado 2020 abr 10];18(1):126-37. Disponible en: http://www.revhabanera.sld.cu/index.php/rhab/article/view/2341

17. Cunha AS, Pitombeira JS, Panzetti PMN. Oncological palliative care: perception of caregivers. J Health Biol Sci. 2018;6(4):383-90. doi: http://dx.doi.org/10.12662/2317-3076jhbs.v6i4.2191.p383-390.2018

18. Pozzoli SML, Cecílio LCO. About caring and being cared for in home care. Saúde Debate. 2017;41(115):1116-29. doi: https://doi.org/10.1590/0103-1104201711510

19. Figueiredo T, Silva AP, Silva RMR, Silva JJ, Silva CSO, Alcântara DDF, et al. How can I help? feelings and experiences of the familiar caregiver of cancer patients. ABCS Health Sci. 2017;42(1):34-9. doi: http://dx.doi.org/10.7322/abcshs.v42i1.947

20. Ferreira MLSM, Mutro ME, Conde CR, Marin MJS, Meneguin S, Mazzeto FMC. Caring for family with cancer. Cienc Enferm. 2018;24(6):1-11. doi: 10.4067/s0717-95532018000100206

21. Lima SF, Silva RGM, Silva VSC, Pasklan ANP, Reis LMCB, Silva UC. Representações sociais sobre o câncer entre familiares de pacientes em tratamento oncológico. REME Rev Min Enferm. 2016;20:e967. doi: 10.5935/1415-2762.20160037

22. Oliveira JM, Reis JB, Silva RA. Search for oncological care: perception of patients and family members. Rev Enferm UFPE On Line. 2018;12(4):938-46. doi: https://doi.org/10.5205/1981-8963-v12i4a231359p938-946-2018

23. Silva RAR, Souza Neto VL, Oliveira GJN, Silva BCO, Rocha CCT, Holanda JRR. Coping strategies used by chronic renal failure patients on hemodialysis. Esc Anna Nery. 2016;20(1):147-54. doi: 10.5935/1414-8145.20160020

24. Carbogim FC, Pereira RZA, Luiz FS, Andrade RO, Tony ACC, Paiva ACPC. Coping of family of patients in oncological treatment. Rev Enferm Atenção Saúde. 2019;8(1):51-60. doi: 10.18554/reas.v8i1.3409

25. Piollia KC, Decesaroa MN, Salesa CA. (Not) taking care of yourself as a woman while being a caregiver of a partner with cancer. Rev Gaúcha Enferm. 2018;39:e2016-0069. doi: https://doi.org/10.1590/1983-1447.2018.2016-0069

26. Marques G. A família da criança com câncer: necessidades sócio-econômicas. Rev Gaúcha Enferm. 2017;38(4):e2016-0078. doi: http://dx.doi.org/10.1590/1983-1447.2017.04.2016-0078

27. Silva I, Barros MM. Las experiencias de los cuidadores familiares de niños y adolescentes con cáncer. Rev Chil Ter Ocup [Internet]. 2019 [citado 2020 abr 10];19(1):35-48. Disponible en: https://revistas.uchile.cl/index.php/RTO/article/view/49807

28. Yoshimochi LTB, Santos MA, Loyola EAC, Magalhães PAP, Panobianco MS. The experience of the partners of women with breast cancer. Rev Esc Enferm USP. 2018;52: e03366. doi: http://dx.doi.org/10.1590/S1980-220X2017025203366

29. Vale JMM, Marques Neto AC, Santos LMS, Santana ME. Health education to the family caregiver of diseased cancer patients in palliative home care. Enferm Foco [Internet]. 2019 [acesso em 2019 nov 17]:10(2):52-7. Disponível em: http://revista.cofen.gov.br/index.php/enfermagem/article/view/1684/519

30. Bianchin MA, Silva RD, Fuzetto LA, Salvagno V. Sobrecarga e depressão em cuidadores de pacientes oncológicos em tratamento quimioterápico. Arch Health Sci [Internet]. 2015 [acesso em 2020 maio 06];22(3):96-100. doi: https://doi.org/10.17696/2318-3691.22.3.2015.245

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Corresponding Author

Leila Mariza Hildebrandt
E-mail: leilahildebrandt@yahoo.com.br
Address: Carajás Street, nº 82, Pindorama District, Ijuí City
ZIP Code: 98700-000

Authorship contributions

1 - Jonata de Mello
Conception or design of the study/research, analysis and/or interpretation of the data, final review with critical and intellectual participation in the manuscript.

2 - Dionatan Almeida de Oliveira
Study/research design, analysis and/or interpretation of the data.

3 - Leila Mariza Hildebrandt
Conception or design of the study/research, analysis and/or interpretation of the data, final review with critical and intellectual participation in the manuscript.

4 - Leonardo Bigolin Jantsch
Final review with critical and intellectual participation in the manuscript.

5 - Danusa Begnini
Final review with critical and intellectual participation in the manuscript.

6 - Marinês Tambara Leite
Final review with critical and intellectual participation in the manuscript.

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